MODELS OF MORAL REASONING IN END OF LIFE

CLINICAL DECISION-MAKING FOR PERSONS IN END-STAGE DEMENTIA

Joseph Dimech

A thesis presented in the Faculty for Social Wellbeing

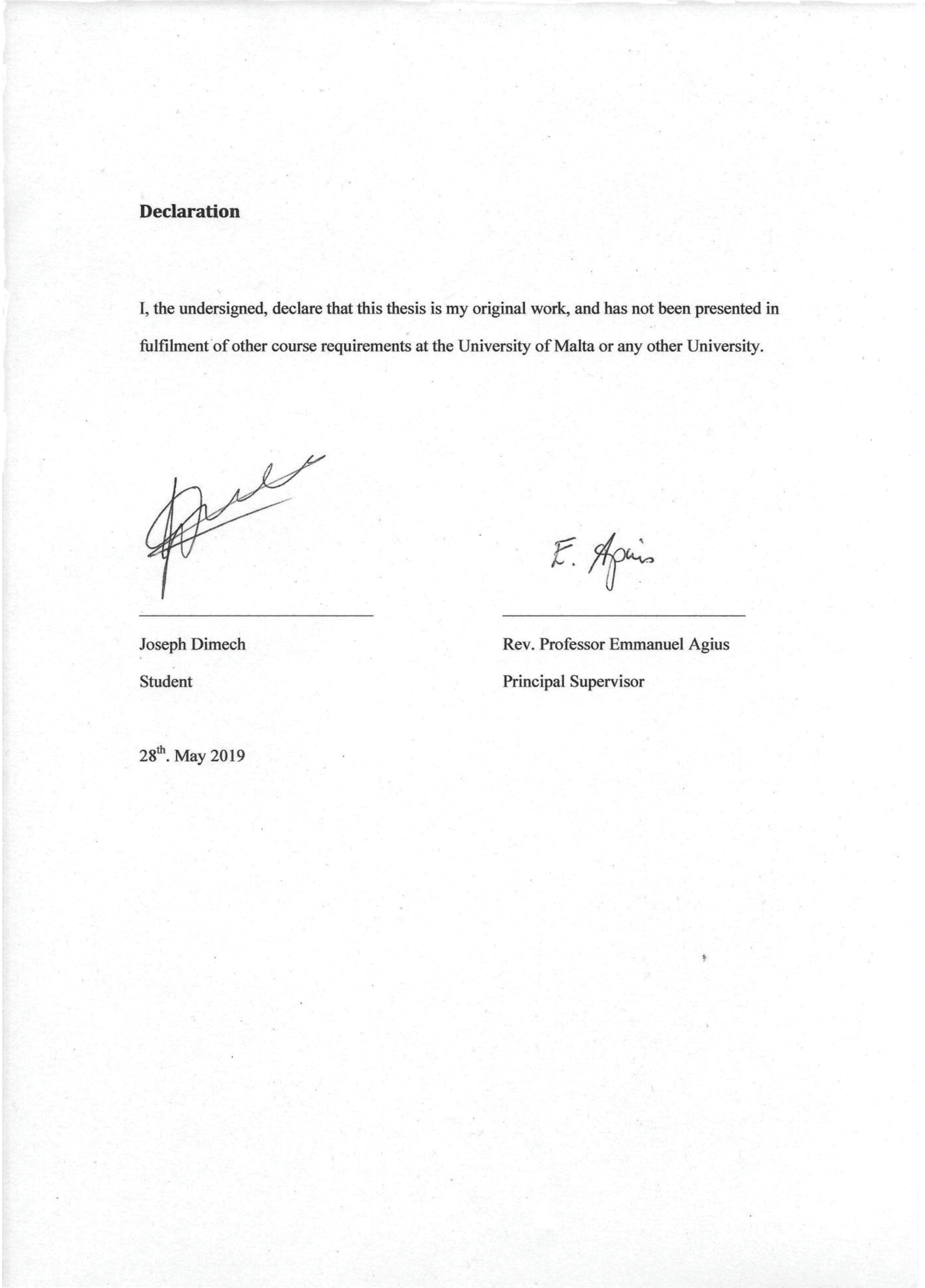
at the University of Malta for the degree of Ph.D.

June 2019

Correspondence concerning this

thesis should be addressed to:

joseph.dimech.00@um.edu.mt



Declaration

I, the undersigned, declare that this thesis is my original work, and has not been presented in fulfilment of other course requirements at the University of Malta or any other University.

E. Agius

Joseph Dimech
Student

Rev. Professor Emmanuel Agius
Principal Supervisor

28th. May 2019

Dedication

I dedicate this thesis to my wife, Marie, as without her patience, encouragement and support, this work would still be just another unaccomplished dream in my bucket list!

Abstract

Clinical decision-making in the end-of-life of older adults in end-stage dementia is a complex issue, with a composite interplay between clinical, social, legal and ethical issues. End-stage dementia seriously hinders the affected person's physical and cognitive capabilities and leaves the patient unable to participate in decision-making regarding their health. The emotionally involved family and clinicians are faced with complex ethical dilemmas as they have to take the responsibility to decide for the patient how to proceed as the patient starts experiencing life-threatening swallowing difficulties. This study was an attempt to understand what ethical models if any, do underpin the decisions of clinical teams and other stakeholders when the patient in end-stage dementia experiences severe life-threatening swallowing difficulties. This question was investigated through a qualitative case-study approach. Participants were six different clinical teams and involved families who went through the decision-making process on how to address the swallowing difficulties of six different patients at St Vincent de Paul LTCF. Data consisted of retrospective semi-structured interviews with each member of the team and relatives who participated or was entitled to participate in the decision. All data were transcribed and subjected to a qualitative thematic analysis. The study showed that the professionals and family members found it hard to decide whether the person would benefit from tube feeding with the intent to prolong life, or else from a comfort-seeking approach to oral feeding to promote dying with dignity. They used different ethical care models in each case. Some cases gave rise to strong discord among the clinicians and relatives, with the involvement of conflicting values and different interpretations given to beneficence, non-maleficence, sanctity-of-life and quality-of-life, raising questions as to how far the whole process maintained a patient-centred approach. In other cases, all stakeholders were included in a consensus-building approach that appeared to safeguard better the patient's dignity and interests in care. The findings revealed the need for the introduction of care practice guidelines and advanced directives to safeguard the patient by regulating better planning and interventions in end-stage dementia care. Furthermore, it is suggested that professional guidelines should promote a consensus-building approach as the best way of ensuring a patient-centred and ethically appropriate decision-making process.

Keywords: end-stage dementia, swallowing difficulties, long-term care, moral reasoning, ethical models, decision-making, consensus-building

Acknowledgements

My warmest appreciation goes to my three Doctorate Supervisors who have mentored me over the years, each one in their special way. First of all, my sincere thanks go to Rev. Professor Emmanuel Agius, as my Principal Supervisor, who was with me from the very beginning and has guided me to reach the true path and appreciation of ethical decision-making. I am also truly grateful to Professor Paul Bartolo, who has given me his full support and expertise to help me draw up valid ideas to develop my empirical research better. Last but not least, my heartfelt thanks also go to Professor Julian C. Hughes, who through his well-targeted points and suggestions has provided me with guidance to make my thesis more holistic and richer in context.

I would like to show my gratitude to the late Professor Joseph Troisi who, although no longer with us, continues to inspire this work as it was through his foresight that I endeavoured to study the phenomenon of end-of-life decision-making in dementia. I am also grateful to his successor, at the Department of Gerontology and Dementia Studies, Professor Marvin Formosa, for his presence and support throughout these years.

Finally, this work is a down to earth research effort on the team approach, to this end I express my full appreciation to the St Vincent de Paul LTC Facility Administrators, Clinical Team Colleagues, Patients and their Relatives, as their input in this thesis was none other but fundamental.

Joseph Dimech

Table of Contents

Glossary of Terms

Advance care planning: is a process that enables individuals to make plans in conjunction with the health care team about their future health care. Advance care plans provide direction to healthcare professionals when a person is not in a position to either make and/or communicate their own healthcare choices.

Advance directive: is a written declaration made by a mentally competent adult before they lose the capacity to make decisions about medical treatment. It allows a competent adult to specify which medical interventions they wish to refuse and the situations/circumstances where the refusal would apply

Aggressive care: describes a particular approach to a life-threatening illness or condition. A patient receiving aggressive care will receive the benefit of every medication, technology, tool and trick that doctors can devise to treat his or her illness.

Alzheimer’s disease: a neurodegenerative disorder of the brain with distinct pathology causing a progressive loss of cognitive function

Appropriate treatment: health care in which the expected clinical benefits (e.g., improved symptoms) of care outweigh the expected negative effects (e.g. adverse drug effects) to such an extent that the treatment is justified.

Attitudes: reactions to and evaluation of individuals, situations and objects. May be positive or negative

Authenticity: the attempt to live one's life according to the needs of one's inner being, rather than the demands of society

Autonomy: the freedom to make choices based on consideration of internal and external circumstances and to act on these choices.

Axiom: a statement taken as being true

Behaviour: the way in which one acts or conducts oneself

Beliefs: a set of ideas and thoughts that a person uses to construct attitudes, views and behaviour

Beneficence: addresses the idea that a provider's actions should promote good.

Best interests: “a judgement based on what would be most beneficial to a patient” (Gordon & Baker, 2011, p. 162)

Caring: “an emotional commitment to, and willingness to act on behalf of persons with whom one has a significant relationship” (Beauchamp & Childress, 2013, p.35).

Case-study: a process or record of research into the development of a particular person, group, or situation over a period of time

Categorical imperative: one which represented an action as objectively necessary for itself

Clinical decision-making: is a complex process involving observation, information processing, critical thinking, evaluation of evidence, applying relevant knowledge, problem solving skills, reflection and clinical judgement to select the best course of action, which optimises a patient’s health and minimizes any potential harm

Cognition: is a processing of awareness that includes perception, memory, understanding, and thinking

Consensus-building: is essentially mediation of a conflict which involves many parties. Usually, the conflict also involves multiple, complex issues

Curative care: health care practices that treat patients with the intent of curing them, not just reducing their pain or distress

Decision-making: a case of choosing between different alternatives

Deductive: reaching an answer or a decision by thinking carefully about the known facts

Dementia: a chronic or persistent disorder of the mental processes caused by brain disease or injury and marked by memory disorders, personality changes, and impaired reasoning

Deontology: follows the law, where the duty and rules focus on the rightness or wrongness of actions themselves

Dysphagia: difficulty or discomfort in swallowing, as a symptom of disease

End-of-life care: helps all those with advanced, progressive, incurable illness to live as well as possible until they die. It enables the supportive and palliative care needs of both patient and family to be identified and met throughout the last phase of life and into bereavement.

Ethical principle: is a base philosophical stance which directly or indirectly leads to an ethical standard.

Ethical theory: is the systematic effort to understand moral concepts and justify moral principles and theories. The four broad categories of ethical theory include deontology, utilitarianism, rights, and virtues.

Ethics: is a set of standards that guides behaviour of individuals and as members of an organisation

Extraordinary treatment: extraordinary or disproportionate treatment is used to describe those means or measures which are not usually available, do not offer a reasonable hope of benefit and cause unbearable pain and suffering.

Euthanasia: the act of causing a painless and planned death, such as relieving a person's suffering from an incurable disease.

Extraordinary treatment: is complex, invasive, expensive and heroic

Hospice care: care provided for those with chronic or terminal illness and their families. Individualised symptom control programmes are implemented which aim to minimise the physical, emotional and spiritual distress

Hypothetico-deductive theory: a scientific inquiry proceeds by formulating a hypothesis

Inappropriate treatment: health care in which the expected clinical benefits (e.g., improved symptoms) of care are less than the expected negative effects to such an extent that the treatment is unjustified.

Inductive: using a particular set of facts or ideas to form a general principle

Justice: individuals should be treated the same

Laissez-faire: the policy of leaving things to take their own course, without interfering

Living will: a written statement detailing a person's desires regarding EOL medical treatment in circumstances in which they are no longer able to express informed consent.

Maxim: person’s reasoning to be morally valid

Mental incapacity: an inability through mental illness or mental retardation of any sort to carry on the everyday affairs of life or to care for one's person or property with reasonable discretion

Morality: is a set of coded principles or rules that deal with what is right or wrong; actions that imply good or bad behaviour

Moral reasoning: is a thinking process with the objective of determining whether an idea is right or wrong. To know whether something is "right" or "wrong" one must first know what that something is intended to accomplish.

Moral virtue: a dispositional trait of character that is morally valuable

Nonmaleficence: represents the doctor's attempt to avoid any act or treatment plan that would harm the patient or violate the patient's trust, and has been popularized in the phrase “first, do no harm.”

Nosocomial infection: a hospital-acquired infection.

Ordinary treatment: refers to treatment that is simple, natural, non-invasive, inexpensive, a routine.

Palliative care: is an approach that improves the QOL of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

Palliative sedation: is the palliative practice of relieving distress in a terminally ill person in the last hours or days of a dying patient's life through deep continuous sedation

Paternalism: an action performed with the intent of promoting another's good but occurring against the other's will or without the other's consent

Physician-assisted suicide: the voluntary termination of one's own life by administration of a lethal substance with the direct or indirect assistance of a physician.

Power of attorney: the authority to act for another person in specified situations, or all legal, or financial matters

Principlism: is a practical approach for ethical decision-making that focuses on the common ground moral principles of autonomy, beneficence, nonmaleficence, and justice.

Proxy decision-maker: when a patient is unable to make decisions to decide for themselves about personal health care, someone else provides direction in decision-making, as the surrogate decision-maker

Quality-of-life: the standard of health, comfort, and happiness experienced by an individual or group

Rights: that which is morally correct, just, or honourable

Sanctity-of-life: is a principle of implied protection regarding aspects of sentient life that are said to be holy, sacred, or otherwise of such value that they are not to be violated

Substituted judgment: Substituted judgment is often invoked as a guide for decision-making when a patient lacks decision-making capacity and has no advance directive. Using substituted judgment, doctors and family members try to make the decision that the patient would have made for themselves if he or she were able to make decisions.

Utilitarianism: the doctrine that actions are right if they are useful or for the benefit of a majority

Values: principles or standards of behaviour; one's judgement of what is important in life

Virtue ethics: right actions as to what a virtuous agent would do

Vitalism: the belief that human life is absolute

(*Adapted from various online encyclopaedias*)

Abbreviations

ACP:	Advance care planning
ADRQL:	Alzheimer Disease Related Quality-of-life
ALS:	Amyotrophic lateral sclerosis
ANH:	Assisted nutrition and hydration
APA:	American Psychological Association
ADE:	Active direct euthanasia
BMA:	British Medical Association
CANH:	Clinically-assisted nutrition and hydration
CASCADE:	Choices, Attitudes, and Strategies for Care of Advanced Dementia at the EOL
CDR:	Clinical Dementia Rating
CPR:	Cardio-pulmonary resuscitation
EOL:	End-of-life
ESD:	End-stage dementia
FAST:	Functional Assessment Staging of Alzheimer's disease test
GDS:	Global Deterioration Scale
GMC:	General Medical Council
GSF:	Gold Standard Framework
HALY:	Health-adjusted life years
LPOA:	Lasting power of attorney
LTC:	Long-term care
MAPP:	Making Advance Planning a Priority
MMSE:	Mini Mental State Examination
MDH:	Mater Dei Hospital
NG:	Nasogastric
NSO:	National Statistics Office

NICE:	National Institute for Health and Clinical Excellence
PEACE:	Palliative Excellence in Alzheimer Care Efforts program
PIG:	Gold Standard Framework Proactive Identification Guidance
POA:	Power of attorney
PEG:	Percutaneous endoscopic gastrostomy
QALY:	Quality-adjusted life-years
QOL:	Quality-of-life
RCP:	Royal College of Physicians
RIG:	Radiologically-inserted gastrostomy
SLP:	Speech language pathologist
SVP:	St. Vincent de Paul Long-term care Facility
UNESCO:	United Nations Educational, Scientific and Cultural Organization
UOM:	University of Malta
WHO:	World Health Organisation

Image 1: St. Vincent de Paul Long-Term Care Facility (Aerial View, 2011)

Introduction

It has been reported that the Maltese Population (*National Statistics Office [N.S.O.],* 2017) is ageing, particularly in the 70y+ age group. One of the consequences of such advancing age is that older persons are prone to suffer from complex problems related to their medical, cognitive, functional and social state (Cummings, 1999).

Dementia, also termed as *major neurocognitive disorder* under DSM-5 criteria (American Psychiatric Association, 2013), has been declared as a primary source of old age dependency in Europe (*Alzheimer Europe*, 2008b), which seriously effects families and carers, and also leads to "substantial health, societal and economic consequences" (Rait et al., 2010, p. 1). However, Rait et al. remarked that the major impact of dementia is felt by the person afflicted, who individually may experience not only major impairment, but also increased care needs, social emargination and financial difficulties (Seymour, Witherspoon, Gott, Ross, & Payne, 2005).

As dementia progresses to the end-stage, persons affected end up not only with high levels of dependency and morbidity (Van der Steen et al., 2014), but also with the inevitable devastating loss of cognitive function that affects the individual’s capacity to decide for themselves of "what should be done with his or her own body" (Cassel, 2010, p. ix). Scheirton (2010) remarked that such insult on the decisional capacity of the individual creates a dilemma of who would be responsible for making decisions, an issue that would increasingly involve others, namely family members, caregivers and health care providers.

Through the ages, senility and associated loss of faculties have always been accepted as a normal characteristic of ageing (Pace, Treloar, & Scott, 2011). In contrast, the current generation is less acquainted with the ultimate effect of ageing, namely death and dying, than in previous cohorts (*Department of Health*, July 2008). This renders our generation at a loss to decide difficult clinically-related ethical decisions that are to be taken in the end-of-life [EOL], particularly in dementia as the patient's wishes are often unknown (*General Medical Council* [GMC], 2010, May 20). Also, Cassel (2010) reported that modern medicine, with its emphasis on high technology, tends to distance itself from the EOL, as it is seen as a failure in the cure orientated programme of care. This attitude to EOL care has to be seen in the context of terminal care in end-stage dementia, where the decline in health is frequently unpredictable, and prognostication is truly problematic to identify (*National Institute for Health & Care Excellence [NICE],* 2010, June).

To complicate the issue further, the advent of tube-feeding in the management of swallowing difficulties in end-stage dementia has caused a drastic shift to medicalise the EOL (Hughes & Williamson, 2019). *Consensus Document EndCare* (2018) remarked that fine-bore tube feeding has exposed patients with dementia to an invasive procedure without faculty to consent. Additionally, tube feeding has exposed frail persons with dementia to possible new morbidity and mortality factors that could alter the picture of the terminal phase of life.

To clarify and streamline terminology, this thesis refers to all forms of tube feeding (nasogastric [NG] tube, percutaneous endoscopic gastrostomy [PEG] tube, radiologically-inserted gastrostomy [RIG] tube, and artificial nutrition and hydration [ANH], collectively as clinically-assisted nutrition and hydration [CANH] (*British Medical Association [BMA]*, 2018).

Dekkers (2010) pointed out that ethics gives due importance to the respect of the human being as a "free, self-sufficient, rational, independent and autonomous subject" (p. 120), wherein due regard is given to the idea that persons with dementia still retain a self.

Knowing this, Dekkers (2010) added that the orientation of attention to how we live together and how we respect each other, in the face of suffering, focuses our interest to the systematic understanding of human conduct with a convergence on the neediest vulnerable persons in our society.

It is known that the question of control and "who decides what" (*Royal College Physicians [RCP],* 2010, p. 75) are basic moral queries that relate directly to the individual's autonomy (ten Have, 2010). Ten Have added that such issues can be addressed ethically through the provision of models that thoroughly take in hand cases, with the intent to facilitate clinical decision-making.

Recent years have evidenced increasing policy concern to find appropriate answers to meet the basic requirements of persons with dementia (Goodman et al., 2010). It remains a challenging issue to note that dementia studies have concentrated more on the earlier phases of the condition, giving proportionally lesser regard to the questions related to care in the later phases (Abbey, J., Wilson, Chang, & Abbey, B., 2007; van der Steen, 2010).

The fact that dementia is a major player in the causation of disability in the later stages of life (Goodman et al., 2010; see also *WHO,* 2003), this highlights this condition as a major complicating disease process that merits attention in the clinical management of EOL care (Goodman et al.).

To this complexity associated with end-stage dementia decision-making, Gillick (2000) remarked that none is more ethically debatable and heart-wrenching for all involved, than decisions on the modality of management of feeding and hydration difficulties in the terminal phase of life.

1. The Maltese Scenario

A. General context.

Malta is made up of an archipelago of islands, of which the island of Malta and that of Gozo is inhabited by a high-density population, which in 2016 stood at 460,297 persons (*NSO*, 2018), all living in a restricted 316 square kilometre surface area (*World Population*

Day, July 11, 2016). Unless stated otherwise in this thesis, wherever reference is made to Malta, this is to be considered as a reference to the Maltese islands.

In the past six decades, Malta's economy has evolved from a British colonial administration "to a market-driven economy with an emphasis on higher value-added economic activities in services, notably financial services and tourism" (*NSO*, 2014, p.iii). Vassallo (2014) remarked that our British colonial past continues to leave its mark on Maltese medical practice, as clinical care does mostly reflect the traditions of good medical care as practised in the UK.

Fiorini (2015) reported that in view of Malta's relatively small population there is present only one general hospital (Mater Dei Hospital [MDH]), whilst with regards to geriatric medicine as a speciality, care of older persons in Malta does comprehensively cover the "acute, rehabilitative and chronic" (p. 124) aspects of clinical practice.

Brinkworth (2015) documented that "Malta is one of the fastest ageing populations in the European Union" (p. 6), with 19.0% of the population being aged 65 years and over (*World Population Day,* July 11, 2016). Furthermore, life expectancy at birth in Malta in 2015 stood at 84.0 years for females and 79.7 years for males (*NSO*, 2016).

Despite increased exposure to more liberal values, following its entry in the European Union in 2004 (Verhofstadt, 2012), Zammit (2015) remarked that Malta remains "a small country that values its family, its religion and its traditions" (p. 230). In this situation, the Roman Catholic Church is the official religion of the Republic of Malta (Ellul, 2014). However, Haber (2015) remarked that cultural and religious values, particularly in the younger generations, might be slowly dwindling.

Over the past 30 years, various government administrations have strived to promote the integration of Malta's older population with the community and the idea of ageing in place (Farrugia-Bonello, 2015). The inclusion of the aged in community life continues to be done through several national policy initiatives. Particular reference can be made to the

National Strategic Policy for Active Ageing (2014-2020). Included in this policy document are the following recommendations:

- “The social inclusion of vulnerable older adults in society.
- Improving services in health prevention and promotion; acute and geriatric rehabilitation, mental health and wellbeing and community care services.
- Supporting initiatives that facilitate the creation of age-friendly and dementia-friendly communities and services.
- Maximising autonomy in long-term care [LTC].
- Raising awareness of elderly abuse and neglect.
- Investing further in EOL care” (pp. 21-22), with a focus to encourage the promotion of EOL care policies on various issues, including developing guidance on artificial feeding.

B. Dementia in Malta.

Concerning the prevalence of dementia, Scerri, C. (2012), estimated that in 2010, the number of persons who have dementia in the Maltese Islands stood at 5,198. Innes, Kelly, Scerri and Abela (2016), remarked that most of these persons who have dementia are still living in the community and the indications showed that most of them have as yet not been diagnosed as suffering from this condition. Abela, Mamo, Aquilina and Scerri (2007) pointed out that projection of dementia prevalence in Malta was expected to almost double by the year 2035. To this end, Scerri, C., (2015) remarked that this burgeoning prevalence of dementia through time was progressively leading to increased socio-economic stress on the Maltese society and additional strain on National Health Services. Scerri, C., added that in the voluntary sector, the Malta Dementia Society has been for many years doing a lot of work to provide support to persons with dementia and their family members.

In a drive to improve the welfare of persons with problems with mental health, the Maltese Government in 2012, passed revised legislation (*Mental Health Act* [Cap 525] (2012), which brought forward a better definition of mental capacity and protection of the rights of the mentally vulnerable. One point enacted under the law was that in situations of lack of mental capacity, care planning should be done jointly between clinicians and relatives (J. Cachia, personal communication, January 8, 2019). Of note, however, this revision did not include the issue of advance directives for EOL decision-making in mentally incapacitated persons.

One direct development as a result of this act was the appointment of a Commissioner for Mental Health and the passing of a Guardianship Act (*Code of Organisation*, 2012, Act No. XXIV of 2012), with the objective to facilitate the appointment of guardians to manage the welfare affairs of persons with disability or mental disorder.

On the other hand, in 2010, the Maltese Bioethics Consultative Committee published online guidelines regarding hydration and nutrition (Asciak, 2010). This document emphasised the significance to differentiate between ordinary and extraordinary care and its relation to the quality-of-life [QOL] of the person in end-stage dementia. Despite these guideline documents and law revisions, Abela and Mallia (2010) (see also *Consensus Document EndCare,* 2018) pointed out that GP's do still feel poorly protected from a legal point of view about withholding and withdrawal of futile treatment in the EOL.

In response to the complexity and the moral concerns created in terminal care, and the difficulty experienced by clinicians "about legal issues and lack of understanding of relatives of what ought to be done" (Mallia, 2018, p. 6), 2016 saw the birth of the EndCare project. This initiative involved the University of Malta in association with Dublin University and the University of L'Aquila, and institutions like the United Nations Educational, Scientific and Cultural Organisation [UNESCO] and the Pontifical Academy for Life of the Vatican" (p. 7). The proceeds of the EndCare project led to the publication in April 2018 of the *Consensus Document Endcare* as a guidance document for practice, which included a reference to the ethical, social and medical issues faced in the management of nutrition and hydration problems in end-stage dementia. To date, this consensus document still lacks endorsement by the Maltese Medical Council.

Concerning perceptions to dementia, research published by Scerri (2010, 2012) (see also *Empowering Change,* 2015) shed light on the intricate situation that is faced by persons with dementia and their carers in Malta. In this study, 613 respondents were exposed to an online or printed questionnaire, with all participants coming from statutory LTC homes and members of the Malta Dementia Society living in the community. Of interest was that only "36% of respondents felt that local healthcare professionals were armoured with the necessary know-how to manage dementia" (*Empowering Change.* p. 69), while 40% of respondents were concerned about EOL care.

Further to the above, this research by Scerri (2010, 2012) (see also *Empowering Change,* 2015), also reported that in 38% of respondents, dementia was considered a forbidden taboo subject for discussion, while 67% remarked that there was not enough awareness of dementia in Maltese society. In fact, on disclosure of a diagnosis to persons with dementia, Caruana-Pulpan and Scerri (2014) reported that only a limited number of Maltese GP's disclosed a diagnosis to the person suffering from the condition. Furthermore, Caruana-Pulpan and Scerri (2014) reported that Maltese GP's had limited knowledge of dementia care, and this led them to withdraw from actively addressing the problem faced in early dementia. A direct consequence of the above is that the autonomy of persons in the early stages of dementia is strongly challenged (Dworkin, 1994; see also *Alzheimer Europe,* 2009b) as they are left in the blind about their diagnosis, and thus they have limited possibility to actively participate in the planning of clinical decision-making (Scheirton, 2010) including EOL care.

In one of the national initiatives taken to promote a better future for persons with dementia, the Maltese Parliamentary Secretariat for Rights of Disabled Persons and Active

Ageing published a *National Dementia Strategy* for Malta for the years 2015 – 2023. The major aims declared in this strategy include (*Empowering Change*, 2015; Scerri, 2015):

- The promotion of early diagnosis and encouraging advance directives.
- The improvement of a person-centred approach to dementia.
- The provision of increased awareness, understanding and support to caregivers.
- Persons with dementia are helped to make decisions about their health and welfare.
- The provision of long-term and palliative management through a team approach.

Arising from this initiative was the launching in June 2016 of a first contact Dementia Intervention Team, to support persons with dementia and their family to continue care in the community (Gobey, June 6, 2016).

Whilst it has been reported that the majority of persons with dementia in Malta are cared for by their families in the community (Scerri, 2015), it needs to be said that Innes, Abela and Scerri (2011) found that family members giving care to persons with dementia in Malta were often under stress with care and had a poor knowledge about dementia. In line with this finding, *Consensus Document EndCare* (2018) added that little was being done to prepare patients, their relatives and clinicians regarding feeding in the EOL, to this end many tended to fall in the trap to push feeding in the EOL to the point that this only prolongs EOL agony.

C. Long-term care provision in Malta.

In Malta, LTC for older people is provided by the State, Charitable Institutions, and Private Enterprise (Borg Xuereb, 2015). Statutory regulatory certification of LTC for older people is broadly divided into two cardinal sectors (*National Minimum Standards*, 2015; Diacono, 2015):

a. The Care Homes are community-based units offering residential and nursing care (G. Pavia, personal communication, November 9, 2016). In 2015, the *National Minimum Standards for Care Homes* was published for public consultation as a regulatory framework specifically for care homes. This proposed regulation aims to promote person-centred care, where active ageing, autonomy, rights and dignity are given worth. These standards do encourage that residents play a “key role” in the decision-making process leading to the setting up of their plan of care (standard: 14.6). In this regulatory framework, mentally capable residents do retain the right to refuse treatment (article: 6.6). Wherever this is not possible due to mental incapacity, their “legally-appointed representative is granted authority to advocate in their stead” (article: 14.6).

b. Apart from the Care Homes, the legal framework defines a separate certified category of LTC units termed *The Institutions*, with specific reference being made to St Vincent de Paul LTC Facility [SVP]. It is relevant to point out that SVP was identified as the site where the field work of this research was carried out in 2017.

Diacono (2015) remarked that SVP offers a range of services of a nursing home and a geriatric hospital. Information obtained from the Medical Superintendent’s Office at SVP (October 3, 2017) showed that SVP had 1,083 beds (F: 71%; M: 29%), thus making SVP as being Malta's largest LTC geriatric facility that provides 24-hour nursing cover and on-site 24-hour medical cover with close geriatrician attention (*Dept. of Health*, 2013). Fiorini (2015) pointed out that all admissions to SVP are offered a comprehensive geriatric assessment by the geriatric multi-disciplinary team and followed up in time according to need. Fiorini added that such comprehensive medical and nursing care does help provide a hospital in the institution care set-up at SVP. Furthermore, SVP has fully fledged in-house departments for Social Work, Physiotherapy; Occupational Therapy; Speech-Language Pathologists [SLP]; Dentistry; X-Ray Unit; Pharmacy; and Podiatry. Also, SVP avails of multiple visiting medical specialist clinics, namely regular attendance by a Psychogeriatrician; Vascular Surgeon; Dermatologist; Gynaecologist and Pain Specialist. All this spells out in avoidance of inappropriate hospital admission of frail elderly in their EOL (Goodman et al., 2010).

Although over the years there have been studies that identified an element of patient abuse at SVP (Fenech, 2001; Brincat, 2008) and research has shown dignity concerns for older people living in this institution (Scolaro, 2016), major measures have been done through time to provide better care that safeguards the dignity of persons in care in this institution (Formosa, 2016). However, Formosa remarked that long-term care for older people in Malta needs to develop policies that give importance to safeguarding patients' dignity and human rights through respect of their beliefs, values, life choices and enabling self-determination. Formosa added that such policy upgrade should also consider quality person-centred care in the EOL through the provision of a palliative approach where dying with dignity is given prominence.

Originally, SVP was opened in the year 1892 with 930 beds, to serve as a Poor House and House for the Incurables (Cassar, 1994). Over the past 60 years, various government administrations have taken the necessary measures to eradicate this stigma associated to SVP (Cassar; Dimech, June 4, 2012) through various refurbishment programmes to meet the evolving needs of older people in modern times. Still, in the very old generation of today, memories of the past are still vivid, and feelings of dishonour do still linger when admission to SVP materialises, even though with time, such cases are progressively becoming less common (Dimech).

In recent years, admissions to SVP have been restricted to older people who either need high dependency complex nursing care and close medical attention, or else are admissions with problem challenging behaviour related to dementia (*St Vincent de Paul Admission Criteria*, October 2015). Otherwise, admission to SVP is also possible for older persons in need of palliative care in their last six months of life. At the time of this study's fieldwork, of the thirty-four nursing wards at SVPR, five wards served as dementia care units for persons with challenging behaviour; two of which being purpose-built units for such care.

In April (2018), the nursing department at SVP issued a standard operative procedure titled *Caring for Dying, Deceased Residents and their Relatives*. This document aimed to help regulate nursing care of all dying patients, and thus was not specific for dementia. The *Caring for Dying* document focused on promoting "privacy, dignity and respect", where care should centre on ensuring that the best interests of patients are safeguarded. In this document, reference was made to the fact that in the EOL, many patients lose their appetite, and this should be accepted in terminal care. To this aim, in the EOL one should avoid, where possible tube feeding, while nurses and carers were advised to continue to support patient feeding by providing food and liquids by mouth.

Giving data of cognitive decline in the SVP population, in a whole population dependency assessment (n=1,138), carried out by the Superintendent's Office in 2016, and utilising a modified version of the Crichton Scale (*SVP Dependency Evaluation*, 2016), 33.6% [382 residents] were found to be lucid, 13.2% [151] were mildly confused, whilst 15.4% [175] were moderately confused, and 37.8% [430 residents] were found to be severely confused.

Furthermore, at the time when the fieldwork for this study was carried out, of the patients with problem feeding at SVP, fifty-one patients were reported to be tube-fed (NG = 12 patients; PEG = 23; Low-Profile Gastrostomy [LPG] = 13; RIG = 3) (G. Axiak, personal communication, September 22, 2017). Knowing that the total SVP patient population stood at 1,083 residents (Superintendent's Office, personal communication, October 3, 2017), this translated in a figure of 4.7% of the total SVP residents as needing tube feeding. This figure of 4.7% residents who are tube-fed, in Malta's main statutory high dependency institution, did compare favourably to the 7.1% who were identified by the Minimum Data Set to be tube-fed in US nursing homes (n=1.41 million) (Amella, Lawrence, & Gresle, 2005), and to the 5.6% of nursing home residents in Germany (n=66,507) (Wirth, Bauer, Willschrei, Volkert, & Sieber, 2009). The Maltese proportion of tube-fed persons at SVP did also compare quite well with the study carried out in Italy by Bellelli, Frisoni and Trabucchi (2005) who indicated a prevalence of tube feeding in individual nursing homes ranged between 2.0% up to 6.6%.

When I performed a secondary analysis on the fifty-one residents who were tube-fed at SVP, thirty-five of these residents were found to be aged 65 years and over. Of these thirty-five aged residents that were tube-fed, eighteen were in the advanced / end-stage of dementia, while the remaining seventeen residents had a non-dementia related diagnosis. Regarding gender distribution, it was interesting to note that of the eighteen tube-fed residents with dementia; only two were males while sixteen were females. The mode of tube feeding in patients with dementia was distributed as follows: NG = 9; PEG = 6; LPG = 3; RIG = 0. These statistics confirmed the views expressed in the document *Consensus Document EndCare* (2018), which reported that one of the concerns in Maltese clinicians relates to the clinical management of feeding and hydration problems in dementia. Furthermore gender predominance of tube feeding in women confirm prevalence studies that dementia and its progression is more commonly found in the female population than in males (Erol, Brooker, & Peel, 2015).

It has been reported that care provision for older people in Maltese LTC settings does suffer from some notable challenges, where Borg Xuereb (2015) remarked that “LTC remains under-resourced, inequitable, fragmented and ineffective” (p. 319). Scerri, A. (2015) pointed out that hands-on care in the Maltese LTC settings is principally provided by carers, given the scarcity of nursing staff, where a sizeable number of carers and nurses are of non-Maltese origin (Borg Xuereb). Furthermore, it was reported that residents in institutions do suffer from deficient attention, with hydration singled out as inadequate (Scerri, A.; see also Camilleri, 2006; National Audit Office, 2005). Scerri, A. argued that staff shortages could be a plausible reason for such lacuna in care. All this was reported to be particularly relevant in end-stage dementia care given the patients’ frailty (Scerri, C., 2015). Scerri, A. added that better staffing levels and better training (Formosa, 2016) could help improve the quality of care in Maltese long-term institutions. Also, Brincat (2008) remarked that more time is needed during feeding time while the quality of food needed improvement.

The problem of bed-side care to patients with dementia with swallowing difficulties, came up to legal scrutiny when on March 7, 2012, a 64-year-old male patient with swallowing difficulties in dementia, was found dead in the toilet after he allegedly choked after eating a piece of chicken ("Nurses had clear", July 10, 2014). I am aware that in this case, a nurse and a nursing aide are currently appealing from the sentence of negligence in front of the Maltese Law Courts.

It is pertinent to finish this section by stating that I form part of the system of care as practised in Malta. I am a consultant geriatrician with 35-year experience in the care of frail older people, both at the community/acute/ rehabilitative settings, but mostly related to working in LTC settings, including the institution under study.

2. The Research Question and the Rationale behind it

In the quest to find appropriate systems to centralise medical services around patients, Soler (2005) remarked that the Maltese Health Care system has to take account of inadequate local formal guidelines to safeguard patient involvement in their programme of care. Expanding on this issue, *Consensus Document Endcare* (2018) pointed out that Maltese legislation is lacking in the regulation of situations of care regarding the provision/withholding/ withdrawal of extraordinary treatment in the EOL, of which CANH is a relevant example. Vassallo (2014) found that in geriatric practice, Maltese health professionals are faced with the absence of approved medical guidelines about the management of CANH when associated with mental incapacity.

Furthermore, advance directives, which form part of the framework of advance care planning for the EOL, are rarely used, as Maltese law is silent on this matter (Cassar, 2010; *Consensus Document EndCare,* 2018). Mallia (2010) pointed out that this situation leaves

Maltese physicians in considerable difficulty as happened in the case of Eluana Englaro in Italy. Mallia (2011, July 27) added that the lack of moral guidance, and consequent lack of a "proper framework of practice" (para. 9) pushes physicians into a state of crisis to define how to safeguard autonomy in end-stage dementia. The pitfalls resulting from this medico-legal vacuum, render not only medical, ethical and legal decision-making in the Maltese scenario more complex (Deguara, 2011) but also force Maltese physicians to steer away from tackling such hot issues in decision-making (Mallia, 2010). Furthermore, Abela (2015) reported that GP's tended to take EOL decisions based on their personal religious / philosophy of life beliefs. Such beliefs-based practice has to be considered in the context that many stakeholders "may not be aware of what their religion, for example, allows or not." (*Consensus Document EndCare,* 2018, p. 20).

Adding to this argument, Vassallo (2014) remarked that the medico-legal void regulating EOL care in Malta has not helped to find structured solutions to conflict on clinical care between the family and clinicians in severe dementia. One such conflict was pointed out by Cassar (2010) who stated that family involvement in medical decisions in dementia could end up sidelining the principle of autonomy as there aren't present explicit regulations that indicate consent from the patient for them to be involved. On this issue, Mallia, in his interview with the online newspaper *The Malta Independent* (Schembri Orland, 2016, July 24) remarked that in a back-drop where public knowledge on EOL care is limited, doctors might at times "feel obliged by family members to administer extraordinary treatment" (p. 1).

On the other hand, the fact that at SVP, the involvement of the family in the care of their elders was reported to be rather poor (Borg Xuereb, 2015), this has rendered more difficult the institution of meaningful communication between these two stakeholders, leading to additional conflict. In fact, lack of appropriate communication is known to be a major causative problem of conflict in decision-making between relatives and clinicians in end-stage dementia care (*Consensus Document EndCare,* 2018).

In this particular Maltese medico-legal scenario, it remains very difficult to understand what ethical models of decision-making are being applied by clinicians and family members to safeguard the best interests of persons in end-stage dementia. Furthermore, the lack of agreement on a plan of care might result in care strategies that might miss the central issue to meet the "wishes and needs of the person with dementia" (Bayer, 2006, p. 101).

Therefore in the formulation of the research question, I argued in favour to carry out an in-depth analysis of what ethical models of decision-making were being used in end-stage dementia care. Such analysis of ethical models through moral reasoning could be of help to define new avenues of EOL care strategies that give a more structured and balanced decisional process that better safeguards human dignity and interests of the person in care. In such approach, I was guided by a number of scholarly journal articles and reports (Hughes & Williamson, 2019; Agius, 2010; Chun-yan & Tao, 2004; Karlawish, Quill & Meier, 1999) that promoted a consensus-building approach, as this ethical model is inclusive of all stakeholders, whilst giving due attention to the patient’s dignity and interests in care. Although such appraisal in favour of consensus-building was given due consideration throughout my studies, I still kept a reflective open mind to consider all alternative ethical models in decision-making to explore which model of moral reasoning is the best for use in clinical settings in end-stage dementia care. Therefore, the research question addressed the following query, namely:

“What ethical models, if any, are being used and underpin the decisions of clinical teams and other stakeholders in relation to swallowing difficulties in end-stage dementia?”

To better focus on the issues at hand, this thesis concentrated on the high dependency nursing care sector in Malta, which is known to be the foremost contributor to EOL care in end-stage dementia (Mitchell, Kiely, & Hamel, September 2, 2004a). Attention was focused on long-term institutions in Malta, with SVP being given exclusive consideration, because of its status as Malta's largest LTC institution providing care for persons with dementia ("Department of Health", 2013). In fact, at the time of the study, SVP had five dementia care wards, two of which were Malta’s only purpose-built specialised dementia care units (*Empowering Change*, 2015). Furthermore, SVP harbours a high prevalence of dementia frailty, many of which are patients who are close to their EOL (Balzan, Ferry, Mangion, & Zammit, January 24, 2015; *SVP Dependency Evaluation,* 2016; *Annual Mortality Registry,* 2011).

To be able to focus on a meaningful EOL care situation, the fieldwork focused on the attitudes and dispositions in care concerning decision-making in the management of swallowing difficulties in end-stage dementia. Van der Riet, Good, Higgins, and Sneesby (2008) reported that judgments concerning EOL management of swallowing difficulties management in dementia are intrinsically difficult team-based decisions that evoke complicated medical and ethical issues, and yet are amenable to improvement through the development of appropriate care guidelines.

Given the complexities in causation and possible reversibility of other causes leading to feeding and swallowing problems, unless otherwise indicated in this thesis, wherever reference is made to feeding difficulties, the discussion of clinical and ethical management will generally orientate towards issues related to severe/life-threatening EOL swallowing difficulties in end-stage dementia.

3. Chapter Outline

Hereunder is a chapter outline that will be followed in this thesis:

Chapter one, titled “Decision-making in End-Stage Dementia” gives an overview of decision-making theory as applied to the study in question. It also addresses the issues/opportunities that are involved in early phase dementia decision-making, as compared to what is implied when clinical decisions are taken once competence is lost.

Chapter two, titled "Thorny issues concerning Clinical Decision-making in Dementia," looks at the reasons why staging of dementia is so important for the clinical management of persons afflicted with this condition, particularly concerning care in their last phase of life. The focus on the EOL, leads to consideration of what is implied by palliation, aggressive medical management and euthanasia. Such account also explores the conflicts that such care choices do inflict on decision-makers, particularly on issues related to EOL swallowing difficulties

Chapter three, titled "Safeguarding the Human Dignity of Persons with Dementia" involves a critical analysis of models of moral reasoning in ethical decision-making. The arguments discussed in consideration of the ethical models involved, lead up to reasoning in favour or against the virtues of consensus-building approach, which seems to provide the best opportunity for the sort of moral reflection that is considered to overcome the clinical dilemmas of EOL care decisions in dementia.

Chapter four, titled "Methodology, Results and Analysis of Data" looks at the scientific methodology as it relates to a qualitative approach. Attention is also given to explain the decision to use multiple case-study design. Furthermore, explanation is given regarding the aims of the study, choice of participants, sampling technique, and inclusion /exclusion criteria as they relate to decision-making in the management of swallowing difficulties in end-stage dementia. Also, attention to critical analysis of the results will be carried out in keeping with the care processes that are guideline-based for good practices in other European countries.

Chapter five discusses "Research Findings". This chapter starts by giving a brief profile regarding the six cases studies and how decisional stakeholders interacted between them to come to a decision point in each situation of care in end-stage dementia. Following which, the emerging themes as they came out through thematic analysis (Braun & Clarke, 2006) are related to the research question. The sequencing of themes takes account of which ethical principles, ethical theories, and values underpin moral reasoning to decide management of swallowing difficulties for persons in end-stage dementia.

Chapter six concerns the “Discussion” of the research findings as they relate to the literature review. This chapter carries out a moral reasoning approach to the models of decision-making involved in the management of swallowing difficulties in end-stage dementia. At the end of this chapter, arguments are brought forward in favour or against of consensus-building approach as being the ethical model that showed most promise in the management of complex EOL decision-making in end-stage dementia.

Chapter seven concerns the “Concluding Reflections”. This chapter rounds up the whole thesis with a brief overview of reasoning, methodology, and findings arising from the research. It includes a section on proposals for recommendations to help promote an ethically appropriate decision-making process in dementia that can be implemented in institutional care in Malta. In the end, recommendations for future research are listed.

This thesis has followed the American Psychological Association [APA] writing style requirements (2010, 6th. Ed.). The literature review was primarily based on access to the search engine for online resources [HyDi] at the University of Malta [UOM] Library. Specific access to Maltese literature was gained from various local sources, including the Melitensia Collection (UOM). Additional resources were accessed from EBSCO host, CINAHL, PubMed, Medline Plus, Cochrane Database, ProQuest and Social Science Premium Collection.

Chapter 1: Decision-Making in End-Stage Dementia

In this chapter, the complexity underpinning end-stage dementia decision-making is given attention. This is followed by an overview of decision-making theory leading to a discussion on team decision-making. In the end, an account is given on decision-making before and after mental capacity is lost.

1. Introduction to Decision-Making

A. The complexity associated with decision-making in end-stage dementia.

The progression of dementia to its end-stage does lead to worsening cognitive decline in association with social losses, functional deterioration and physical debility (Seymour et al., 2005). Linked with cognitive deficits in end-stage dementia, decision-making capacity is lost, leading to the ethical difficulty to find ways to ensure that patient preferences remain relevant and respected in their EOL (*Dementia Long-Term*, 2009). The resulting inability of the person with dementia to make informed choices regarding care in their last phase of life, places a high level of responsibility on emotionally involved family members and clinicians, who are thus faced with a complex decisional dilemma on how to interact together to safeguard the patient’s dignity, rights, needs, values, wishes, feelings and interests in care (Scheirton, 2010; Sasson, 2000; Sloane & Zimmerman, 2010; *GMC*, 2010) (the complexity of decision-making in dementia is also considered in Chapters 2, 3 & 6).

Furthermore, it is common to see that the clinical alternatives available in end-stage dementia decision-making are not clear-cut (Hughes & Baldwin, 2006), particularly where it concerns decisions regarding the management of swallowing and feeding difficulties in end-stage dementia (Gillick, 2000). Consequently, the problem in end-stage dementia decision-making relates to a real life situation to deal with, “the messy, eclectic world of morals”

(Hughes & Baldwin, p. 31), where the clinician is asked to face decisional doubt of what is appropriate or futile, and also where "cost-benefit analysis is open to differing interpretations" (Pace et al., 2011, p. 239). This complexity leads to the application of various, often conflicting ethical models in decision-making (Hursthouse & Pettigrove, 2018), where the real challenge is to find what is the right management in the face of feeding and hydration difficulties in end-stage dementia (Bowker, Price, & Smith, 2006). As Hughes and Baldwin remarked, the ultimate aim is to appreciate the difficulties encountered in decision-making leading to an exploration of an ethical "variety of approaches as a way of challenging our attitudes" (p. 35), leading to interventions that safeguard the dignity and interests of vulnerable persons with dementia in care (Agius, 2010; Hertogh, 2006).

B. The process of decision-making.

Clinical decision-making is "a complex process involving observation, information processing, critical thinking, evaluation of evidence, applying relevant knowledge, problem solving skills, reflection and clinical judgement to select the best course of action, which optimises a patient's health and minimizes any potential harm" (Standing, 2010, p. 6).

Decision-making is a complex yet challenging process, particularly in planning the EOL, where, despite all good intentions, not all challenges will find a favourable solution. In truth, nobody can perfectly foretell the future, in a situation where persons in care do tend to change their choices as the disease process progresses and worsens (Emanuel & Scandrett, 2010). Furthermore, decisions taken by patients in dementia are frequently malleable or influenced by others, where none influences them more than their caring physician and family members (Emanuel & Scandrett; Pace et al., 2011).

The process of decision-making involves a set of significant steps to be followed (Pekel & Wallace, 2006), which determine the process leading to a plan of care (see Table 1).

2. Decision-Making Theory

Decisional theory analyses behaviour that is goal-directed, in a situation that is exposed to various options (Hansson, 2005). The application of decisional theory in everyday medical practice does not come naturally to the physician (Elstein, 2001), who instead base decisions on “insufficiently grounded evidence-based explanations” (Reyna, 2008, p. 823). To this end, the application of “evidence-based predictive scientific theory” (p. 823) could be of help for clinicians to base clinical decisions on descriptive scientific theory leading to better validity and generalisability.

Standing (2010) remarked that decision-making models find scope in their collaboration with clinical decision-making experiences, in the quest to “help inform, analyse, explain and justify their actions” (p. 9). In reality, there exist various decisional models available, and thus, the researcher must be wary of deciding which model would be most appropriate for current usage to avoid unwarranted outcomes (Klein & Calderwood, 1991). Even though in reality, the distinction between theoretical models is often blurred (Dillon, n.d.), decision-making can be sub-divided into three levels of decision-making models (Baron, 2012), namely:

- Normative decision-making
- Descriptive decision-making
- Prescriptive decision-making

A *normative decision-making* model is an evaluation of standards, in the sense of explaining behaviours as they should be done (Baron, 2012). Such models are often used in large-scale experimentation and survey research (Standing, 2010), and in the assessment of risk (Shaban, 2012). In ethics, normative decision-making gives an account of what “actions are right and wrong and why” (Beckwith, 1996, p. 40).

Descriptive decision-making models are theories used in studies that aim to give answers to how people make decisions and the underlying judgements behind such decisions

(Baron, 2012). Shaban (2012) remarked that descriptive models are naturalistic and give arguments to explain where and how persons decide atypically away from normative models.

In other words descriptive scientific theory is an exercise to improve validity and generalisability to grounded tasks, techniques and themes (e.g. patient-centred decision-making) on explanations that are evidence-based on real behaviour as applied to human judgment and decision-making (Reyna, 2008). The utilisation of the descriptive model can also follow the hypothetico-deductive theory (Thompson & Dowding, 2002). Likewise, descriptive models of judgement and decision-making give importance to "investigating, heuristics, uncertainty, biases, and error in judgment decision-making" (Shaban, 2012, p. 3).

Descriptive models can be sub-classified as being holistic (i.e. look at a subject as a whole rather in components) or non-holistic. An example of a holistic evaluative strategy is seen in behavioural decision theory (Dillon, n.d.).

Prescriptive decision-making models are frameworks of research that apply the assumptions derived from previous studies and help improve judgments and decision-making by examining how people make up decisions (Shaban, 2012).

A commonly used prescriptive model for judgmental decision-making is in the setting up of assessment tools, clinical guidelines and clinical policies (Shaban; Standing, 2010), which all have a common aim that to improve quality in care.

Shaban (2012) also referred to additional theories of clinical judgement. Namely:

- The social judgement theory.
- Intuitive judgement.
- The expert-novice theory.
- The cognitive continuum model.

Li (2008) stated that the *classical model of decision-making* is a traditional approach that integrates the notion of discussions leading to rational decisions. Thus it finds its usefulness in prescriptive based guideline development (Klein & Calderwood, 1991). The classical model theory begins with a search for the right questions, leading to a search for unearthing creative answers and ending up ensuring that the choice taken is useful (Shaban, 2012). Li explained that such “rationality is equated with scientific reasoning, empiricism and positivism and with the use of decision criteria of evidence, logical argument and reasoning” (p. 151).

It must be pointed out that evidence-based medicine and clinical decision analysis are both derived from classical decision theory and help in the development of practice guidelines (Elstein, 2001).

Klein and Calderwood (1991) remarked that classical decision models assume that there is the isolation of goals, with utilities being deduced to be independently assessed from context, where probabilities can be exactly calculated. Klein and Calderwood added that these assumptions are quite difficult to be found in the real world.

A. Naturalistic decision-making.

Naturalistic decision-making is a methodology of how to study people in decisions involving cognitive functions that are often complex and done in practical situations (Klein, 2015). Naturalism concentrates on the study of expert behaviour through descriptive models, while it stays away from the normative-descriptive controversy that is often seen in the “heuristics-and-biases tradition” (Elstein, 2001, p.364).

Elstein (2001) added that there exists a close similarity of naturalistic decision-making to what happens in clinical medicine. To this end, naturalistic theory has shown promise in improving the knowledge related to clinical decision-making.

Elstein (2001) remarked that diagnostic decisions are usually deduced by the generation of a structured and unstructured hypothesis known as a hypothetico-deductive method, which is a hypothetical method that can be grasped under the framework of naturalism (Mantzavinos, 2005).

Naturalistic research concentrates on expert versus novice responses, including decisions that rely on case presentations with controlled databases (Elstein, 2001). On the other hand, they also tend to "treat case content as the independent variable, decisions or judgement as to the dependent variable and do not ask subjects to justify their responses'" (p.364).

At the same time, it is known that in natural settings, decision makers do tend to rely heavily on heuristics and intuition as an interpretation of experience (Klein, 2015). One way how to avoid normative-descriptive tension in heuristics and biases traditions can take the format of naturalistic decision-making through the application of the descriptive model to study expert behaviour (Elstien, 2001).

In all this, Klein (2015) remarked that naturalistic analysis does help delve deeply to identify differences in decisions taken by different expert decision makers. Elstein (2001) argued that naturalistic decision-making, unlike classical decisional and behavioural decisional theory, does mainly find scope in the analysis of mistakes and may help to identify organisational factors that adversely affect performance.

B. A theoretical account of team decision-making.

Referring to social decision theory, many rules that were developed to address individual decision-making, do find a reason to be also utilised in group decision-making (Hansson*,* 2005). Hansson added that collective decision theory is a model of situations where decisions are taken by more than one person, who may or may not see eye to eye on how goals and outcomes can be achieved. Thus the main principle of social decision theory in teams is "the aggregation of individual preferences [choices] into collective preferences [choices]" (p. 79), which in social theory is the attempt to find a model to combine individual choices into a set of social preference/choices.

An analysis of the social processes of decision-making needs to be supplemented by a cognitive analysis of team decisions (Zsombok, 2014), this is particularly true in advanced teams who utilise cognitive or thinking processes, to come to team decisions.

The study of the process and outcome in team decision-making (Zsambok, 2014) has shown that teams work more efficiently when they have a mutual mental model, particularly if the members of the team have a common mission. Furthermore, team decision-making renders better outcomes where the processes of the team are based on realistic assessments that are commonly understood by all members of the team (Zsambok). Also, Kolbe and Boos (2009) remarked that poor group decision quality (process loss) is most strongly influenced by an insufficient exchange of information that does relate to the decision in question.

Several variables characterise a naturalistic decision-making approach in teams (see Table 2).

Kolbe and Boos (2009) remarked that based on functional theory, effective group decision-making should consider: the "performance-related criteria, but also to social and egocentric aspects" (p. 2) and in so doing give value to the limitations of the organisation, the promotion of a basic understanding of interaction and the intention to reach each individual's goals.

The individual members of the team form the structure of the team, which structure leaves an important influence on team decision-making performance (Zsambok, 2014). Zsambok added that team performance is also dependent on the individual characteristics of its members, namely:

- "Information (who knows what)
- Expertise
- Resource ownership
- Authority (hierarchical versus non-hierarchical)
- Responsibility

- Communication" (p. 118)

Concerning cognitive approaches to decision-making, healthcare decision-making is frequently a complicated process necessitating input from "ill-structured, uncertain, and potentially conflicting information from various sources" (Kushniruk, 2002, p. 365). To this aim, naturalistic studies have been carried out in areas of complex decision-making processes. Kushniruk added that such work rotates around nonobtrusive observation studies or the involvement of retrospective reports on the investigation of decision-making in key situations. In so doing, cognitive methods that study team decision-making do offer a valid basis to define better the strategies and difficulties faced by decision-makers in the outside world.

3. Decision-Making in Dementia: the Patient-Doctor Relationship

Elwyn, Edwards, Gwyn and Grol (1999) referred to three models of decision-making that are commonly applied in doctor-patient relationships in general practice, these are:

- A *paternalistic approach* where the physician takes full responsibility for clinical decision-making.
- *Informed care choices* are where the physician gives the patient full details on the condition in contention and leaves the final decision on treatment choice in the hands of the patient.
- *Shared decision-making* comes in between the above two models, where after appropriate communication to the patient of the disease, risks and benefits of treatment, a joint decision is agreed upon between the person in care and their physician. This shared decision can henceforth be drawn up as care plan to eventually be transcribed into medical decisions (*Alzhiemer's Association*, 2007).

In many countries, when a person becomes mentally incompetent the health care team is legally obliged to turn to the family to decide in the patient's name (Bowker et al., 2006; Chun-yan & Tao, 2004). In so doing, they should respect any advance directives that had been drawn up by the patient in days when the capacity to decide was still present (Emanuel & Scandrett, 2010). All decisions being done in the patient's best interests (*RCP,* 2010). The Maltese *Mental Health Act* (2012) stipulates that wherever the patient's mental capacity to decide is lost, decisions should be taken in a shared manner between the multi-disciplinary team and involved relatives (see also Introduction) leading to a joint care plan.

Whilst decision-making regarding feeding difficulties in the EOL is ultimately a clinical decision (Arenella, 2005), such decisions should incorporate a team approach that includes input from the family and the patient's past wishes, with a clear intention to respect the persons' values (Scheirton, 2010; Gillick, 2000) and ensure compassion, comfort and dignity (Byrd, 2004).

One problem faced in end-stage dementia is the attitude of health professionals and the family to EOL care, where the clinicians and the family impose their preferences and values (Carmel, Werner & Ziedenberg, 2007). One possible consequence of such behaviour is that the wishes of the patient ultimately end up not being implemented (Shah & Lloyd-Williams, 2003). For such reasons, all those concerned must aim to utilise increased communication and clinical decision-making techniques that are based on ethical principles. Mitchell and Lawson (1999) remarked that such an approach is particularly relevant wherever it concerns the management of nutrition and hydration issues in end-stage dementia.

4. Team Decision-Making

Geriatric practice is based on a *multidisciplinary team* approach (Bowker et al., 2006), where the clinical team meets regularly to communicate; address goal setting; review progress, and set up care planning. In fact a multidisciplinary team approach is one of the recognised models of care in nursing homes, where team interventions, do help improve the quality of the comprehensive care that is offered to institutionalised older adults suffering from chronic conditions (Boult, C., Green, Boult, L., Pacala, & Snyder, 2009). In decision-making regarding swallowing difficulties, the team is composed of the doctor, nurses and carers, the SLP, nutritionist, dietician and family members (*RCP,* 2010).

Effective Decision-making (n.d.) (see also Johnson & Johnson, 2000) described various styles of practice that characterise team decision-making (see Table 3).

A. Shared decision-making and consensus-building approach.

Shared decision-making "is a process in which clinicians and patients work together to select tests, treatments, management and support packages, based on clinical evidence and the patient's informed preferences" (*Measuring Shared Decisions*, 2012, p. 4). It, therefore, involves the process where decision-making is evidence-based and also helps to address options and uncertain goals. All this happens in a situation where the patient is receiving counselling on decision-making (*Measuring Shared Decisions*), and where respect is given to the patient's values, needs and wishes (Epstein et al., 2005).

In shared decision-making, the patient and the clinician should be involved, although the family may also be asked to participate (Barry & Edgman-Levitan, 2012). Assistance in decision-making by the clinical team is fundamental as patients do usually lack a cultured knowledge on their health status and the series of interventions they need. Furthermore, family knowledge is also lacking where it comes to outcome and prognosis of the disease/s they suffer from (Rosenfeld, Wenger, Kagawa-Singer, 2001).

Lewis et al. (2006) stated that patients and family members give value to shared decision-making as the favoured model of care in end-stage dementia. In fact, in situations of mental incapacity, family members favoured the model of "dual authority" (p. 624), where they would be flanked by support and responsibility on decisions by the physician in care (Rosenfeld et al., 2001).

On the other hand, shared decisions give the healthcare system the chance to achieve improved health and better care, with improved patient satisfaction and better treatment compliance (*Shared Decision-making*, 2013). In shared decision-making, the contribution of both the patient and the clinician are seen as equally important, and each brings their beliefs, values and expertise into the decision-making process (Elwyn et al., 2012). This values-based approach helps to assist in the development of patient-centred care, where the focus is the patient and the family rather than the disease itself (Sepucha & Scholl, 2014; Elwyn et al.), leading to the development of a care plan (Emanuel & Scandrett, 2010). Furthermore, studies have shown that where patients are exposed to shared decision-making, they are more inclined to choose options that are less invasive for their EOL (Sepucha & Scholl).

Patient centred care has a moral philosophy with three main values (Epstein et al., 2005, p. 1517; see also McWhinney, 1995), namely:

- “Considering patient’s needs, wants, perspectives and individual experiences.
- Offering patients the opportunity to provide input into and participate in their care.
- Enhancing partnership and understanding in the patient-physician relationship.”

The potential positive outcomes of shared decision-making include its ability to improve health outcomes based on evidence-based practice (*Shared Decision-Making,* n.d.). It needs to be appreciated that the process of implementation of shared decision-making is highly dependent on the attitude of clinicians towards the process. It is thus fundamental that the clinician accepts their implementation along with their associated “guiding ethical principles’ (Elwyn et al., 2012, p. 1361).

Patient decisional aids (PDA) **s**eek to offer the patient the necessary support to ensure that they have understood the options and implications of the communication between them and the clinician (*Measuring Shared Decisions*, 2012). Personal decisional aids have been produced to help relatives in decision-making to manage swallowing difficulties in dementia, which results were deemed encouraging and helping to meet the true needs for support by the family in such circumstances (Mitchell et al., 2008)

Consensus-building is an approach to decision-making that gives high priority to reaching an agreement between all stakeholders and respect for the patient in care (Chun-yan

& Tao, 2004). To this end, it is the preferred decision-making model of choice to best meet the principles of shared decision-making (*Measuring Shared Decisions*, 2012).

There exist three formal approaches of consensus methods that are often utilised in healthcare; these are (*NICE,* 2006, March): “the Delphi method; the nominal group technique and the consensus-development conference” (p. 9.2). *NICE* remarked that each method has its positive points and limitations while acknowledging that hybrids (informal approaches) of consensus methods do exist (see also Chapter 3, Section 8). *NICE* added that the choice of method should be based on the needs of the group.

The *Delphi technique* is one format of consensus decision-making (“Skill Building Group”, 2011) where individual group members, who are experts in their field, are “asked to independently provide ideas, input, and alternative solutions to the decision problem in successive stages” (p. 3). In medicine, the Delphi method is principally involved in clinical guideline setting.

The *nominal group technique* is a practical, orientated structured consensus approach that is often utilised to seek convergence in complex issues in healthcare (Jones & Hunter, 1995). This method helps to generate a wide range of ideas, which may include clinical questions, to help find solutions. The facilitator helps to structure the questions that need to be answered, and also allows all individuals involved to express their views (*NICE*, 2006, March).

The *consensus-development conference* draws experience from the “judicial decision-making process” (Murphy et al., 1998, p. 6) and does relate to a group of about ten people who are asked to verify “evidence by various interests groups or experts” (*NICE*, 2006, March, pp. 9.2.4).

5. Having the Foresight to Plan Ahead

It is to the credit of modern medicine and technology that today we are in a position to offer patients a diagnosis of dementia in its earliest stages of development (*World Alzheimer*

Report, 2011). Such a diagnostic breakthrough has allowed local health and voluntary organisations to push forward policies for early dementia management through the development of national dementia strategies (Goodchild*,* 2009). To this end, in 2015, the Maltese Parliamentary Secretariat for Rights of Disabled Persons and Active Ageing published the National Dementia Strategy (*Empowering Change,* 2015) for Malta for the years 2015 – 2023 (see also Introduction).

Coming to a diagnosis in the early phase of dementia does give benefit to allow sufficient leeway for timely intervention, treatment and research (*APA*, 2013). The *World Alzheimer Report* (2011) categorised a list of benefits that justify early diagnosis (see Table 4).

It is relevant to point out that in the early phase of dementia, persons afflicted with this condition, remain capable of making decisions about their care, even though at times they would require support by others to do so (*Nuffield Council Bioethics,* 2009). Such cognitive preservation is a major point in favour of early diagnosis as with the progression of dementia, persons do eventually end up losing their decision-making capacity (Linzer, 2002).

Therefore, early diagnosis in dementia grants the patient the chance to declare their personal preference for their EOL before they lose their capacity to take decisions (*Alzheimer's Association,* 2007). Furthermore, through such early intervention, if the person with early dementia is appropriately guided to plan their future care, this could notably help to alleviate the decisional burden on the family and friends, concerning often difficult care decisions that will ultimately arise towards the EOL (Scheirton, 2010). At the same time, the identification of treatment goals, in respect of the patient's desires, may also help to reduce friction between professional staff and the family in the end-stages, to the point that this safeguards consensus agreement in EOL care (Gastmans, 2016). Nonetheless, the progressive nature of dementia demands that advance directives are repeatedly reviewed to re-evaluate the changing care situation through time (Gastmans).

Panke and Volicer (2002) reported that early diagnostic disclosure of dementia to patients helps them to make informed care choices. The early awareness of their diagnosis enables the patient to be able to participate in *advance care planning* [ACP], where disease trajectory and possible treatment options are discussed. Such patient involvement grants them the opportunity to draw up a plan of preferences for care in their EOL when in end-stage dementia their decisional capacity is lost (Soler, 2005).

Planning for future care in early dementia regarding feeding difficulties in the end-stage of the disease process involves an evaluation of various options. The position document commissioned by the Royal College of Physicians in association with the British Society of Gastroenterology (*RCP,* 2010) recommended that the person concerned in planning for future care should be given information on the following:

- “Details of what a PEG tube is and how it is placed.
- Its daily use and care and that it may not manage all the patient's problems.
- Discussion on the potential impact on morbidity and mortality.
- Details of how to make wishes known in future” (p. 71).

It is relevant to point out the views of cognitively preserved older people on tube feeding if they were eventually to lose their cognitive capabilities. On this issue, Gillick (2000) reported that most persons when staying in nursing care would prefer not to be administered artificial feeding, especially if such intervention required additional restraint.

Furthermore, the fact that the use of CANH in terminal care remains a controversial issue (Bowker et al., 2006), makes it even more pressing that information on its risk/benefits in EOL care be communicated to the patient (RCP, 2010), earlier on in dementia and therefore in due time to express their own informed care choices for their terminal care. Consequently, unless one has sufficient reasons not to inform, it is the right of the individual to be given a diagnosis (Nuffield Council Bioethics, 2009) (see also Chapter 3, Section 6).

Furthermore, it is known that education of patients in the early phases of dementia can empower them to better deal with the progression of their disease (Scheirton, 2010), and grant them the chance to participate in ACP (Panke & Volicer, 2002). To this aim, the NICE-SCIE (2007) guideline recommended that on diagnosis, barring situations where the patient requests to be left in the blind about their disease, professionals are advised to give the person with dementia and their relatives information about, “the signs and symptoms of dementia, the course and prognosis of the condition, treatments, and support services. (p. 163)

Also, one must not discard the fact that granting the patient the chance of early recognition of their diagnosis of dementia, might enable them the opportunity to change existing living wills, set up new ones, or designate a health proxy designation (Panke & Volicer, 2002).

In the presence of pressure to deny the patient their diagnosis, the proper attitude of the doctor is to respect the patient’s autonomy and ask the patient what they want to know about their medical condition (Soler, 2005), as denying the patient a diagnosis amounts to the deception that undermines the doctor-patient relationship.

A. Advance care planning in dementia.

The importance of advance care planning [ACP] for EOL care in dementia is a logical solution to facilitate control on one’s future self, particularly if one accepts the issue that persons in the end-stage of the disease are considered as suffering from a terminal illness (Caplan et al., 2006). The early participation of the patient in future care planning goes in line with the principle of health promotion palliative care, which aims to ensure control of the self in the face of a terminal illness (Blackford, Strickland, & Morris, 2007). To achieve such control on their lives in dementia, the patient needs to be adequately supported to “enable people to make genuine choices about their care” (*Better Palliative Care,* 2004, p. 19). One application of such ACP in long-term-care does apply to the management of swallowing difficulties (*Commission Social Care*, 2008).

In practice, the family or another proxy should be involved from earlier on in the disease process, where they should be given an explanation of the current stage of dementia and what they would expect later on in the disease process (Gillick, 2010). Henceforth Gillick added that in drawing up an ACP, the family can be helped to foresee EOL feeding difficulties in dementia and at the same time be prepared to come to terms, from earlier on, of what problems can arise in the EOL.

Evans and Robinson (2010) remarked that discussions on ACP should preferably start while the patient is still living in their own home, however, when this is not possible, discussion on advance directives should start at the point of entry to a care home, as part of the admission process. However, one must acknowledge that on admission to long-term care, it is often too late as mental capacity would have already been lost (Stewart et al., 2011).

On the other hand, while drawing up an ACP in dementia, the family is frequently observed to be in turmoil to decide and identify what is best for their elders (Gillick, 2010). To start with, relatives do not easily accept dementia as a terminal condition, at the same time they are at a loss, to consent or refuse burdensome and often painful life-prolonging treatment interventions on their elders who, being in the end-stages of dementia, are incapable of understanding what is going on (Gillick). Another problem that is encountered with the involvement of the family is that, at times, such communication does unearth unrealistic expectations, which require further discussion with the family to help them come to terms with the terminal condition of their elders (Evans & Robinson, 2010).

Gillick (2010) added that the involvement of the family in ACP, wherever there is absence of advance directives, does help reduce the emotional burden of the family, as it does help them to prepare for difficult EOL decision-making.

To ensure maximal return from advanced care planning, the person with dementia and their carers need to be given adequate resources and information on advocacy services and support, to learn how to plan for their future care and welfare through advance directives (Scheirton, 2010).

The filling out of an ACP document should never be a one-time event, but should actually be a dynamic document (Evans, & Robinson, 2010). The supporting clinicians should also draw benefit of episodes when the patient is lucid, whilst at the same time offering a chance to discuss the experience of the progression of dementia, which in itself serves another important role of helping those involved “come to terms” (p. 145) with the condition.

Advanced care planning being patient-focused, does help to satisfy policy guidance on EOL palliative care (*Alzheimer Europe*, 2008). The inclusion of ACP in EOL care does help sustain QOL and quality palliative care for patients with dementia in nursing care (Caplan et al., 2006).

In EOL care, multi-disciplinary team involvement goes in line with recommendations drawn up by the Gold Standards Framework for Care Homes, which advices for, monthly reviews of the patient’s condition by the team with the involvement of the resident and family; a completion of the ABCD prognostic register, and updating of ACP (Watson, Hockley, & Murray, 2010).

Advance care planning fall under two types, the first type are those drawn up before the loss of mental capacity, and the second, ACP is written after capacity is lost. Gillick (2010) reported that the results of these two formats of ACP are usually influenced by the “cultural, legal and institutional factors” (p. 263) that are present in that particular circumstance.

Some experts argued that what is fundamentally important in ACP is not that the patient documents their advance wishes or drawing a living will for their EOL care. However for them it makes more sense to identify a family member to act as a proxy of their trust to whom responsibility for terminal care would be delegated in situations where the patient cannot decide for themselves (Rosenfeld et al., 2001).

B. Advance care directives.

In most cases, ACP does eventually lead up to the drawing up of advance directives documents (Godfrey & Hackett, 2015). Caplan et al. (2006) clarified the distinguishing features between ACP and advance directives. ACP refers to “the discussion held by a person with their health advisors, carers and families, with the intent of framing an advance care directive” (p. 582); whilst an advance directive is a “written legally binding document that expresses preferences for future medical treatment” (p. 582). Bowker et al. (2006) added that advance directives do come in force when the patient loses decisional capacity.

Many bioethicists advocate the use of advanced care directives or living wills as a format that helps the person with the mental capacity to retain control, even after they become incompetent (Wellie, 2010). Therefore such advanced directives, help to promote the principle of personal autonomy (Bowker et al., 2006).

Advance directives consist of a set of specific written instructions about one’s future health care that in many countries are legally binding for health professionals (Wellie, 2010). In fact in the UK, the *Mental Capacity Act* (2005) acknowledges the legality behind the desire of persons to make known their wishes for future care (*Nuffield Council Bioethics*, 2009), and if doctors are found to provide a rejected treatment they face the possibility of being sued for battery (Bowker et al., 2016). Although advance directives can be done verbally with a trusted acquaintance, it is best that advance directives are drawn up in writing and witnessed (“Frequently Asked Questions”, 2010). It is relevant to point out that advance directives cannot relate to requests for futile treatment, but instead concern personal wishes for refusal of certain care interventions (*RCP,* 2010).

Advance directives are instructions which fall under three categories (Bancroft Hecht & Shiel, 2011):

1. Living will;
2. Health care proxy;
3. Power of attorney.

Referring to the legality and ethical protocols of decision-making in mental incompetence in Malta, Cassar (2010) remarked that “advance directives in Malta are not popular and Maltese Law is silent on the subject matter” (p. 49). Cassar (2013) added that Maltese law does not “provide for situations where a health practitioner refrains from administering extraordinary treatment such as ANH... to a terminally ill patient” (p. 12). The Bill concerning *National Minimum Standards* (2015, September) for care homes in Malta, has gone a step further on this issue by recommending the need to safeguard resident’s choices in situations of dying and in the face of future incapacity to express one’s wishes “to the extent possible” (article 10.3) under law.

Knowing these legal shortcomings, it is uncommon for Maltese health professionals to base clinical decisions on advance directives and the role of advance directives remain dubious (Cassar, 2010; Bowker et al., 2006). Mallia (2011) remarked that the rule of law is important in a democratic society, and henceforth to respect and honour patient rights as in advance directives, these have to be enshrined in law to be acceptable to clinicians for inclusion in their practice. Mallia (2011) added that the fact that there is no law governing advance directives in Malta, even when such documents have been written, it remains at the discretion of the attending physician whether to honour them or not, whilst the attending family may also be inclined to over-rule such past wishes (Mallia, 2010). Consequently, in practice, when faced with problems of mental incapacity in dementia, the Maltese medical profession usually turns to the family to gain insight on the patient’s wishes (Cassar) and thus practically disregards patient autonomy.

In situations where advance directives are not present (or not legal as in Malta), the clinician is obliged to prescribe clinically appropriate treatment (Bowker et al., 2006) that respects their best interestss (*RCP,* 2010). In such cases, decisions should give importance to the patient's religious beliefs, culture and values (Goodman et al., 2010). Goodman et al. added that such decisions are often influenced by professional training, an appreciation of what is palliative care in dementia in that setting, and the views of significant others. In such situations, the involvement of the family is appropriate to help safeguard patient personal values in EOL care (Cassel, 2010).

C. Power of attorney.

In the UK, when in mental capacity a person grants a lasting power of attorney [LPOA], this authorises another person to speak on their behalf for both health and welfare decisions in eventual incapacity (Welie, 2010).

Maltese law is silent regarding LPOA. In fact, in Malta, there exist two formats of power of attorney [POA]. One of them is called a *General Power of Attorney*, which is similar in use to the POA in the UK, this legal document holds until the person retains mental competence. Apart from the above, in Malta there is also a non-general, task-specific *Power of Attorney*, which grants authority to an attorney to be delegated the responsibility for a particular financial task, this is usually used to specifically help in the cashing of a retirement pension or for other bank related transactions. Before 2012, when mental incapacity used to set in, the only option available that was to applicable by Law for legal representation of the patient, was to seek interdiction of a person lacking mental capacity, and in so doing the Law appointed a curator as a delegate for decisions (B. Gafa, personal communication October 24, 2011). The duties of a curator include taking care of the well-being and the personal interests of the person under interdiction (*Code of Organisation,* 1855; Substituted by XXIV. 1995.344).

In 2012, the Maltese Parliament passed a Guardianship Act (*Code of Organisation*, 2012, Act No. XXIV of 2012), giving a legal title to a person/s who offer and are approved by the Guardianship Board, to serve as a guardian for persons, who are interdicted or incapacitated and thus incapable to manage their own affairs. Such guardians take up the responsibility of the "personal and proprietary well-being" of the incapacitated person and have to act in the best interests of the person under guardianship. Its advantage is that it is a much simpler and faster process to draw up than sanctioning for interdiction; it also involves no legal fees and does not necessitate the involvement of a specialist in psychiatry for guardianship to be implemented.

Mamo (personal communication, September 26, 2015) added that apart from interdiction and guardianship, in Malta there exists a "Specific Incapacitation Order" under the 11th Schedule of the *Mental Health Act* (2012, Cap 525), where a person is temporarily (maximum 26 weeks) certified for temporary incapacitation.

D. Arguments that question the validity of advance planning in dementia.

Despite finding the approval of bioethicists, who claim that advance directives do help surrogate decision-makers bridge the gap to provide a better QOL for persons with dementia (Welie, 2010; Caplan et al., 2006), in reality, ACP is not very popular (Godfrey & Hackett, 2015). Only 0.2% of Australian nursing home residents have drawn up such advance plans (Nair, Dobson, McPhee & Saul, 2008); while in England and Wales only 8% of the public had filled out an ACP leading to advance directives (*Advance Care Planning*, 2009).

The reasons behind the lack of application of advance directives in clinical practice are quite varied, and there exist a multitude of variables and situations that act as barriers to hinder their use (see Table 5).

To counteract the barriers associated with the use and recognition of ACP, Stewart et al. (2011) recommended that all concerned: namely the clinician, the patient, and family, should be given appropriate training in drawing up ACP's. Furthermore, clinicians should be given specific training to improve communication skills and be better able to explain in simple terms any medical terminology and prognostic statistics (Welie, 2010).

6. When it is too late to Decide

A. Mental capacity assessment and issues of decision-making.

It is relevant to point out that persons by default are presumed to retain capacity unless proven otherwise (*Mental Capacity Act*, 2005). Also persons in early dementia should be provided with sufficient support from skilled health professionals to enable them to make decisions on their care (Panke & Volicer, 2002).

Darzins, Molloy and Stang (2000) remarked that when mental capacity is lost, this is not an all or none phenomenon; capacity can vary with the difficulty of the specific task at hand and also about issues in discussion.

One of the cardinal consequences of advanced dementia is that the person affected develops problems with cognition to the point that they lose the capacity to make decisions about their welfare and care (Panke & Volicer, 2002). In fact, from a medico-legal point of view, such loss of mental capacity to decide ends up affecting the management process of decision-making in feeding difficulties *(RCP*, 2010).

Since 2007, in the UK, once a situation of mental incapacity is diagnosed, both health and social entities are obliged to follow the *Mental Capacity Act* (*NICE,* 2006, November). This act endorses five main principles, namely (*NICE*):

1. Adults are presumed to have capacity unless proven otherwise
2. Persons must be supported to ensure maximal decision capabilities
3. Eccentricity or unwise decisions per se are not to be considered as a sign of mental incapacity
4. Decisions taken for mentally incapacitated persons should be done in their best interests
5. Decisions taken for mentally incapacitated persons should be least restrictive, and should also respect the patient's rights and freedom.

An operational definition of decisional capacity includes the following:

1. “To understand the specific situation, relevant facts or basic information about choices.
2. To evaluate reasonable implications or consequences of making choices.
3. To use reasoned processes to weigh the risks and benefits of the choices.
4. To communicate relatively consistent or stable choices” (Darzins et al., 2000, p. 6).

7. The Conclusion to the Chapter

Clinical decision-making in the various stages of dementia, particularly when compounded by situations where mental capacity is lost, is a complicated situation of care that entails careful planning to help meet the best interests of the person with dementia. Such a problem is more evident when clinicians and the family are faced by EOL care situations which, as shall be seen in the next chapter, are often difficult to discern, given the complex issues associated to the attitudes, beliefs, values, and personal wishes of all stakeholders involved.

Chapter 2: Thorny Issues concerning Clinical Decision-Making in Dementia

Decision-making in the management of swallowing difficulties in end-stage dementia is a complex issue that involves various variables that need to be addressed to come to judgement that best meets the needs of vulnerable persons in care. One pressing practical decision that has to be addressed is what type of care strategy needs to be identified and followed to best meet the needs and values of a person in their terminal phase of life.

This chapter considers this clinical dilemma, where consideration is given to the care strategies that need to be considered as dementia progresses to its end-stage. Such analysis considers a reasoned appraisal of dementia staging, prognosis and a risk/benefit appraisal of management options involved in swallowing difficulties in end-stage dementia care.

1. The Relevance of Dementia staging for End-of-Life Decision-Making

In *Alzheimer's type of dementia*, researchers have identified "common patterns of symptom progression" ("Stages Alzheimer's disease", 2003, p. 1). This pattern in disease progression has been used to grade dementia progression in stages. The benefits of staging dementia include the development of a better apprehension of disease progression ("Stages Alzheimer's disease") and it also helps the person in care, the family and clinicians appreciate the current status of the disease and subsequently take appropriate decisions for current and future care.

Pace et al. (2010) pointed out that disease progression is a slow continuous process and thus benchmarking in stages, is in practice not clear-cut and does show evident differences between different persons ("Stages Alzheimer's disease", 2007). Furthermore, Komarova and Thalhauser (2011) added that variation in the progress of Alzheimer's disease might also be the result of various sub-groups being present in different persons afflicted with this condition.

Alzheimer-type dementia has been at the forefront of studies upon which length and staging of dementia have been scrutinised ("Stages Alzheimer-type", 2011). To this effect, the results of research on staging dementia may not closely apply for other forms of dementia, with different pathogenesis other than that of Alzheimer's disease.

Examples of commonly used staging tools are:

- Clinical Dementia Rating (CDR) (Hughes, Berg, Danziger, Coben & Martin, 1982)
- Global Deterioration Scale (GDS). (Komarova & Thalhauser, 2011).
- Functional Assessment Staging of Alzheimer's disease [FAST] (Reisberg, 1988).

The FAST has sixteen distinct stages in succession, ranging from normal status to end-stage dementia (see Table 6) (Reisberg, 1988; Komarova & Thalhauser, 2011), and gives more importance to individual functioning in ADL's rather than to cognitive deterioration ("Stages of Dementia, n.d.). The FAST remains the score that has been most validated as a measure of Alzheimer's disease ("Functional Assessment Staging", n.d.).

One important limitation of the FAST is that it correlates solely to the progression of Alzheimer's disease ("Functional Assessment Staging", n.d.). The focus on Alzheimer's disease creates a practical problem in the sense that if the FAST scale is used solely to stage the terminal months of life in dementia, it would only be accurate in those patients with Alzheimer's disease (Hanrahan, Raymond, McGowan, & Luchins, 1999).

In medical practice, clinicians do tend to distinguish three stages of the disease (Birch & Stokoe, 2010) that reflect dementia progression into three broad phases (*National Audit Office* 2007) namely: *early; middle* and *late-stage dementia*. In this classification, the *National Audit Office* derived an association between such three phases and the Mini-Mental State Examination [MMSE] (*NICE*, 2006, November) as follows:

1. Early phase symptoms to normal ageing (MMSE: 21-30);

2. Middle stage symptoms (MMSE: 10-21);
3. Late stage symptoms (MMSE: 0-9):

The main inclination of clinical management in a three-phased staging in dementia is that “most individuals focus on life prolongation when dementia is mild, on the function when the dementia is moderate, and on comfort when dementia is advanced” (Gillick, 2010, p. 268).

A. Qualifying end-stage dementia.

There exists considerable disparity in the terminology used to identify dementia towards the EOL. These include the following terms: *end-stage dementia; terminal dementia*; *end-of-life dementia; late-stage dementia; final-stage dementia; severe dementia; very severe dementia; palliative-stage dementia; and advanced dementia* (Purtilo & ten Have, 2010; *NICE*, 2006, November; Aminoff & Adunsky, 2006; Abbey et al., 2007; “Dementia Information Carers”, 2007; Raymond, Koopmans, Ekkerink, & van Weel, 2003; Claire, Quinn, Hoare, Whitaker & Woods, 2014).

Aminoff and Adunsky (2006) delineated a distinction between advanced dementia and end-stage dementia, as in their opinion, the former could incorporate persons who “are functionally non-dependent and have a low percentage of bed-ridden patients” (p. 600). To this end, Aminoff and Adunsky added that patients with end-stage dementia do specifically refer to persons in their last six months of life, where the high dependency and high grade of suffering end up taxing the reserves of patients, relatives and society alike (Welie & Gordijn, 2010). Also, the *American Geriatrics Society* (2014) specified that when swallowing difficulties are present, this is an indication that the disease process has reached the end-stage of dementia.

For this document, a decision was taken to utilise the terminology of *end-stage dementia*. The reasons for such a choice were based on its common utilisation in the literature to identify the last few months of life of persons who have severe dementia. End-stage dementia is also identified as the phase of high dependency, maximal cognitive decline and high levels of suffering (Aminoff & Adunsky, 2006). The document “Stages of Alzheimer-type Dementia” (2011) listed the more common signs and symptoms present in end-stage of dementia (see Table 7).

Aminoff and Adunsky (2006) argued that management of persons in end-stage dementia is comparable or worse than the care of persons with cancer, given the associated “complexity of medical, nursing, cognitive, emotional, religious, ethical and social problems” (p. 600). In fact, the severity of dementia leads to increased stress on the family and caring professions alike, with patients in end-stage dementia having a closer to death experience, given less than six-month life expectancy.

One of the difficulties delineating end-stage dementia care is that current tools and guidelines make it difficult to identify the exact point when a person diagnosed with dementia enters the final stage of the disease (Birch & Stokoe, 2010). Nonetheless, certain staging tools do exist to quantify the severe phase of dementia (see Table 8).

Furthermore, in end-stage dementia there abound difficult decisions about the re-orientation of care, from curative to palliative approaches, in the quest to maximise QOL (Birch & Stokoe, 2010), in the best interests of the person in care.

2. Prognostication and Decision-Making in Dementia

Mortality prediction paves the way to anticipate treatment decision-making for EOL care planning (Flacker & Kiely, 2003), and helps guide conversations between clinicians and family members to promote terminal care (“Stages of Dementia”, n.d.). This association between mortality prediction and care planning makes survival time determination in end-stage dementia a relevant measurement to help determine the EOL clinical action that is needed (Mitchell, Miller, Teno, Davis, & Shaffer, 2010), in palliation (Levy, Morris, & Kramer, 2008). However, determination of what life is left is not always easy and clear-cut in the advanced stages of dementia (Pace et al., 2011), as at times patients, who appear to be close to impending death, do ultimately recover (Gardiner, Cobb, Gott, & Ingleton, 2011).

Due to the fact that the course of dementia is generally prolonged (Scheirton, 2010), life expectancy for persons suffering from this condition does not depend on disease projection alone. In fact, prognosis is also affected by the age of onset; gender; the degree of disability; the presence of co-morbidities; and the nature of palliative care offered in the last stages of life (Xie, Brayne, & Matthews, 2008). The clinical picture in the near dying phase of dementia is frequently made more complicated by associated serious disorders, including pneumonia, febrile episodes, and eating problems (Mitchell et al., 2009), where co-morbidities worsen QOL and health outcomes in dementia (Nelis et al., 2019). Goodman et al. (2010) remarked that such difficulties leave a direct effect on the clarity in decision-making of which management strategy to follow in dementia.

Referring to comparison of dementia with other terminal conditions, Pace et al. (2011) stated that for cancer and most organ failures, the sudden deterioration that is experienced towards the EOL, makes it easier to progress from a curative approach towards EOL palliative management.

An important issue which contributes to the difficulty in defining a clear prognosis in dementia is the fact that this neurocognitive disorder is not often considered, by both physicians and the family, as being a terminal illness, and this disrupts the process to predict prognosis and ultimately hampers appropriate treatment (*APA*, 2013; Bayer, 2006).

Consequently, the prognostic uncertainty in dementia makes it difficult for the health care team to decide when and what palliative measures are to be taken (Bowker et al., 2006). Also, such doubt leads to considerable anxiety in relatives, who in their despair in seeing their older family member approaching death (Mitchell et al., 2010), become ever more concerned to avoid unnecessary aggressive interventions that would only lead to further unnecessary suffering.

Thomas et al. (2011) argued that it would be relevant to give more importance to addressing patient needs, as ultimately needs planning are more down to earth requirements than listing a prognosis. To this end, the National Council for Palliative Care (UK) (Gibson et al., 2009) has brought forward a set of needs-based criteria (see Table 9), which make it easier to identify patient requitements in the final stages of dementia.

In the USA, the estimation of six-month life expectancy for persons in the advanced stages of dementia is an administrative requirement to identify eligibility for Medicare Hospice Benefit (Mitchell et al., 2010; “Hospice Eligibility Criteria”, 2008). Hanrahan et al. (1999) remarked that if the progression of dementia follows an ordinal fashion, a score of 7c on the FAST (Reisberg, 1988), would be an appropriate score to identify six-month survival. It is worthy of mention that to be eligible for Medicare Hospice Benefit, apart from a FAST score of 7c, the patient must have also "experienced at least one of the following medical conditions over the previous twelve months” (Mitchell et al., 2010):

1. "Aspiration pneumonia.
2. Pyelonephritis or other upper urinary tract infection.
3. Septicaemia.
4. Multiple decubitus ulcers ≥ stage 3.
5. Recurrent fever after antibiotics.
6. Severe eating problems or tube-feeding accompanied by a > 10% weight loss over the past six months or serum albumin < 2.5 gm/dl" (p. 4).

The Gold Standards Framework [GSF] in the UK does “aim to train and support staff to enable a high standard of care for people in the last years of life” (*Gold Standards Framework,* 2018). The GSF Proactive Identification Guidance [PIG] serves as a prognostic indicator to identify the last six to twelve months of life in various diseases, including dementia, and thus indicates appropriateness to start EOL care. The GSF-PIG (2016) delineated the FAST score + co-morbidities as the tool to follow for one-year estimation of survival in dementia.

While various critics deem the FAST as an unreliable indicator of six months mortality (Brown, Sampson, Jones & Barron, 2012), the FAST has been claimed to be the most validated measure of progress of Alzheimer's dementia ("Functional Assessment Staging", n.d.). In this controversy, Levy et al. (2008) argued that "current dementia-staging criteria alone do not yield sufficient information to guide EOL decision-making."

One relatively simple method to help identify prognostication in the EOL is for the physician to ask the *surprise question*, namely, "would you be surprised if this patient died within the next year?" Nelson (2015, p. 1) added that if such a question where to be asked by experienced oncology physicians, such judgement would be accurate in 60% of cases. However, nursing home physicians were reported to be quite inaccurate to identify the EOL in dementia (Bayer, 2006) and this is of practical significance in finding the appropriate timing to start palliation in institutions for older people.

"Stages Alzheimer-Type" (2011) reported that most persons with dementia do live on average between 7-15 years; where the estimated "median length of survival from diagnosis to death is of 8 years" (Seymour et al., 2005, p. 32).

A major factor affecting prognosis in dementia relates to the type of prevailing dementia illness (Xie et al., 2008). Persons suffering from the Creutzfeldt-Jakob disease progress rapidly with a short life expectancy of between 5 to 12 months from diagnosis, while others, including Alzheimer's disease, range between 2 to 20 years or longer (*Encyclopaedia Mental Disorders*, 2011).

The relationship of survival and disease progression to the late stages of dementia was studied by Raymond et al. (2003) in 890 Dutch nursing home patients, all starting from the point of diagnosis. The mean survival was 7.0 years post-diagnosis and ranged from early death to late survival beyond 25 years after diagnosing dementia. Furthermore, 1 in 7 patients with dementia survived to late phase dementia. Of these, 90% were women, and 60% had Alzheimer's disease. Koopmans, van der Sterren, and van der Steen (2007) remarked that these results were worthy prognostic indications that could be passed on to relatives.

On the other hand, using data from the Minimum Data Set (New York) in a study population of 1609 newly admitted nursing home patients with advanced dementia, Mitchell et al. (2004a) reported that 71% had passed away within six months of admission.

3. Long-Term Care and the Person in End-stage Dementia

Nursing homes provide a home for older people who require support and care (Froggatt & Parker, 2010) and have the potential to impart a significant impact on the social, physical and psychological health of their residents. Froggatt and Parker added that older people in long-term-care do go through three principle transitions, namely “living with losses; dying; and bereavement” (p.183).

Nursing homes have been reported to be unprepared to cater for terminal care. One of the main reasons for such lack of preparedness is that little importance is given in nursing homes to discuss EOL wishes (Levy et al., 2008). Levy et al. added that the fact that staffing is limited and mostly made up of untrained care assistants who lack basic skills in assessment and communication (Seymour et al., 2005), does adversely affect their input in EOL care. Moreover, it has been reported that the environment in nursing care is not ideal for people with dementia (Hertogh, 2006).

The document *Putting People First* (Goodchild, 2009), stressed the argument that persons with dementia in care should receive input that maximises their QOL, dignity and respect. *NICE* (2006, November), listed the guiding principles of person-centred care for people with dementia in LTC settings, namely:

1. “Human value of people with dementia, regardless of age and cognitive ability.
2. [Safeguarding the] Individuality of people with dementia, with their unique personality and life experiences, and experiences of their illness.

3. Importance of the perspective of the person with dementia.

4. Importance of relationships, interactions and engagement with others and the potential for promoting well-being" (p. 12).

Care planning for residents with dementia in long-term-care should follow an inter-disciplinary approach (*Dementia Long-Term Setting*, 2009), during which the family is involved, and the patient's wishes respected. Team meetings should give due attention to the development of patient-centred treatment goals, with clear objectives that are revised through time as the patient's condition and needs develop towards the EOL. *Alzheimer's Association* (2007) listed a structured agenda to follow during care planning meetings for residents with dementia in long-term-care (see Table 10).

Institutions for older people should aim to provide supportive care for persons with dementia, wherein support should make it possible "to create an open culture of living and dying in care homes" (Froggatt & Parker, 2010 p. 186). Supportive care in dementia does provide a framework to "include a biomedical approach, psychosocial and spiritual holism, along with the broader concerns (for the family and their bereavement) of palliative care" (Hughes, Lloyd-Williams & Sachs., 2010, p. 6). In dementia, this means better patient participation and increased family involvement in the disease process, with the better promotion of ACP. This approach would ultimately reflect in better decision-making (Hughes et al.).

End-of-life care and EOL decision-making are interlinked and interdependent. Confidence in the administration of proper EOL care does give health professionals better certainty on when and what EOL decision-making would be appropriate (Watson et al., 2010).

End-of-life care in care homes for persons with dementia implies that there be taken major ethical decisions to delineate the level of care that would be appropriate to meet needs, improve QOL, and at the same time give allowance to patient preferences and a better definition of decision-making strategies (*Dementia Long-Term*, 2009). A cardinal issue that marks the respect offered to the resident in long-term-care is to give them their autonomy for choice on matters, small and large, that relate to their life in the care home (*Commission Social Care,* 2008). On the other hand, the family is to be involved in decision-making, where the cognitive status of the person with dementia is lacking (Evans & Robinson, 2010).

Alzhiemer's Association (2007) remarked that persons dying from end-stage dementia find it difficult to voice their preferences, but do communicate by non-verbal behaviours, including facial expressions and body movements. This difficulty to communicate does render persons in end-stage dementia vulnerable, particularly so, in those long-term-care facilities who give little lee-way to personal preferences (Owen et al., 2006).

To improve care practices in the EOL, staff in long-term-care facilities can practice a shared-decision-making strategy in end-stage dementia (Owen et al., 2006) through the observation of the resident's behaviours, as a means to define a useful level of communication, which understands the resident's preferences through their body language (*Alzhiemer's Association*, 2007). *Alzheimer's Association* added that the practice of using the same pool of staff that gets accustomed to the person's behaviour would be an asset.

4. To Feed or not to Feed a Person in End-Stage Dementia

A. End-stage dementia and swallowing difficulties.

End-of-life oral feeding difficulties are a common occurrence with different causation in the advanced stages of dementia (Hanson et al., 2011), particularly so in long-term-care (Mitchell, Kiely & Gillick, 2003). *In the Choices, Attitudes, and Strategies for Care of Advanced Dementia at the EOL* [CASCADE] study by Mitchell et al. (2009), where 323 nursing home residents with advanced dementia were studied, 86% of patients in advanced dementia had feeding difficulties and experienced six-month mortality close to 50%. Excluding age and other co-morbidities, potential reasons for this high mortality rate relate to the fact that inadequate nutrition and hydration in the EOL do cause physical concerns

(Hughes, 2006). At the same time, Summersall and Wight (2006) remarked that swallowing problems lead to increased risk of aspiration, while protein-energy malnutrition causes increased risk of infections, morbidity and pressure sores.

Feeding is a highly emotive issue which incorporates significant inter-cultural, social, religious and symbolic meanings, to both patients and family alike (*American Geriatrics Society,* 2014). It is known that food and water are important for life (Howland, 2009), to the point that refusal to eat and drink leads to clear debilitating and fatal consequences. *RCP* (2010) stated that if all food and drink is withheld, death may follow between 3 to 14 days afterwards; while if food is stopped with the continuation of adequate hydration, the Northern Ireland hunger strikes showed that death ensues within 57-70 days.

All this falls on a backdrop where the patient lacks insight and the capacity to decide for themselves (Candy et al., 2011) and consequently, their wishes on tube-feeding towards the EOL are frequently unknown (Mitchell & Lawson, 1999*).* As a result, care choices, have to be taken by others *(American Geriatrics Society,* 2014), who, as they are not guided by an expression of the patient's preferences, are seriously impaired with an uncertain path to follow to deal with feeding difficulties, whilst respecting the values of the patient in care (Mitchell & Lawson). It is thus a common occurrence to label the decision to tube feed or not tube feed persons with dementia associated with swallowing difficulties, as being a very difficult one (Dunlop, 2006). Such a decision is particularly problematic when the decision process is not supported by clear consensus (van der Steen, 2014).

The presence of swallowing difficulties (dysphagia) is usually a manifestation of dementia severity (Birch & Stokoe, 2010). It is only in the late phase of dementia that swallowing problems become significant (Morris & Volicer, 2001) to the point that decisions to consider enteral tube feeding are considered (Sampson, Candy, & Jones, 2009). Feeding difficulties in such situations are commonly related to several physical and cognitive issues, namely the

1. “Inability to recognise food.
2. Difficulty placing food in the mouth.
3. Inability to control food or saliva in the mouth.
4. Difficulty initiating a swallow.
5. Coughing.
6. Choking and spluttering.
7. Frequent chest infections” (Chadwick, Kelly & Watson, 2007, p. 1).
8. Gurgly or wet voice after swallowing regurgitation.
9. Complaints about swallowing difficulties (Pasman, Onwuteka-Philipsen, van der Wal, & Ribbe, 2003).
10. Dehydration.
11. Weight loss and malnutrition (Palecek et al., 2010).
12. “Prolonged meal times.
13. Withdrawal from mealtimes” (*RCP,* 2010, p. 1).

Summersall and Wight (2006) defined a management protocol to be followed in the management of swallowing difficulties in advanced dementia, as it relates to the level of *dysphagia* severity in advanced dementia (see Table 11).

Mukherjee, Ewins, Green, and Hodby (2017) drew up a model of management of swallowing difficulties in dementia, based on a multi-disciplinary team approach, where patients with potentially reversible etiological causes were identified and offered a trial of aggressive tube feeding in an attempt to improve and reverse their swallowing difficulties. Mukherjee et al. pointed out that such patient selection is necessary to differentiate them from those patients who, as a result of degenerative pathology, solely needed palliative comfort feeding.

The document *RCP* (2010) explored the possible feeding options that the team should discuss with carers before taking the best possible decision. These range from:

- Full oral feeding.
- A combination of oral plus tube feeding.
- Palliative oral feeding which is given mainly for pleasure and enjoyment.
- An exploration of more invasive non-oral methods.

Morris and Volicer (2001) stressed that the care goals in end-stage dementia should give importance to the maintenance of comfort while ensuring dignity in care. In such situations, force-feeding should be avoided (Tilly & Reed, 2006), and instead, alternative treatment options need to be considered, where conservative hand feeding is usually preferred over tube feeding (Gillick, 2000).

Cunningham (2012) remarked that the inability to eat and drink does incur in the family scary visions of malnutrition, dehydration and starvation. When faced by older family members with feeding difficulties, family members often see CANH as being important to maintaining life (Sampson et al., 2009). Thus lack of mobilisation of tube feeding could potentially increment fears of death and suspicions of neglect, abandonment and euthanasia (*American Geriatrics Society*, 2014). On the other hand, the administration of enteral tube feeding does tend to provide the family with a sense of achievement (*RCP,* 2010), and helps to allay their fears. In such situations, guidance and support must be provided to family as they experience the deterioration of their relative in a situation where death is close (Byrd, 2004).

About this issue, Vassallo (2014) pointed out that in Malta it is not uncommon to find persons in the severe stages of dementia who are being fed for prolonged periods via feeding tubes, simply as a measure to allay family anxiety, even though best evidence says otherwise.

B. Methods of nutrition and hydration in end-stage dementia.

Careful hand feeding is the preferred feeding option in the management of swallowing difficulties in the advanced stages of dementia (*RCP,* 2010). This approach is feasible in dementia till death (Treloar, Crugel & Adamis, 2009). Such a choice is based on the understanding that tube feeding carries its risks and discomforts, while it lacks clear benefit in end-stage dementia (*RCP*).

Careful hand feeding does help to maintain a better QOL in end-stage dementia and leaves some rudimentary satisfaction similar to normal oral feeding (*RCP,* 2010). In fact careful hand feeding gains additional significant meaning in advanced dementia, as it probably remains one of the few daily activities from which both the patient and the family find pleasure in doing (*American Geriatrics Society*, 2014), and also provides better quality time by the carer (Byrd, 2004).

Whilst many do worry of the risk of aspiration in hand feeding, it must be pointed out that not all cases of pneumonia in dysphagia are due to aspiration, with a number being directly the result of nosocomial infection arising from respiratory musculature frailty (*RCP,* 2010).

Following a bench-mark meta-analysis of studies on feeding difficulties in the advanced stages of dementia, Finucane, Christmas, and Travis (1999), argued that the proper preferred management of feeding difficulties in advanced dementia is through “a comprehensive motivated, conscientious programme of hand feeding” (p. 30). This view is concurred by the *Alzheimer’s Association* (Volicer, 2005), which added that hands-on care strategies by well-trained staff that include: “massage; oral hygiene; changes in diet; and hand-feeding” (pp. 2-5), can do a lot to manage swallowing difficulties appropriately; minimise risk of infection, and thus avoiding tube-feeding. At times to help overcome an inability to swallow thin liquids, these may need to be thickened to an appropriate consistency to allow a slower more controlled swallowing (Morris & Volicer, 2001), while the provision of dietary supplements can help to improve the nutritional value of the feed (*RCP,* 2010). To this end, the involvement of SLP’s and dieticians is necessary to help manage feeding difficulties in dementia (*RCP*), while medication causing altered taste should be withdrawn (British National Formulary, 2018), to help improve oral intake.

Good nursing care is basic to the provision of appropriate hand feeding in swallowing difficulties in dementia. However, the issue of staff shortage and inappropriately trained carers is a crucial limiting factor for suitable care in oral feeding, as it is known that hand feeding a person with advanced dementia is more time consuming and involves increased caution to help provide a safe swallow (*RCP,* 2010).

Clinically-assisted nutrition and hydration refers to the provision of food/drink via a tube or via intravenous methods (*BMA,* 2018), and to this end is considered as a medical treatment (Schwartz & O'Sullivan Maillet, 2013). The issue of the use of feeding tubes in the EOL brings up a variance of opinion on involved benefits and risks. These considerations do end up charging the debate on what constitutes: *basic care* versus *medical care*; what is *ordinary* versus *extraordinary* care (*Scottish Council Human,* 2010); and what is *appropriate* or *not appropriate* care in the advanced stages of dementia.

The use of parenteral nutrition via intravenous or subcutaneous methods in the end-stages of dementia are not popular given logistics, risks, costs, plus the need to include input from an expert nutritional team (Sampson et al., 2009). To this end, enteral tube feeding is the preferred method when CANH is being considered. At the same time, subcutaneous hydration may have a role in the short term when accompanied by swallowing difficulties, particularly if the patient experiences signs and symptoms of dehydration that include thirst. It is relevant to point out that intravenous and subcutaneous fluid replacement do not constitute a nutritional substitute (Dunlop, Ellershaw, Baines, Sykes & Saunders, 1995*).* On this issue, van der Steen et al. (2014) remarked that there is no consensus regarding the use of subcutaneous fluid replacement in dementia palliative care.

Enteral tube feeding commonly refers to "the provision of food and fluids via an NG tube or via a PEG tube" (*RCP,* 2010). Given relative discomfort to NG tubes (Howland, 2009) these are usually administered in the short-term, while for longer periods, PEG tubes are preferred (Byrd, 2004).

It is known that the utilisation of NG tubes is associated with lesser risks than PEG tubes, yet they can easily be dislodged even though re-passage is associated with limited distress (*RCP,* 2010). Where appropriate, nasal loops may help limit NG tube repeat removal, however, the use of nasal tube bridles is only indicated for patients who cannot pull the "bridle to such a degree to cause serious damage" ("AMT Bridle", 2011, p. 2).

For such reasons the use of a PEG tube is seen as being of preference in the long-term, as it is simple, safe, and is easily managed by nursing staff in nursing homes (Howland, 2009). On the other hand, the utilisation of RIG tube insertion for enteral feeding has been shown to have less morbidity and mortality than a PEG (Chircop, K., March 2017, personal communication).

In Malta, long-established care practices in geriatrics have shown a preference to utilise NG tubes as a long-term method of enteral tube feeding in patients with dementia in nursing homes (Vassallo, 2014).

A Cochrane review identified a number of clinical indications for enteral tube feeding (see Table 12). In addressing the benefit-burden equation of indication to tube feed, Dunlop (2006) recommended that one should ask:

- "What is the purpose of the feeding tube?
- Is it intended as a treatment to allow for the restoration of normal function?" (p. 3).

(E.g. reversibility post-stroke).

- "Is it to delay death?" (p. 3), or used to prolong life?

At times, in the face of feeding difficulties in dementia, the insertion of a feeding tube is seen as the best option (*RCP,* 2010). This has to be understood in an international medical scenario, where research and medical opinion still tends to defer with arguments in favour and against CANH in end-stage dementia (see Tables 13 to 15), leading to a denial of consensus on the issue (van der Steen et al., 2014; Sampson et al., 2009). Consequently, these conflicting findings lead to a conclusion that there exists no concrete evidence that

CANH is beneficial in the advanced stages of dementia (*BMA,* 2018; Finucane et al., 1999; *RCP*, 2010).

At the same time, it needs to be appreciated that the utilisation of enteral tubes does lead to increased morbidity and mortality. Such problems created by tube feeding justify the claim that such tube insertion is really an invasive procedure and consequently necessitates written consent by the family before the intervention (Potack & Chokhavatia, 2008).

The controversial effect of PEG feeding on survival is evident in the following examples. The study by Mitchell, Kiely and Lipsitz (1998) on 5,266 nursing home patients with swallowing difficulties (where half of the patients had dementia), showed that 50% of patients with dementia had passed away within a month of PEG insertion, and 90% had one-year mortality. On the contrary, Rudberg, Egleston, Grant, and Brody studied 1,545 patients with dementia and swallowing difficulties, and reported a significantly better one-year mortality with tube-fed patients, as there was reported only 50% mortality in tube-fed patients, as compared to 61% one-year mortality in the control non-tube fed group.

In a critique on this controversy of the relationship of PEG feeding and survival in dementia, Buff (2006) reported that information available does arise only from retrospective or cohort studies and not the gold standard of randomised controlled trials, which were not done in dementia given ethical, religious and technical reasons.

In consideration to either tube feeding or not persons in end-stage dementia, one must acknowledge that various authors do consider enteral feeding in end-stage dementia as causing increased burden, hampering QOL and potentially increasing complications (van der Steen, 2014*;* Howland, 2009), and therefore should be “discouraged in individuals with severe dementia” on clinical grounds (Howland, p. 697). The American Geriatrics Society took a similar position, as did the American Academy of Hospice and Palliative Medicine (*American Geriatrics Society*, 2014). On the same line of thought was the *BMA* (2018), in common endorsement with the RCP, the British Geriatrics Society and supported by the

GMC. All these bodies stressed that PEG feeding should be avoided in advance dementia in favour of assisted oral feeding.

Nonetheless, it needs to be pointed out that evidence does show that indication for enteral tube feeding in advanced dementia is rare but may occur, particularly if dementia is associated with a brain stem stroke (*RCP,* 2010). Likewise, survival with CANH seems to improve in younger healthier persons with dementia, and situations related to oropharyngeal malignancy (Howland, 2009).

Consequently, the benefits and harms of CANH in end-stage dementia remain unclear (Sampson et al., 2009), and this reflects in widespread disagreement on the clinical guidelines to follow when faced with decisions on CANH in end-stage dementia, based on sound scientific data (Lopez, Amella, Mitchell, & Strumpf, 2010; van der Steen et al., 2014). To this end, Rosin and Sonnneblick (1998) argued that tube feeding in dementia should not be based on religious beliefs. Furthermoret *RCP* (2010) stated that wherever CANH is contemplated as a feasible option by the multi-disciplinary team and relatives, it would be best to adopt clear objectives in mind to be reached in a specific time frame, where the aim should always rotate around safeguarding the patient’s best interests (*BMA*, 2018). In such situations, *RCP* added that the administration of an NG tube would be the more appropriate less invasive option to use in the short term, with a clear team plan to review at a later date, to see if the specified objectives were reached.

In end-stage dementia, it is not uncommon to find persons who tend to refuse to eat (Tilly & Reed, 2006). The basis of clinical management of such situations is first to be certain that such swallowing difficulties are indeed a direct result of the progression of dementia; consequently one has to exclude, in the first instance, any reversible causes of deterioration in medical condition (Howland, 2009). At the same time, attempts to improve diet should include referral to a dietitian, use of dietary supplements and resort to appetite stimulants (Bowker et al., 2006).

Ultimately, the clinical management of swallowing difficulties in advanced dementia should take in consideration that this condition is associated with a poor prognosis (Howland, 2009) and that multiple morbidities can be contributing to the problem in nutrition. In the administration of enteral tube feeding, the multidisciplinary team should, at onset have a clear mind of what are the indications and a detailed assessment of risks/benefits before implementation (*RCP,* 2010; Gallagher, 2012). Thus the clinician should confront the patient with an open mind and concentrate care management to answer the questions (*RCP*):

1. “What is the underlying diagnosis?
2. What is the mechanism of the oral feeding problem?
3. Can the person eat and drink, and if so, at what risk?” (pp. 9-10)

To achieve appropriate goals, the physician-led nutrition support team is in an ideal situation to coordinate all team skills required (*RCP,* 2010). In such a team, an SLP (Bowker et al., 2006) is the professional suited to assess swallowing safety. Other team members involved in decision-making include the doctor, dietician, nutrition nurse, carers, the patient (where still possible) and the family (*Alzheimer’s Association*, 2007). When a decision is taken to manage feeding difficulties in the advanced phase of dementia, such decisions should be documented appropriately and subsequently turned into a care plan (Gallagher, 2012; *RCP*).

Ultimately, the aims to administer CANH should rotate around the issue to improve the overall condition of the patient (see Table 16), which criteria should be discussed and agreed upon with the patient and their relatives.

5. Dying with Dementia

It has been documented that 30% of older people aged 60 years + will eventually die with dementia (Brayne, Gao, Dewey, & Matthews, 2006). In a study of 529 persons with dementia, as compared to participants without dementia, Xie et al. (2008) reported that study participants with dementia had a mortality that was three times higher than those without dementia in the first year after dementia was diagnosed (Rait et al., 2010). The increase in relative mortality applied both for persons in the more advanced stages of dementia and also for those with mild cognitive impairment.

In contrast to the implications of the above findings, many clinicians do find it difficult to identify end-stage dementia as a terminal illness. Consequently, a dementia diagnosis is often overlooked in death certificates (Sachs, Shega, & Cox-Hayley, 2004).

Nursing homes are principal providers of EOL care, in particular for persons with advanced dementia (Mitchell et al., 2004a). It is known that approximately 100,000 people die each year in care homes in England and Wales (Seymour et al., 2005), of which two-thirds have dementia (Matthews & Denning, 2002). To this end, it is imperative that nursing home procedures are organised in a manner to help respect the needs and aspirations of the patient and their families for their EOL care. Henceforth, long-term-care settings do require the provision of an appropriate level of EOL care which harbours a palliative approach that respects the wishes of residents through ACP, where residents feel that they retain control on their EOL (*Quality Markers*, 2010).

In the UK, *National Minimum Standards* (2004) listed a set of standards to be followed in care homes for older people, where the service user and their relatives are made aware that their needs for care are treated with sensitivity and their values are respected (see Table 17)

Persons in nursing homes with end-stage dementia are in the terminal phase of life and thus should receive a palliative approach to care. However, a study of New York State nursing homes (Mitchell et al., 2004a) showed that when compared to terminal cancer patients, patients with dementia “were more likely to experience burdensome interventions such as tube feeding” (p. 321).

A. Addressing the challenging decisions involved in end-of-life care.

There exists no clear definition of the EOL; this is one of the many reasons that lead to uncertainty on when to start palliative care in chronic diseases like dementia (Olde Rikkert & Rigaud, 2010). In clinical practice, the identification of the EOL remains crucial to re-orientate and focus appropriate management (Dyer, n.d.; *Describing Death America*, 2003) to terminal care.

Hertogh (2006) stated that dementia should be classified as a terminal illness, particularly in its advanced stages (Hertogh, 2006). This view mirrors the recommendations that have been issued by various clinical and policy guidance bodies (*NICE*, 2006, November; Birch & Stokoe, 2010; *Alzheimer Europe,* 2008). To this end, persons who have dementia should be exposed to care interventions that apply palliative care frameworks, advance care planning, and EOL care tools. Furthermore, as in the late phase of dementia, the patient's life-span is short, aggressive treatments do offer avoidable burden and thus should be sidelined in favour of a palliative approach to care (Brauner, Muir & Sachs, 2000).

It is an undeniable fact that dying is an integral part of living (Owen et al., 2006). Thus it is to be expected that terminal health care management should maintain a high quality of care as that provided earlier on in life (Owen et al.). Despite the great scientific achievement of modern medicine, death and dying remain subjects to be shunned away (Seymour et al., 2005), with a general consideration of our mortality being put aside as forbidden subjects for discussion rather than upholding it as an integral part of our lives.

Candy et al. (2011) remarked that the inertia in opening discussions on future care in dementia relates to the fact that the management of feeding difficulties in the EOL and the consideration to start tube feeding, tend to be highly emotional debatable decisions. Such deep sentiments affect not only the family but also clinicians, in a situation where both relatives and clinicians may not see dementia as a terminal illness (Kumar & Kuriakose, 2013). Such non-appreciation of dementia as a terminal illness happens when those concerned do believe that technological advances are capable of deceiving death (Gillick, 2000). Ultimately this leads to a prevailing attitude in certain clinicians and relatives alike to avoid tackling EOL clinical decisions (Byrd, 2004).

A critical point in decision-making in the clinical management of EOL care is the differentiation between *basic care* from *medical care*, with the latter being considered as an aggressive approach to care in end-stage dementia (Furlong, 2010). McCormick (1978) denoted the difficulty in defining the boundaries of what constitutes appropriate care towards the EOL and clearly stated that appropriate care in the dying phase is strongly influenced by the level of medical technology that is available in that clinical context.

Basic care includes, “warmth, shelter, pain and distressing symptom relief, hygiene measures and the offer of oral nutrition and hydration” (p. 40), likewise pressure sore prevention can be considered as basic care (*RCP*, 2010). *RCP* added that such practice of basic care applies to persons who are mentally incapacitated if this is in their best interests. Basic care thus includes the coverage of the “fundamental needs of a person” (*Scottish Council,* 2013, p.2). In the provision of basic care, oral feeding and hydration should always be provided and offered to the patient, but never forced on a person if actively refused by the patient (*RCP*). The situation where the patient refuses to eat does not exclude that carers should make repeated attempts and be appropriately resourceful to offer oral food and fluids.

On the other hand, medical treatment includes intentional interventions that require medical or nursing skills, performed to support the best interests of the patient, and “staving off death” (*RCP*, 2010, p. 31). *RCP* added that such procedures do have, however, the potential to put the person at risk of developing serious side effects.

There is no doubt that feeding and hydration are fundamental requisites for life (*RCP*, 2010) and thus when lacking, are highly emotive issues to discuss and take decisions upon, particularly by the family (Bowker et al., 2006). The conflict lies in the fact that some professional quarters do consider CANH as basic and non medical care (Craig, 2004), whilst various other professional and ethical bodies affirm that tube feeding and hydration do constitute medical treatment and thus not qualifiable as basic care (*RCP*, 2010; *American Medical Association*, 1992).

Futile treatment refers to situations of care where "further treatment would be ineffective in the sense of neither improving the well-being of the patient nor allowing him a further period of life with a QOL acceptable to him" (Birnbacher, 2007, p. 48). On this issue, the *GMC* (2012) remarked that a clinician has no moral obligation to administer futile and burdensome treatment, and these should be considered at the point when considerations are in process to withdraw or withhold life-prolonging treatment in the EOL. To this clarification, one must add considerations if a proposed treatment is proportionate and ordinary, as opposed to treatment that is disproportionate and extraordinary (*Scottish Council,* 2013).

While experienced doctors should be ever alert to identify when it is time to withhold or withdraw aggressive treatment in the EOL (Hertogh, 2010), decisions to understand when a treatment is futile is often quite difficult (Bowker et al., 2006).

RCP (2010) stressed that in this difficult clinical situation, clinicians should not fail to act as moral agents by being resourceful to decide to stop CANH treatment if warranted as futile in the picture of EOL care, and thus not in the patient's best interests (*BMA*, 2018).

When instituting a trial of CANH, the main argument on clinical decision-making on futility turns around the issue of whether such intervention will lead to an overall improvement in the patient's condition (*RCP*, 2010). For such reason in end-stage dementia, the multidisciplinary team in communication with the family should discuss this issue and together set criteria of goals to be reached if a trial of tube feeding were to be carried out, namely:

- "Decrease in discomfort/symptoms as medication can be given.
- Increase in the weight if the patient is underweight.
- Improvement of healing of pressure ulcers.

- Increased capacity for rehabilitation.
- Reversal of confusion” (pp. 69-70).

Consequently, one feels confident to remark that wherever the administration of CANH does not lead to improvement of the “overall condition of the patient” this renders it futile (*RCP*, 2010, p. 70). However, when aggressive treatment is *withdrawn* or *withheld,* as it is deemed futile, such a decision creates a lot of turbulent discussions (Bregje et al., 2001), as foregoing treatment concerns answering an important moral question (Hughes, 2006), namely “is it a good or bad thing to withdraw or withhold food and fluid from someone?” (p. 114).

Common examples of treatment that are withdrawn and withheld in the EOL include the use of antibiotics for curative purposes, cardiopulmonary resuscitation [CPR], renal dialysis; mechanical ventilation, CANH; and treatment merely to correct laboratory results (*GMC*, 2012).

If a decision to forego nutrition and hydration is taken hastily and inappropriately, the consequences are usually irreversible, to this end, decisions to stop CANH should be governed in institutions, by clear protocols that necessitate the support of input from an ethics committee (Schwartz & O’Sullivan Mailliet, 2013). It is pertinent to clarify that it is unethical to stop or withhold medical treatment, food or drink (be it via oral route or tube/parenteral form) if the actual reason is to cause harm or death to a person (*Scottish Council,* 2013). In a meta-analysis on CANH, Monturo (2009) identified various inductive categories that could explain the context of withdrawal and withholding CANH (see Table 18).

Withholding or withdrawal of aggressive treatment decisions in end-stage dementia can be a result of the expressed wishes of the still competent patient, who, through advance directives or living wills, had indicated in the past such preference for their EOL (Davies, 2009). One such example can relate to the withdrawal or withholding of aggressive nutrition interventions, which ideally should have originally been based on an informed decision

(*NICE*, 2006, November). One important principle that has to be followed up is that such directives cannot lead to withholding nor withholding of basic care, neither can such advance directives be accepted if they end up asking for futile treatment (Bowker et al., 2006).

When the expressed wishes of the patient are absent, decisions for withholding or withdrawal of treatment in end-stage dementia are taken by the family or health care proxy (Gillick, 2000), who with the support of the health care team should take decisions that respect the patient's values and beliefs. Such decisions should also give due consideration to the observed reaction of the patient to the change in treatment.

The health care team and the family do find great difficulty to withdraw and withhold treatment in the EOL (*RCP*, 2010). Such psychological and emotional challenges are ever more difficult, when the treatment proposed to be withdrawn, is apparently minimally invasive, probably pain-free, potentially effective and could increase life expectancy (*GMC*, 2012). In all this, the element of local attitudes to clinical practice and values does often carry a lot of weight in the decision taken (Goodman et al., 2010)

Commenting on the Dutch nursing home practices on withholding and withdrawal of CANH, Bregje et al. (2001) remarked that of 6060 deaths in 1995, the cases where CANH was foregone was identified in 23% of deaths. Of interest was the fact that of those were withdrawal and withholding CANH was carried out, the majority of cases were suffering from dementia. Bregje et al. remarked that to most nursing home physicians in Dutch practice, such withdrawal and withholding of treatment in dementia is considered a natural action to help improve the quality of dying, diminish suffering, and to stop treatment intervention that was considered futile.

Withdrawing and withholding of treatment is a complicated decision that clinicians and family members have to deal with in the EOL in dementia. One of the reasons behind such complexity relates to the difficulty to generalise processes with a one size fits all approach. In addition, there is also a lack of clear boundaries in dementia EOL between what is appropriate and beneficial care and what is mainly burdensome high-risk care, which would only act as a source of unnecessary distress (*GMC,* 2012).

While it has been stated that there is no innate "moral difference between withholding and withdrawal of treatment" (*RCP*, 2010, p. 42), however, many health care professionals and family members do find it more difficult ethically to withdraw treatment rather than withholding a treatment (*GMC*, 2012). The difficulty in withdrawing treatment relates to technical and emotional difficulties that are so much stronger when one ponders to stop a potentially life-saving treatment, contrary to the less difficult act of refraining from starting treatment in the first place (Bowker et al., 2006).

The situation is further compounded by the fact that in end-stage dementia, there is innate lack of real-time expression of what are the wishes of the person in care, with a consequence that decisions have to be taken by others, who do not necessarily share the same values or have the patient's best interests at heart (*RCP*, 2010).

It is relevant to clarify that Chun-yan & Tao (2004) remarked that withholding and withdrawal of aggressive treatment in the EOL, does not amount to euthanasia, but it is a means how the patient and family's preferences are taken in account to avoid futile treatment in a legally acceptable framework.

To help support decisions regarding CANH particularly in those thorny situations where withholding and withdrawal of CANH are deliberated, the *BMA* (2018) recommended that in cognitive decline, decisions should be taken in the patient's best interests, by clinicians and involved relatives. This guidance further recommends that once the agreement is reached by these two stakeholders, a second medical opinion is solicited to assess and endorse the decision taken to ensure that the patient's best interests is safeguarded.

There is thus the need to work within an ethically and legally permissible framework to ensure that actions taken to withhold or withdraw nutrition support in the EOL help to structure the uncertainties in such decision-making (*GMC*, 2012).

In situations of severe discord, where the situation is complex, and the decision-making process regarding the withdrawal of nutrition ends up unearthing conflict between those concerned, one final possible solution is that the case is referred for the attention of the court (Bowker et al., 2006). After the Leslie Burke Case (who suffered from a progressive degenerative neurological condition), Judge Munby in his Court of Appeal Ruling (*RCP*, 2010) regarding the withdrawal of CANH, highlighted that court involvement should concern situations where:

- There is a doubt about the capacity of the individual.
- There is a lack of consensus among the medical professionals on the patient's prognosis; best interests; expected outcome of withdrawal of CANH; and or disagreement on the decision to withhold such CANH.
- Anyone with a vested interest in the case disagrees on the issue of the withdrawal of nutrition as being in the best interests of the patient.

6. Palliative Care

One must clarify the distinction between *terminal care* that refers to the dying phase of life, as opposed to *palliative care* that encompasses alleviation of suffering throughout the progress of a terminal illness (Mazzola, 2015). Mazzola added that care of the dying, although strongly influenced by palliation, is characterised by difficult clinical decision-making in a terminal care situation that has strong psychological and spiritual connotations, particularly in cultures where religion bears a strong meaning.

Olde Rikkert and Rigaud, (2010) highlighted the World Health Organisations [WHO] (2003) definition for palliative care for the needs of persons with dementia, by stating that in dementia it concerns "integral, active, and multidimensional care for patients with incurable diseases, aimed at optimising QOL both for the patient and the family" (p. 80). Consequently, palliative care interprets a holistic multi-disciplinary approach to the care of patients who are likely to die soon, and where curative treatments are no longer possible (Bowker et al., 2006).

Thus palliative care aims to help those concerned, namely the patient and relatives, to come to terms with death while optimising the time left by diminishing suffering and providing good quality care. Palliative care does not only invoke symptom assessment and control, but also relief of physical symptoms, psychological, spiritual and family support. Such a thorough assessment is crucial in patients with dementia, given the difficulty in recognition and communication of their ailments (Aminoff & Adunsky, 2006). It is relevant to point out that the role of palliative care has been expanded to incorporate persons with an incurable life-threatening illness, as is dementia (Birch & Stokoe, 2010), wherein death is not necessarily imminent, and prognosis extends to months or even years.

While "good palliative care" is not equivalent with "facilitating death", palliation is practised to enrich QOL and helps to preserve dignity and comfort in the EOL (Shah & Lloyd-Williams, 2003) in a patient-centred approach (Hertogh, 2010). In fact, in terminally ill patients, palliative care practice does not include treatment merely to prolong life, but includes measures to ensure a good quality dying process and death (Shah & Lloyd-Williams), where dying is considered a natural process of life. These measures include:

1. An evaluation of all symptoms and diagnosis.
2. Give information to the patient on the causation and treatment in such a manner to help patient empowerment and avoid unrealistic hopes.
3. Treatment includes:
    i. Patient counselling
    ii. Symptom control
    iii. "Correcting what can be corrected" (Bowker et al., 2006, p.704).
4. Individual treatment planning & monitoring if ineffective.
5. In dementia palliation, a reduction or removal of aggressive treatment (Brauner et al., 2000).

The application of palliative care to care homes carries with it certain characteristics that need to be upheld in line with the specific considerations of care in a LTC setting. *Quality Markers Care* (2010) specified quality markers that need to be encouraged in the quest to improve EOL care in care homes (see Table 19). The principle of the provision of palliative care was also proposed as a standard for care homes in Malta (*Minimum National Standards*, 2015)

EOL tools have been applied to help improve care in care homes. Such tools have been promoted by the *EOL Care Strategy* (2008) in England and include the Gold Standards Framework in Care Homes (GSFCH) (2003).

A. Palliation in end-stage dementia.

In end-stage dementia, as death is close, QOL and quality of care, particularly in LTC revolve around the following issues (Sloane & Zimmerman, 2010):

- “Relieving physical symptoms.
- Knowing and honouring the individual’s wishes.
- Assuring dignity.
- Caring for spiritual needs.
- Supporting involved family.
- Providing a satisfying dying experience” (p. 195).

It needs to be pointed out that the main difference between EOL care in dementia and non-dementia patients relates to the increased involvement in the decisional making process of the family, as their loved ones cannot decide for themselves (Sloane, Zimmerman, Williams, & Hanson, 2008). Henceforth, clinicians need to appreciate this distinction and should aim to provide a channel for increased communication with the family to allay their anxieties and better support them to provide appropriate decisions that reflect the best interests of their family member in care.

The literature indicates wide approval to directly manage advanced dementia through a palliative approach (Hertogh, 2006; Pace et al., 2011; van der Steen et al., 2014). Such an approach has to be taken in the light that patients with dementia do experience more prolonged morbidity than cancer patients towards the EOL (Seymour et al., 2005).

In end-stage dementia, refusal to eat and swallowing difficulties can lead to considerable loss of weight (Birch & Stokoe, 2010, p. 35). At the terminal end of life in dementia, the most frequent signs and symptoms reported are dyspnoea, pyrexia and pain. With aspiration pneumonia being the most commonly reported cause of death when it comes to patients who pass away with dementia (Birch & Stokoe). The actual death in dementia is quite often due to an acute illness, rather than from dementia itself; this does render EOL palliative planning in dementia more complex (Sloane et al., 2008).

Olde Rikkert and Rigaud (2010) remarked that palliative care plans in dementia should be developed by consensus between patients, family and staff, and wherever available, advance directives should be discussed. Such communication and care plan revision should be carried out periodically, with the plan of care updated in line with the evolving clinical picture. Another important principle to be followed is that of non-abandonment, wherein physicians should pursue care to their patients up till death. Ultimately, proper palliative care for the family should include support for the family's bereavement, by taking into account the family's factual, medical and spiritual needs.

Even though many do believe that persons with dementia are entitled to palliative care, it is known that only a limited number of persons in the advanced stages of dementia are exposed to a palliative approach (Volicer, 2005). Many factors are related to such barriers to palliation in dementia (see Table 20).

Such problems to institute a palliative approach makes clinical EOL management in dementia quite challenging, leading to a lesser than adequate EOL care for patients with dementia as compared to those without dementia (Goodman et al., 2010). This situation does end up taxing the skills and capacity of those involved (*NICE*, 2006, November), while patients in end-stage dementia in LTC end up receiving sub-optimal palliative care (*Nuffield Council Bioethics*, 2009). Such care deficiencies include less pain relief; poorer medical services; less attention given to their spiritual needs; while decisions to avoid inappropriate hospitalisation are not taken until death is looming close (Goodman et al., 2010; Hertogh, 2006).

On the issue of the institution of a poor palliative approach in the EOL in long-term-care, various authors (Levy et al., 2008; Watson et al., 2010) remarked that better prognostication of the EOL in LTC could help improve the state of care. Programs like the Making Advance Planning a Priority [MAPP] and the Gold Standards Framework for Community Homes not only help to identify residents at particular risk of dying but do end up opening up the way for improved filling out of advance directives, reduced referrals to inappropriate hospitalisation and increased interventions in palliative care. Similarly, the Palliative Excellence in Alzheimer Care Efforts [PEACE] program was set up in Chicago, to meet the hospice needs in persons who have dementia (Shega et al., 2003). The PEACE program involves “advance care planning; patient-centred care; family support; and a palliative care focus from the diagnosis of dementia through its terminal stages” (p. 315)

B. A palliative approach to feeding difficulties in end-stage dementia.

Swallowing problems and associated feeding and hydration issues are frequently present in the last six months of life in dementia (Morris & Volicer, 2001*).* Harwood (2014) remarked that feeding in the EOL has an unclear role and harbours varying opinions. One extreme view argues that falling short from the provision of food and drink might expose the care team to accusations of neglect or poor care; on the other hand of the scale supporters that promote avoidance of artificial feeding declare that there is no need to continue the provision of futile CANH in the EOL.

In this dilemma, palliative specialists support the view that terminally ill patients do rarely benefit from medically assisted feeding and hydration (van der Riet et al., 2008). Furthermore, *RCP* (2010) remarked that while food and fluids orally "should always be offered, palliative physicians do believe that force-feeding a dying patient does not help to relieve suffering" (p. 79).

One development arising from such an EOL palliative strategy is that persons in end-stage dementia do entail that their care plan reflects a shift away from unsuitable aggressive treatment, including measures to forego CANH as it leads to more suffering rather than reduce it (DeLegge, Borak, & Moore, 2005).

In the last days of life, good mouth hygiene is reported to be more appropriate care than attempting to feed. Likewise, withdrawal of intravenous fluids in the semi-conscious EOL phase does help to diminish the risk of pulmonary oedema, peripheral oedema and increased secretions (*RCP*, 2010), all of which do tend to increase discomfort in terminal care (Gillick, 2000).

Hospice is one element of palliative care that offers particular sensitivity to the patient and family members in terminal care (Kissell, 2010). Dame Cicely Saunders pioneered the hospice philosophy of care, and she drew up an organised list of services aimed to "help patients and families clarify and achieve their goals, maximise patient comfort and QOL, and provide ongoing support for the patient's family after they die" (Reifsnyder, 2005, p. 74).

A hospice model of care for patients with advanced dementia upholds the principles of palliative management in this terminal condition (Furlong, 2010). The principles of the hospice model, as described by Volicer, Rheaume, Brown, Fabinszewski and Brady (1986), (see also Furlong), are based on progressive instructions in palliative management (see Table 21), as they relate to the terminal illness as the patient progresses closer to death.

Care offered in hospice includes avoidance of tube feeding; foregoing hospitalisation; and foregoing CPR status (Furlong, 2010). When it comes to the management of feeding difficulties in the EOL, hospice care tends to avoid CANH, as it is believed to increase burden and suffering to the patient. It is known that patients dying in cancer do not feel like eating and the "policy of the hospice is to offer everyone food, and it is their option whether or not to take it" (van der Riet et al., 2008, p. 149).

However, when it comes to patients with dementia, only a minority of patients are exposed to hospice (Aminoff & Adunsky, 2006), with only 7-11% of patients in end-stage dementia being observed to do so (Sachs et al., 2004). This has led Seymour et al. (2005) to label such older people who are denied hospice in the EOL as "disadvantaged dying" (p. 6).

In Malta, EOL support to persons with dementia remains in an embryonic phase with the only provider being the Malta Hospice Movement (*Malta Healthcare Decision-making,* 2011). The Manager of the Maltese Hospice Movement (A. Shah, personal communication, March 16, 2011) disclosed that there were no immediate plans to offer a service to older people in end-stage dementia.

7. The Paradox of Curative Care in End-Stage Dementia

In end-stage dementia, one of the cardinal questions that need to be answered is what constitutes good management in the last months of life, and what makes up a good death? (Seymour et al., 2005).

The point of departure in *medicine* is guided by its definition, which is that of a "science or art of healing" (Mosby's Dictionary Medicine, 2010, p. 132). On the other hand, Regnard and Huntley (2006, p. 36) stated that clinical decisions in the EOL "should be based on whether an intervention is realistic, practical or beneficial", and thus not having the primary objective to heal. Gopalraj, Grooms, Setters, Kaundar, and Furman (2012) remarked that these modalities of care do often tend to overlap. One example of such overlap was that while all clinicians are aware that dementia is a terminal illness and thus amenable to comfort care, many clinicians do often prefer to utilise tube feeding in dysphagia in the quest to prolong life as far as possible. Gopalray et al. added that one such reason for introducing such aggressive care in end-stage dementia is lack of knowledge on palliative practices in dementia. This situation does create a fundamental difficulty in the clinical decision-making process, particularly in end-stage dementia (Goodman et al. 2010). Table 22 indicates the reasons that are known to contribute to this dilemma in care strategy where palliation is disowned in favour of a futile curative approach in dementia.

Curative care leads to healing and is most effective when the disease process, especially in cancer, is caught early. In principle, a curative approach does often rotate around the use of technology and invasiveness and generally aims to prolong life and where possible also aims for a better QOL (van der Riet et al., 2008). By aggressive medical treatment in the advanced stages of dementia, one does include CANH (*GMC*, 2012).

In finding an explanation of what constitutes *curative treatment*, it is convenient first to explore what constitutes a cure. A cure in medical terms always refers to the healing of a disease process or a special situation including skin breakdown, where a particular treatment intervention leads to health restoration or recovery from the disease process, and ultimately the patient is made to feel better (*Farlex Partner Medical*, 2012). However, a cure approach strongly contrasts with the progressive, irreversible degenerative picture that underpins a diagnosis of dementia, which thus necessitates sidelining curative approaches in favour of palliation (Pace et al., 2011).

8. Euthanasia and Physician-Assisted Suicide: Where do they fit in?

Euthanasia is defined as “the intentional termination of life, by someone other than the patient, at the patient’s request”, “*assisted suicide* is the intentional assistance to a patient with the termination of his or her life and given at his or her request” (Jeffrey, 2009, p. 488). Therefore about intentionality, assisted suicide cannot materialise in the late stages of dementia where decisional capacity is lost (“Suicide Assisted Suicide”, n.d.). On the other hand, euthanasia in Alzheimer’s disease depends on the intervention of another third person/agent to perform the act of termination of life and can thus be carried out when the person with dementia is too far gone cognitively to decide for themselves ("Suicide Assisted Suicide").

The literature does observe a sub-division of euthanasia to *active* and *passive* with the former meaning when third persons, frequently health professionals, do something to terminate a life. On the other hand, passive euthanasia is "when the patient dies because medical professionals either do not do something necessary to keep the patient alive or when they stop doing something that is keeping the patient alive" ("Active Passive Euthanasia", 2014). One such example of passive euthanasia in dementia is when food or liquid is stopped (Hughes, 2006).

Other deliberations do sub-divide euthanasia to *voluntary*, *non-voluntary*, or *unvoluntary* (*RCP*, 2010) with the first meaning there is a known expressed wish, the second the wish cannot be confirmed, while in unvoluntary the wish is against euthanasia.

Hughes (2006) remarked that in dementia, the usual form taken is that of non-voluntary euthanasia, where passive non-voluntary euthanasia implies that persons are "allowed to die because treatments are not given" (p. 51). Concerning the above, some ethicists argue that the intervention to kill may hold a higher moral load, while withholding treatment may be seen as letting nature do its course, so omission may be contended as holding less guilt (Hughes).

With particular reference to passive euthanasia, *RCP* (2010) argued that treatment withdrawal is a debatable issue to be placed as corollary to active euthanasia, and consequently the recommendation is that euthanasia should be used to refer specifically to "active and intended termination of life" (p. 45), as is applied in the Netherlands.

It is known that many EOL issues, including euthanasia, are strongly influenced by the culture of the population concerned (Furlong, 2010). A number of countries in the European Union have legalised euthanasia; these include The Netherlands, Belgium and

Luxembourg (“Where Euthanasia Legal”, 2016). On the other hand, countries like Germany and Switzerland do permit physician-assisted suicide (Dovey, 2015).

In the UK where euthanasia and assisted suicide are not legal (*Nuffield Council Bioethics*, 2009), the principle of *double effect* was accepted through a court ruling, taken by Judge Devlin, in 1957 (Marker, 2012). While Marker pointed out that the double effect cannot be equated to euthanasia/assisted suicide; still ethicists do find a weakness in this doctrine as it is often difficult to delineate (Glover, 1977; see also Hughes, 2006). On the other hand, the document *RCP* (2010) argued that in withdrawal of feeding or hydration in the EOL, the double effect is considered justified if the intention is to promote comfort and diminish suffering. In fact, the application of the double effect to withhold tube feeding or parenteral hydration in the EOL, although potentially leading to starvation and dehydration, would lead in terminal care to less restraint, less chance of pulmonary congestion and hence less suffering.

One must point out that both euthanasia and physician-assisted suicide are not legally practised in the Maltese Islands (“Malta HealthCare Decision-making”, 2011). Vincenti (2008) pointed out that the Maltese people are traditionally strongly committed to respecting life, a position which reflects my personal views as the author of this thesis. In 2015, Abela published results of a postal questionnaire, on the views of all Maltese medical practitioners on euthanasia. This study had a response rate of 39.7% (n=396), with 89% of GP’s being reported to be against euthanasia.

Early in 2016, the debate on euthanasia in Malta took a sudden high media profile, when a 56-year-old male sufferer of amyotrophic lateral sclerosis [ALS] went public and presented his case to the Parliamentary Committee for the Family. He intended to ask the Maltese Parliament to legalise assisted early termination of life in order to preserve his dignity at the terminal end of his disease (Dalli, 2016, July 25). This request got front coverage from all major Maltese media news and further reaction from the social media. A reputed response was given by the ethicist Professor Mallia in an interview published online by of *The Malta Independent* (Schembri Orland, 2016, July 24). Professor Mallia remarked that the Maltese medical profession faces increased difficulty to manage EOL care in view of a deficiency in our legal framework “regarding the right of the patient to refuse treatment” (p. 8). On the other hand, the Roman Catholic Church, through its Bishops published letters to all Members of Parliament and a pastoral letter, arguing on the moral consequences of hastening death (“Safeguard Dignity Human”, 2016, July 25; “Cherishing Life”, 2016, August 6).

The arguments for and against euthanasia and assisted suicide are numerous and contrasting and reflect a wide variety of social, philosophical, medical and ethical deliberation (see Tables 23 & 24).

Bowker et al. (2006) remarked that withholding and withdrawal of life-prolonging treatment is not the same thing as assisting dying. Bowker et al. also added that it is not the duty of the doctor to prolong life at all costs. In addition, Shah and Lloyd-Williams (2003) stated that physicians hold no obligation to provide futile, burdensome treatment. In such situations, good communication with other staff members and relatives does ensure that everyone understands the rationale behind such a treatment plan.

At the same time, the *Human Rights Act* (1998) affirms that a person has the right to refuse treatment, and consequently, patients may request the stoppage of ongoing treatment. While all these decisions could potentially lead to death, by no means are they equivalent to assisted dying.

It is an ethical topic of concern that with time, persons who have dementia will increasingly seek medical advice concerning dying (Nordenram, 2010). “Suicide Assisted Suicide” (n.d.), acknowledged that such reasoning in Alzheimer’s disease bears heavily on the issue that it is a “devastating illness that robs individuals of their sense of self and imposes an enormous financial and emotional burden upon the family and caregivers" (p. 1), all this being coupled with limited care options, in a situation where QOL is poor.

Seymour et al. (2005) remarked that decision-making processes in dementia are far from clear when it comes to the transparency of who is in control and what choices are available in the terminal EOL, particularly on issues of advance care statements and advanced euthanasia statements. Such lack of transparency is ever more pressing in the end-stage of dementia as afflicted persons cannot express their views in real time on treatment choices, given cognitive decline (Bayer, 2006).

It is relevant to point out that suffering in the broad sense was reported to be the most important reason for asking for active direct euthanasia [ADE], with concern for the prevention of degeneration or decay being also important reasons (Gordijin, 2010). Additionally, Birnbacher (2007) found that the fear of loss of control and autonomy, and fear of dependency were noted as being very important determinants behind requests for ADE.

These findings are of particular relevance to patients with dementia as towards the EOL, many patients with dementia do suffer from associated pain (Goodman et al., 2010). It is worthwhile pointing out that suffering in end-stage dementia is of unclear aetiology, yet strongly related to physical pain, psychological distress and religious concerns (Aminoff & Adunsky, 2006). Furthermore, Gordijin (2010) commented that the issue of persons requesting termination of their life is an ethical topic of concern that will increase in time given a global increase in numbers of people who have dementia, and an increase in Alzheimer's patients that will request ADE.

In persons with dementia, there exist three possible scenarios that may argumentatively lead to requests for euthanasia or physician-assisted suicide (Gordijin, 2010)

1. A patient with dementia who is incompetent asks for ADE.
2. A patient with dementia who is incompetent has an advance directive in which he asks for ADE.

3. A still competent person who has dementia asks for ADE.

In the first, it is ethically not justifiable to comply with such a wish (Gordijin, 2010). There is only a weak argument in favour of beneficence in such a situation. In the second scenario, one always ends up querying the validity of the advance directive in such situations, in particular, the physician can never be sure that the person was competent or well informed when he filled up the advance directive. Still, in the Netherlands, such advance directives do hold a legal basis. In the third scenario, possible cases will probably be few. However, the argument of autonomy and beneficence in countries where euthanasia is legally accepted does leave sufficient room in favour to comply with the patient's wish.

It is worthy of mentioning that many older people are willing to talk about their death and sometimes wish to be dead (Furlong, 2010). Often this longing to terminate life would best be addressed by identifying palliative solutions to the underlying feelings and fears and definitely would benefit from repeat discussion at regular intervals. The most important remedy in such situations is the principle of non-abandonment or the security that the patient/doctor relationship will continue with the same physician until death.

9. The Conclusion to the Chapter

In this chapter, attention has been given to the various doubts that arise in what is clinically correct and morally acceptable decision-making in end-stage dementia concerning the emotionally charged issue of swallowing difficulties in the EOL (*Craig,* 1994).

It is clear that doubts abound in clinical practice on which care option to follow. In such situations, one must also give due concern in the family, who do suffer from marked indecisions on what is the right decision to take concerning issues related to nutrition and hydration (Hertogh, 2006). On the other hand, clinicians in dealing with such delicate EOL clinical decisions for persons with dementia are frequently subdued with doubts and pressures, which do adversely affect their serenity to take decisions (van der Riet et al., 2008).

To help support decision-making in the EOL, the next chapter “Safeguarding the Human Dignity of Persons with Dementia”, will give due account to *what* and *how* ethical models of decision-making can help evaluate and clarify the many moral problems and uncertainties that exist in clinical practice in end-stage dementia. The intention is to pave the way to a reasoned, rational outcome that is morally sound and meets the factual needs of the person in care (*Nuffield Council Bioethics*, 2009).

Chapter 3: Safeguarding the Human Dignity of Persons with Dementia

This chapter focuses on an ethical appraisal on how specific stakeholders, namely the person in care, the family and clinicians hold ground in the decisional process. This detailed appraisal of the stakeholders involved in team decision-making serves as an appropriate background to address a critique of ethical models of moral reasoning that are involved in EOL decision-making in end-stage dementia care.

1. The Ethical Challenges faced by Stakeholders in Decision-Making

A. Ethical decision-making in end-of-life dementia: an introduction.

End-of-life decision-making has to take account of modern invasive life-saving medical technology techniques, which when coupled with unclear EOL care guidelines and hesitant choices, do lead to considerable clinical decisional conflict in health professionals and the family on what constitutes appropriate EOL care for their elders (Parker, Erlbaum-Zur & Chichin, 2008; *Consensus Document EndCare,* 2018).

In a backdrop of a complicated ethical situation experienced in end-stage dementia, the conversion from aggressive to comfort care is often experienced as a clinical decisional nightmare, that brings out intense ingrained ethical dilemmas and value-conflicts that need to be confronted and decided upon (Arenella, 2005; Chun-yan, & Tao, 2004).

The resolution of this ethical dilemma (*Nuffield Council Bioethics*, 2009) in EOL care, cries out for appropriate morally acceptable solutions that safeguard the dignity, rights, values, beliefs, feelings, and wishes of the person with dementia (Sasson, 2000; Sloane & Zimmerman, 2010; *GMC*, 2010, guide: 18). Such ethical conflict resolution is necessary to safeguard the best interests of patients in care and ensure an appropriate quality EOL (Parker et al., 2008), in a care environment that strives to maximise person-centred care (*NICE*, 2006, November).

B. Clinicians in ethical decision-making in dementia.

It is known that decision-making in clinical situations is influenced by the "medical indications, patient preferences, quality of patient benefit and contextual features" (Jensen, 1994, p. 18). Such complex influences invoke a work ethic where morality promotes patient well-being, respect and preservation of the dignity of vulnerable patients (Gastmans, 2016), based on the principles of beneficence and non-maleficence (Jonsen, 1994). The promotion of dignity in the EOL involves an appraisal of the risks and benefits of potentially futile treatment. Hughes, Hope, Savulescu and Ziebland (2002) listed the following ethical issues that are often faced by healthcare professionals in dementia practice namely: "autonomy; competence, consent, advance directives, truth-telling; confidentiality, CANH, genetic screening, behavioural control, driving, wandering, research, rationing, and EOL issues" (pp. 35-36) (see also Bolsin, Faunce & Oakley, 2005; Welie, 2010)

Persons with dementia living in institutions are particularly at risk of ethical dilemmas related to "respect of autonomy and dignity, obligations of beneficence, and justification of paternalism, all being deliberations that are based on the determination of competence" (Linzer, 2002, p. 32). Decision-making in institutions is often rendered more complex as decision-makers have to take heed of the different rules and regulations of the institutional setting (Gordijin, 2010). Additionally, institutions are burdened by low staffing levels and financial issues that strongly affect decisions to tube feed or not persons with dementia suffering from swallowing difficulties (Schwartz & O'Sullivan, 2013). Another problem is the depersonalisation that is experienced by residents in care who are often reduced to "just cases, numbers and objects" (ten Have, 2010, pp. 72-73).

Correspondingly, the different "values, ethics and beliefs" (Sasson, 2000, p. 6) of healthcare professionals and carers that are involved in decision-making in dementia do also lead to conflict in the clinical judgment processes in end-stage dementia care. Such values and clinical judgement disagreement may at times result in conflict between healthcare professionals and the family (Agius, 2010), a situation that is commonly present in the management of feeding difficulties in end-stage dementia (van der Riet et al. 2008).

Decisional dilemmas in clinicians are often influenced by contrasting reasoning for or against tube feeding, where clinicians know from evidence-based procedures that there is limited benefit in starting CANH in end-stage dementia (see Chapter 2, section 4).

In this complicated decisional situation, clinicians must strive to provide useful and desirable EOL care (*RCP*, 2010), based on relevant discussions with the patient/family as the patient approaches to the EOL (Shah & Lloyd-Williams, 2003). Such EOL care processes should incorporate patient informed consent in situations where the patient retains competence (*RCP*) or the patient's proxy where competence is lost.

In an ethical appraisal of what constitutes proper care in dementia, Gastmans (2016), remarked that in such interventions clinicians have to seek connection in a caring relationship with the vulnerable individual with dementia who is needy of care, and in so doing such interaction would help improve the patient's status as a person. Furthermore, dignity preservation is a valid yardstick to guide end-stage dementia care (Gastmans) on a "physical, psychological, relational, social, moral and spiritual level" (p. 150).

At the same time, clinicians must take responsibility to provide ethically appropriate treatment in conformity with the clinical situation, care that he/she feels willing to provide (i.e. no conscientious objection), based on available resources while taking responsibility to provide basic care (*RCP*, 2010).

On the clinical dilemma to feed or not to feed in the EOL, nurses are particularly troubled by the moral issues in such situations (Arries & Cur, 2005). Such a dilemma relates to the emotional bonding that characterises the interpersonal relationship that develops between nurses and their patients. Arries and Cur added that this bond ingrained in the reasoning based on virtue ethics, deontology, and beneficence, does go deeper to the reasoning experienced by doctors who do tend to base decision-making on a normative approach that lends importance to principlism ideals in association to consequentialism. Arres and Cur remarked that it is the clinical tradition to expect the doctor to take the final decision regarding care, which is often based on paternalistic reasoning, while the nurses execute and obey orders with little say in the decision taken. Arres and Cur added that this bed-side practice does tend to inflict moral distress on nurses who thus feel marginalised in the decision process, and creates in them deep "moral conflict, burn-out and dissatisfaction" (p. 65).

The use of CANH in the final part of life remains a controversial issue (Bowker et al., 2006), which creates various situations of conflict in decision-making between clinicians and family members (Coetzee, Leask, & Jones, 2003). To help resolve such conflict, all stakeholders need to be involved in the decision-process where all values are respected (Hughes & Williamson, 2019). The benefit of ethical support in decisions regarding CANH in institutional care does help to limit conflict between stakeholders in the decision process and helps minimise "anguish, guilt, anger and resentment among the participants" (Gordon, 2002, p. 324).

C. The family in ethical decision-making in dementia.

The involvement of the family in the care of mentally competent patients remains at the prerogative of the patient in question (*NICE*, 2006, November). However, when the family is involved, they do find difficulty to derive an ethical decision that "balances safety with freedom" (*Nuffield Council Bioethics,* 2009, pp. xvii-xviii) (see also Chapter 1, Sections1 & 3). Such decision-making by the family regarding tube feeding in dementia is often handicapped by the lack of guidance of the past wishes of the patient in care (Gil et al., 2018).

Kissell (2010) warned that benevolence of the family is not always the case as in some instances they are far from being the loving and caring relatives, where the family may be inclined to give preference to their interests rather than the patient's best interests. One possible consequence of such a subjective approach to decision-making in the family is their difficulty to understand that the EOL is near and aggressive measures need to make way to palliative approaches in care (Moe & Schroll, 1997).

On the other hand, it must be remembered that caregivers of persons with dementia do themselves hold the right for respect of their interests, dignity and well-being as they are deeply emotionally engulfed in moral obligations of a "shared future" (Kissell, 2010, p. 104).

The situation of family difficulty is also evident in the stress experienced in carers following placement of their elders with dementia in LTC, which stress does vary according to the relationship they experienced through time with their elders in care (Kellett, 1998; see also Duijnstee, 1994).

In a situation of burden in dementia EOL decision-making, the family do often find that they are poorly supported by clinicians (*Nuffield Council Bioethics*, 2009). To this effect, the family would benefit from appropriate psychological and cognitive behaviour support to ensure that decisions that they take do focus on the actual needs of their relative with dementia (Jones, 1997, see also Hughes, Hope, et al., 2002; *NICE*, 2006, November). Another form of intervention that supports the family is to promote burden sharing of decision-making with professionals in care (Silberfeld, Grundstein, Stephens, & Deber, 1996; see also Hughes et al.), through a consensus-building approach (Agius, 2010; Chun-yan & Tao, 2004). Moreover, if healthcare professionals give the family the necessary time to express their narrative of the story, this could help professionals better understand family psychosocial issues leading to better decision-making (Hughes et al.).

2. The Person in Care: Vulnerability and Dignity Concerns

A. The person in care.

The concept of the individual as a person is a central theme in the ethics of EOL care (Epp, 2003). Such focus on the person gives meaning to the intention to provide a person-centred approach (Kitwood, 1997) that also covers the later stages of life in dementia (Higgs & Gilleard, 2016). In this consideration a person is referred to being a unique human being (McCormack, 2004; see also Dewing, 2008) "having a past, having cultural background, roles, relationships with others" (Dewing, p. 5; see also Cassel, 1982), thus having a present and perceived future. Of further importance is that a person does also express feelings, is a moral agent (*Stanford Encyclopedia Philosophy*, 1995; Gastmans, 2016), and can express autonomous decision-making (Welie, 2010). To this end, each person is by default considered to be cognitively preserved and thus able to make decisions about their care (Hughes & Baldwin, 2006).

In the early stages of dementia when the patient starts to experience cognitive losses (Higgs & Gilleardm 2016), one should attempt to identify/involve older persons with dementia in decision-making about their current care. It must be stressed, that loss of competence for decision-making is not an all or none occurrence, as there exists a grey area of competence preservation in between, in which the opinion of the patient remains a definable central issue (Janssens, 2010)

The complex signs and symptoms related to dementia lead to marked cognitive decline that seriously "challenges the identity and self-hood in care" (Higgs & Gilleard, 2016, p. 773). Such loss of cognition occurs through the effects on multiple domain deficits including "learning, memory, complex attention, language use, executive function, social cognition and perceptual motor skills" (Higgs & Gilleard, p. 733).

In end-stage dementia, the person loses his or her capabilities to communicate, reason, judge and makes autonomous decisions (Higgs & Gilleard, 2016). This creates a situation that potentially renders a crippling insult on their identity and self-hood, leading to a loss of capability to live autonomously as an independent person (Welie, 2010). The loss of autonomy leads to a loss of their ability to take decisions and make meaningful treatment choices (Volicer & Ganzini, 2003).

To maintain a presence of the person in end-stage dementia decision-making, all is dependent on the proviso that the person in the early phase of dementia is granted the possibility to be given a proper diagnosis, with proper details on prognosis and an appreciation of the benefits and risks of possible future care options (Agius, 2010). This knowledge helps enable the process for informed care choices and where possible informed care consent (*European Charter Patients*, 2011). On the other hand, if the patient is denied a diagnosis, this can be interpreted as an act where the individual is devalued in his/her "standing as a person" (Hughes & Baldwin, 2006 p. 83).

i. Values-based decision-making.

The importance of values in persons with cognitive and mental issues was highlighted by Hughes and Fulford (2005) in their description of a values-based framework to guide complex decision-making in mental illness. Such a framework relates closely to the "situated-embodied agent" (Hughes, 2001, p. 86), where it is acknowledged that values are both shared and disputed, yet accepted in their diversity (Woolbridge & Fulford, 2004).

A values-based practice unearths a deeper understanding of the signs and symptoms of the disease process and thus, in synergy with evidence-based medicine, helps guide the decision process in the complex clinical situations in hand (Hughes & Fulford, 2005). One method how to be able to sustain the patient's values in decision-making in end-stage dementia is to propose to persons in early dementia to fill out a values history sheet (University New Mexico, n.d.), to help orientate values-based care in the EOL.

A values-based approach gives a value-laden appraisal of what the patient is telling those around him at that very moment in care. Such a values-based approach helps in the growth of reasoning for reaching agreement in decision-making between decisional stakeholders (Hughes & Fulford, 2005). Hughes and Williamson (2019) remarked that one application of values-based practice concern decisions for or against tube feeding, where the values of all concerned are reasoned out in focus on evidence-based practice, based on consensus, communication, appreciation of all values, and a person-centred approach.

Hughes (2001) in a critique of published opinion on the losses of the person in dementia, pointed out Locke's (1690) view that loss in personal identity in dementia is tied to its effect on memories, beliefs, values, desires and intentions, which are necessary for the formation of a man to a person. In parallel, Parfit (1984) remarked that personal identity is lost in dementia, given the loss of memories, beliefs, and purpose. On the other hand, Hume (1739) wrote that "had we no memory, we should never have any notion of causation, nor consequently of that chain of causes or effects, which constitute our self or person" (Book 1, section V1).

Hughes (2001) contended the Locke's and Parfit's views as they theorise the existence of two different persons, a non-person with dementia and that of a person before dementia (Hope, 1994, see also Hughes). Hughes argued that these above views in dementia relegate the human being to a status of non-person. Furthermore, if one accepts the notion that a person ceases to exist, there would remain no moral obligation to assist the maintenance of body functions at the EOL (Kitwood, 1997).

Nuffield Council Bioethics (2009) argued that despite physical and mental decline, the individual in care still has "personhood, identity and value" (p. xviii). On this controversy, Hughes (2001) stressed for the continuity of the person in dementia through the "situated-embodied-agent" (p. 86) view of the person. Hughes argued that a person is "embedded in a history and culture", where the person is an agent who acts with meaning within his or her limitations of cognitive loss, and who must be situated in his or her clinical reality, experience and connectedness "that shapes how we think of people" (p. 87). This view not only helps sustain a best interests approach for the person with dementia (Chun-yan & Tao, 2004) but also promotes good practice in the EOL (Hughes).

Ideally, end-stage care should not be focused on what is lost, but instead worth should be given to QOL, dignity preservation, self-esteem, and respect for the patient's wishes and values through personal profiles (Epp, 2003). At the same time, the focus of end-care should also give attention to advance directives (Hughes, 2001), where the family is involved in care and decision-making (Epp).

B. The vulnerability of the person's dignity in dementia.

Franklin, Temestedt, and Nordenfelt (2006) described the delivery of dignity in care as showing respect to the patient as a person. The protection of dignity holds high esteem in personal and professional ethical deliberation (Bennahum, 2010) as dignity preservation reflects strongly in the delivery of health and social care (*Nuffield Council Bioethics*, 2009).

The experience of dementia leaves the person concerned with severe losses of memory and personality that particularly challenge one's identity (Cassel, 2010), losses that do strongly affect the person's ability to control decision-making on matters that concern their welfare. As a result, the losses associated with dementia do seriously contest the ethical principles on personal autonomy, informed consent, dignity, beneficence, and non-maleficence (Cassel; Linzer, 2002). To this end, ethical EOL care in dementia does rest on the consideration of three major pillars namely: "vulnerability, care, and dignity" (Gastmans, 2016, p. 146).

It must be pointed out that preservation of dignity is a fundamental component in the ethical framework of bed-side practice. The ethical rules in medical care for patients with dementia (Bennahum, 2010) are the following:

1. The safeguarding of their respect as individuals in acceptance of their autonomy and expressed past wishes.
2. Safeguarding their dignity in care while ensuring comfort (Bennahum).

3. The acceptance of dignity as a standard to promote life preservation (Agius, 2010).
4. Ensure that the best QOL is given during the terminal stage without undue aggressive futile measures to prolong life via artificial means (Bennahum).

It is known that the burden and care needs of illness does adversely effect dignity preservation in LTC care settings (Pleschberger, 2007), particularly where attitudes to care do challenge the self-esteem of the person (*Nuffield Council Bioethics*, 2009). *Nuffield Council Bioethics* argued that such attitudes in care do relegate the person to just an object in care rather than a person whose humanity demands respect of his or her values, autonomy and past wishes. Furthermore, residents with dementia in LTC are further hindered by communication and cognitive difficulties, leading to lack of participation in care decisions that concern their lives including EOL care (Sloane et al., 2008).

It must be appreciated that older people in nursing homes are often highly reliant on staff for care (Hall, Longhurst, & Higginson, 2009), this renders such persons in care more vulnerable and creates a potentially deleterious effect that could erode their dignity.

It is relevant to refer to the work of Chochinov et al. (2002) on the development of a dignity model for cancer patients (see Table 25). Given the multiple dignity concerns involved in institutions, care home staff can do a lot to help foster dignity in their residents (Hall et al., 2009). Such intervention should aim to encourage independence; respect of privacy; social support; care to help maintain a sense of pride in residents, and help residents not to feel that they are a burden. At the same time, while clinicians should aim to help minimise risk, they should likewise promote a dignity-preserving approach to help enable patient self-determination and autonomy (Tuckett, 2006). Chochinov (2007) also promoted a dignity model based on giving attention to attitudes, behaviour, communication and dialogue.

Agich (2003) (see also Hofland, 1990), argued in favour of the introduction of measures to improve the autonomy of frail older persons in LTC and in so doing help confront the economic, physical, social and psychological vulnerability that endanger human dignity in nursing care, these include::

- “Insisting on full-disclosure preadmission agreements.
- The creation of patient ombudsmen or nursing home ethics committees.
- Delineation of a basic set of resident rights.
- Establishment of detailed values histories for each resident” (p. 5).

Schroeder and Gefenas (2009) stated that “to be *vulnerable* means to face a significant probability of incurring identifiable harm while substantially lacking the ability and/or means to protect oneself” (p. 117). The vulnerability that comes across in human life with ageing is much more evident when it concerns the life experience of persons with dementia (Gastmans, 2016; see also Martin & Post, 1992), which according to ten Have (2016) is identifiable as a form of “special vulnerability” (p. 126) in view of the complexities and sensitivity to exploitation. Furthermore, ten Have added that patients in nursing care, places them at an increased risk of vulnerability, where the type of human relationship with others, including clinicians, may at times render them more patronised, deficit, weak and exploitable.

It must be acknowledged that the situation of cognitive losses in advanced dementia does seriously challenge the fundamental principle of autonomy (Cassel, 2010), as in such situations patients are more vulnerable as they are unable to protect their own best interests, and such challenges do threat the patients’ right for justice in care (ten Have, 2016).

One must acknowledge the centrality of vulnerability in dementia. The total vulnerability experienced in dementia has been described as affecting “their frail bodies, but also regarding the psychological, relational, social, moral, and spiritual dimensions of their being human” (Gastmans, 2016, p. 150). Gastmans added that the disadvantage related to vulnerability in end-stage dementia puts them at risk of having their human dignity and respect being adversely affected.

Vulnerability in the EOL is further compounding where the paternalistic attitude of clinicians does not help the person in care to be involved in treatment choices earlier on in the disease process (Tuckett, 2006; see also Becker, 1994), thus leading to an exacerbation of vulnerability in later life care. One of the possible concerns that may arise is that as a result of such vulnerability, persons with dementia are prone to “over- and under- treatment” (Owen, 2006, p. 33).

In order to respond to vulnerability created by cognitive loss (Cassel, 2010), the voice of the person with dementia needs to be sustained to the late stages. At the same time, medical practice and the supporting legal system must overcome legal lacunae (Cassar, 2010), cultural restrictions and hesitant care attitudes on ACP (Caruana Pulpan & Scerri, 2014, *Consensus Document EndCare,* 2018). Also, emotional upheaval (Bowker et al., 2006) needs to be understood and controlled, and insufficient care and support services are made readily available to help facilitate disclosure of an early dementia diagnosis to the person in care (Scheirton, 2010; *NICE*, 2006, November).

There is thus the need to ensure that decision-making in dementia, does reflect the morals, values, beliefs, feelings and wishes of the person in care (Sasson, 2000) while giving due recognition and inclusion to the views and beliefs of other stakeholders involved in the decisional process (Agius, 2010).

At the same time, it needs to be appreciated that life in the terminal phase cannot be preserved indefinitely. It is thus necessary for such instances to give maximal importance to dignity orientated care as life dwindles away (*GMC*, 2010). Such a dignity-based approach includes avoidance of futile, disproportionate aggressive care while upholding dignity preservation through respect, compassion, giving value to privacy, right for confidentiality, and granting the possibility of informed consent where possible.

Ten Have (2016), proposed an approach to vulnerability that moves away from a “general, basic or primary ontological vulnerability" (p. 72), in favour of an anthropological approach, which sees vulnerability as a characteristic of all individuals in the human species.

To help enhance dignity in the face of vulnerability in dementia, care staff need to be appropriately trained to help appreciate the notion of providing care to the person in the face of EOL suffering (*NICE*, 2006, November). Also, appropriate answers to care decisions are needed to promote patient well-being in appreciation of the patient in his or her care experience (Hughes, 2001).

It is worthy of mention that the Maltese Parliamentary Secretariat for Rights Of Persons with Disability and Active Ageing has recently issued a bill for consultation entitled the *Protection of Vulnerable Older Persons and Adult Persons with Disability* (March 30, 2017), to legalislate management guidelines for persons who require protection.

3. Resolving Ethical Dilemmas in End-Stage Dementia

A. Facing ethical dilemmas in end-stage dementia clinical decision-making.

The main “challenge of framing an ethical approach” (Gordon, 2002, p. 322) in the care of non-cancer patients in nursing homes is to define a working formula of what constitutes the EOL, but also the necessity to decide between palliative and futile aggressive management, one example is when to avoid CANH towards the EOL (*Alzheimer’s Association*, 2010, July 5; Gordon).

Dekkers, W.J.M, (2010), stated that in ethical decision-making, respect should be shown to the patient’s wishes. However, giving value to the patient’s preferences in advanced dementia is based on past expression through advance directives and family testimony of their relative’s values, including ethnic and religious beliefs (Gordon, 2002). Such decisions are prone to experience ethical dilemmas through conflict in views between the family and clinicians of what constitutes appropriate management regarding CANH in the EOL (Gordon).

The resolution of ethical dilemmas in geriatric care entails putting into practice appropriate ethical frameworks (Parker et al., 2008) in the form of ethical models as a means to help analyse and elucidate problems to facilitate clinical decision-making (ten Have, 2011). Such an ethical framework in dementia incorporates various components (see Table 26).

Therefore, an ethically appropriate decisional process in end-stage dementia care should be based on the following recommendations (Scheirton, 2010):

1. “The wishes of the individual with dementia.
2. The weighing of the risks and benefits of the decisions.
3. The effect on the physical and emotional well-being of the individual.
4. The effect on the individual’s and caregivers QOL” (p. 267).

It is known that in making an ethical decision regarding tube feeding in dementia (Mitchell & Lawson, 1999), one should ensure compassion, comfort, and safeguard the patient’s dignity (Morris & Volicer, 2001; Byrd, 2004). These in addition to the respect of autonomy, beneficence and non-maleficence (Arenella, 2005), and maximising QOL (Sampson et al., 2009). Furthermore, such ethical decisions in the EOL should also give due attention to justice, sanctity-of-life in stakeholders with strong religious beliefs, and veracity in care (Gordon, 2002). In addition, an ethical approach should also give attention to research-based knowledge of the risks and benefits of administering or withholding CANH (Dunlop et al., 1995).

It is pertinent to mention that the Berg en Dal Declaration listed the guiding ethical principles that guide palliative care in persons with Alzheimer’s disease (see Table 27).

Ethical dilemmas that arise in EOL care do usually relate to decision-making “between two valid positions, each with tremendous emotional impact” (Parker et al., 2008, p. 47). In practice, the ethical deliberation of EOL decision-making regarding swallowing difficulties in dementia does hold two broad yet contrasting morally acceptable proposals of management, namely the confrontation between invasive *life-prolonging* management versus *dying with dignity* through comfort seeking hand feeding measures. In resolving this ethical dilemma, the application of "sound moral judgement" (*Nuffield Council Bioethics*, 2009, pp. 21-22) can be applied to help resolve the clinical situation in care.

As cognitive control is lost in end-stage dementia (Bayer, 2006), there is the need to apply EOL care guidelines in a legally acknowledged ethical framework for the provision of appropriate care in end-stage dementia (*Nuffield Council Bioethics*, 2009). Such a framework would help clarify the ethical problems of choices that balance between safety with freedom; while respecting the patient's best interests and consideration of the needs of others who also play a role in the care process (*Nuffield Council Bioethics*).

B. Moral reasoning in the resolution of ethical dilemmas in end-of-life dementia.

Complex moral decisions are associated with and affected by different contexts, where the resolution of moral dilemmas implies several different proposals and multiple possible solutions (Ursery, 2005). The application of a reasoned analysis gives a logical means to address the resolution of a complex ethical decision and is distinctive in finding a solution to the dilemma through "logical argument and persuasion" (Day, 2006, p. 54). Day added that moral reasoning is known to offer an element of consistency that can serve as a reference for future decision-making.

The application of *moral reasoning* in groups or teams does focus on the attainment of a decisional activity based on holism arising through convergence on common reasoning (Richardson, 2009). In such a situation, the principles of individual moral reasoning do apply for collective moral reasoning; however here, collective moral reasoning must take heed of elements of disagreement. Furthermore, given the possible deep rift in beliefs and moral disagreements that can be encountered in group decisions, an in-depth appraisal based on "*reflective equilibrium*" (p. 26) is necessary to enable the encroachment towards an agreement between parties (Richardson).

This process of deliberation does require that practitioners are trained in moral reasoning techniques, namely (Day, 2006):

- “The moral context.
- The philosophical foundations of moral theory.
- Critical thinking” (p. 55).

C. The moral context in decision-making.

Morality is a set of coding principles or rules (Richardson, 2009) that deal with what is right or wrong. To this end, the application of moral reasoning enables the intervention of “moral facts and moral theories” (Richardson, p. 4) to reach the right answer and in so doing, moral reasoning goes further than the deductive application of moral theory in the quest to find an acceptable reasoned solution.

In moral reasoning, moral agents need to have an in-depth understanding of all the variables and the contexts that relate to the moral dilemma under scrutiny, namely the “facts of the situation, and the values, principles and moral duties inherent to the case” (Day, 2006, p. 55).

When one analyses the possible action that can be instituted to resolve a moral dilemma or values conflict, one must move on to address the possible effects or outcome. Based on the work of Ruggiero (1990), Ursery (2005) went on to qualify how such an action could lead to either benefit or harm, where the effects may be “emotional, physical, immediate, delayed, obvious, subtle, hidden and intentional” (p. 2).

Richardson (2009) remarked that philosophers have been known to list such general moral accounts in sorting order through an inductive thinking process called *casuistry*, which is practised and utilised to help assist the process in moral reasoning.

4. Principlism

Making moral decisions is a complex process and the application of moral rules of judgement does not always lead to fool-proof solutions (Ursery, 2005). To this end, the application of moral reasoning enables the intervention of "moral facts and moral theories" (Richardson, 2009, p. 4) to help find an acceptable reasoned solution. The inclusion of ethical principles in decisional analysis is essential in the systematic approach invoked through moral reasoning (Day, 2006).

The more commonly involved ethical principles in decision-making in elderly care (Gordon, 2002) relate to respect for autonomy, beneficence, non-maleficence, and justice, which together form the ethical theory of *principlism.*

A. Respect for autonomy.

Modern ethics gives due importance to the respect of autonomy of patients as a leading bioethical principle (Welie, 2010). Contemporary ethics, in particular through the liberal tradition, much attention is given to the human-being "as a free, self-sufficient, rational, independent, autonomous subject" (Dekkers, W. J. M., 2010, p. 116). The libertarian-minimalist approach to autonomy goes on to redefine the minimalist role of the health care provider to the point that the clinician is considered an "intruder into the life story of a patient" (Gefenas, 2010, p. 284).

The prevalent thinking of autonomy (Dekkers, W.J.M., 2010) shows similarity to the dualistic Cartesian relationship of body and mind, where the human being is a rational, autonomous agent that has control over their body and is thus an embodied person.

Beauchamp and Childress (2013) stated that in showing respect for the patient's autonomy for informed consent, one should first take in consideration whether the patient wants or not to receive information about their medical condition, and also if they wish to make decisions about their care themselves, or leave it to their family or clinicians to decide instead.

Agich (2003) firmly criticised care practices in LTC as they do tend to adversely affect the person's "control, dignity and identity" (p. 3), to the point that nursing homes are criticised for offering an inhumane service to persons in care. Such "total institutionalisation"

(Agich, p. 5; see also Goffman, 1961) leads to total control on residents' daily lives who are thus isolated leading to identity degradation and "subservience and inferiority" (Agich, p. 8). To this end, Agich promoted a bioethical view of autonomy in LTC termed "*actual autonomy"* (p. 85) as it leads to freedom of the frail and disabled, while also putting control on paternalism.

An individual's respect for autonomy is crucial in EOL care (ten Have, 2010), but such control is challenged by a technology-charged healthcare system where medical power reigns supreme. This situation does pave the way to a paternalistic physician-centred model of clinical decision-making (Cassar, 2010), where persons in care are reduced to "cases, numbers and objects" (ten Have, p. 72).

It needs to be appreciated that when the treatment option of instituting tube feeding is being considered, the potential burden involved in tube feeding demands a definition of treatment goals and informed consent (Druml et al., 2016). Thus the person in early dementia needs to have access to advocacy services in order to plan and draw up appropriate advance directives (*Alzheimer's Disease International,* 2001/2). In situations of the doubt to grant consent, the person with dementia must be assessed for competence (Polden, 1989), and where necessary be supported to decide (Dekkers, W. J. M., 2010).

Mazzola (2015) pointed out that the Italian approach to EOL care is strongly influenced by their traditional Catholic values and the lack of legalised advance directives to regulate autonomy preservation for refusal of treatment in terminal situations of care. This situation, in my opinion, does mirror closely the situation that is present in Malta. Mazzola remarked that in Italy, discussion regarding EOL decision-making in cancer care comes easier between clinicians and the family rather than with the patient. A consequence of this approach to terminal care, Giantin et al. (2012) found that in Italian geriatric settings more than half of their dying patients (51,3%; n =531) were managed with aggressive life-prolonging treatment. Azzopardi et al. (2017) remarked that contrary to age-old cultural perception to hide diagnosis to patients, their study findings showed that Maltese cancer patients wanted to be informed fully about their diagnosis, however when it came to decision-making, 60% of patients under study (n=252) preferred a paternalistic approach and left decision-making in the hands of their physicians.

i. Authenticity.

Given the minimalist libertarian interpretation of classic autonomy theory, Janssens, Zylicz, and ten Have (1999), suggested that the concept of authenticity better corresponds to good experiences in palliative care than the notion of autonomy. Authenticity interprets the individual in their personality and biography. Furthermore, authenticity also acknowledges that the individual's existence is fragile and dependent (Welie, 1999; see also ten Have, 2010), in the context of the values and life story of the person (Gefenas, 2010).

The model of decision-making of autonomy as authenticity leaves space for inclusion in decision-making for people close to the patient who have an in-depth knowledge of the patient's character, and knowledge of their past (ten Have, 2010). This broader perspective of the community through authenticity sees patients as social beings, who can share their suffering, vulnerability and dependency with family members and formal health care professionals.

To this end, authenticity meets more closely the need to protect vulnerable persons with dementia as it rests in a broader meaning of autonomy in a context of complex decision-making in the EOL (Gefenas, 2010).

ii. Respect for autonomy in dementia.

The major ethical problem encountered in persons with end-stage dementia is that they are permanently unable to exercise their right for autonomous decision-making (Welie, 2010). In such cases where mental capacity is lost, the concept of respect of decisions should be taken based on prior autonomous judgements or "precedent autonomy" through advance directives like living wills (Beauchamp & Childress, 2013, p. 228; Dworkin 1993).

The building of dementia decision-making solely on precedent autonomy relates to the theory of autonomy in dementia as viewed by Dworkin (1993), who argued that in the advanced state of dementia, persons retain only previous critical interests arising from their competent past. This view was disputed by Jaworska (1999), who argued that in their advanced stages of dementia, such persons do still retain the ability of having both pre-dementia and current critical interests, where the individual remains a person embedded in his or her humanity, identity, and of subjective value, despite all disabilities (*RCP*, 2010). This position does align itself with the actual autonomy theory as expressed by Agich (2003) where respect for patient autonomy in LTC relates mostly to personal identity, a sense of self, and the unique biography of the person in care. On the issue of precedent autonomy, Dekkers, W. J. M. (2010) argued that the liberal theorisation of autonomy should be applied where it concerns autonomous persons who retain mental capacity, as in the advanced stages of dementia it provides a minimalist account of bioethics (Gefenas, 2010).

It needs to be acknowledged that there exists a gradation in difficulty, a grey area of competence (Janssens, 2010), that relates to autonomous choices through which persons with cognitive decline may still be able to perform simple everyday choices like doing meal preferences (Beauchamp & Childress, 2013). In addition, to exercise autonomy in dementia, patients do often refer to the support given by relatives to ensure that "self-determination, worth, dignity, integrity and personhood" (Smebye, Kirkevold & Engedal, 2016, p. 1) are safeguarded in a person-centred care approach (Kitwood, 1997).

One problem that arises in consideration for precedent autonomy is when an ethical interpretation of a current choice goes against what was previously declared in a distant past through an advance directive (Beauchamp & Childress, 2013). Such a situation creates a conflict on whether one should base decisions on what was previously expressed in the living will, or else give due regard to the current best interests of the incapacitated person in care. *RCP* (2010), remarked that the original competent patient does not exist anymore and thus, the medical profession is duty-bound to care for the best interests of the mentally incapacitated patient, currently in care.

Furthermore, all knowing the evident loss in autonomy and decisional capacity in end-stage dementia, Dekkers, W. J. M. (2010) queried what interpretation should be given to the act where such persons with severe dementia repeatedly pull out feeding tubes? Dekkers interpreted such resistance to treatment as an expression of a primitive attempt to retain a minimal amount of competence, insofar as such actions could be interpreted as an expression of their wish on current care.

B. Beneficence and non-maleficence.

Beneficence is “an obligation to assist individuals to further their interests” (Sasson, 2000, p. 9). It relates to an action to safeguard the welfare (Beauchamp & Childress, 2013), safety and dignity of older frail persons (Linzer, 2002). Beneficence finds its application to the duties of the physician in the provision of good care to preserve life (Monturo, 2009), restore health, and relief suffering (*RCP*, 2010). All such actions are necessary to safeguard the best interests of a patient in care (Kirsch, 2003). In consequence, beneficence acts to tilt the balance in favour of an action that provides more benefit rather than harm (Kirsch) and limits discomfort in favour of a greater good (“EOL Care People”, 2008). This also applies to considerations regarding tube feeding in dementia (Gordon, 2002). Such interpretation of risk and benefit in terms of beneficence does need to take in consideration the relevant prognosis of the patient, their wishes and a need for an in-depth moral interpretation of the medical intervention on the patient’s values and QOL (“EOL Care People).

Beneficence is split into *positive beneficence,* and *utility beneficence*, where in positive beneficence agents are required to perform benefit to others (Beauchamp & Childress, 2013), while utility beneficence introduces utilitarian ideas where agents weigh the intervention about risks and costs to finally identify the best possible result.

Linzer (2002) remarked that autonomy, dignity, beneficence and paternalism are strongly influenced by the patient’s capability to make one’s own decisions. One of the contradictions of the value of beneficence is that it may go against respect for self-rule associated with autonomy (Sasson, 2000). This situation is prone to happen in a care situation where a safety-preserving action by attending clinicians goes against the self-determined choice of the patient, who may opt for a preference that invokes increased risk (Sasson). Such decisional dilemma finds strong difficulty for resolution in situations where the patient has questionable mental capacity, as in dementia.

Non-maleficence does relate to “not inflicting harm to the patient” (Sasson, 2000, p. 14). To this end, non-maleficence is associated with a more profound obligation than does the obligation related to beneficence (Beauchamp & Childress, 2013). Beauchamp and Childress included “do not kill, and do not cause pain or suffering” (p. 154) as being rules of non-maleficence.

One practical clinical example that finds obligation in terms of non-maleficence is that of keeping good standards of care. In so doing the practitioner maintains a practice that stands away from imposing risks and avoids negligence (Beauchamp & Childress, 2013).

Another example of non-maleficence that relates to the EOL is the request of the patient to die with dignity (Kirsch, 2003), a request which may be challenged by health care professionals who fall victim to their urge to act to prolong life. This situation is a classic example of conflict between autonomy and non-maleficence (Kirsch).

Non-maleficence does also help to regulate the issue of futility of treatment where physicians are not obliged to offer treatment that is not necessary or is contraindicated (Beauchamp & Childress, 2013). At the same time, non-maleficence does help to find a moral interpretation to withholding and withdrawal of treatment (see also Chapter 2, Section 5A). Another implied dilemma in EOL care that is associated with non-maleficence is the distinction between what constitutes ordinary care and extraordinary care (Beauchamp & Childress), where in extraordinary interventions, treatment can be legitimately foregone.

One other ethical dilemma in the EOL that does find close relation to non-maleficence is the distinction between "killing and let die" (Beauchamp & Childress, 2013, pp. 151) (see Chapter 2, Section 8). At the same time non-maleficence does also relate to the ethical issue of intended and foreseeable harm, Beauchamp and Childress remarked that this dilemma finds clinical application in the EOL to the rule of the double effect (see Chapter 2, Section 9).

Finally, it is necessary to point out that both beneficence and non-maleficence find meaning in helping to interpret practical ethical dilemmas in EOL care (Beauchamp & Childress, 2013). However, the major limitation of beneficence is that it is not sufficiently grounded on its own to validate all other principles.

C. The principle of justice.

Justice harbours a strong relationship to ethics and morality, where inter-dependence in a community of persons plays an important role to enable equal dignity and respect to all concerned (Velasquez, Andre, Shanks, & Meyer, 1990).

A definition of the principle of justice is that "individuals should be treated the same unless they differ in ways that are relevant to the situation in which they are involved" (p. 1). The principle of justice does relate to other nouns, including fairness and equality; in other words, it gives each person what he or she deserves (Velasquez et al., 1990).

The application of justice in health care relates to equitable access to appropriate services in health (*Convention Human Rights*, 1950, Article: 3) while moving away from discriminatory actions that undermine vulnerable people in the EOL (Agius, 2010).

Justice does relate to the principle of autonomy where together they help to regulate the roles of patients in relation to other stakeholders, namely the family, health care providers and society in its entirety (*RCP*, 2010). On the other hand, justice and autonomy may find dissonance with both beneficence and non-maleficence (*RCP*) in the application of EOL resources, particularly where patients and/or family members do request treatment strategies that are interpreted as futile by health professionals in the management of terminal care. Comparatively, deontology theory is in line with justice as it does turn around the notion that humans are equal and do deserve to be treated with the same dignity (Velasquez et al., 1990). Furthermore, justice, in association to the character traits of "conscience, wisdom, temperance, honesty, compassion and integrity" (Bolsin et al., 2005, p. 615), does enable virtue theory to be applied in the application of the doctor/patient relationship.

Theories of justice are subdivided into multiple sub-categories (Velasquez et al., 1990), namely:

- Procedural justice (*due justice*) is where a person receives the same treatment as all others (Summers, 2009).
- *Comparative justice* concerns delivery of healthcare resources to individuals (Kirsch, 2003).
- *Distributive justice*.
- *Corrective justice*.
- *Compensatory justice*.

Rawls (1999), proposed a theory of justice that implies a social contract approach in safeguarding justice for the disabled in real life circumstances, where dignity and person worth are respected in a move to address their vulnerability in care (see also Purtilo, 2010).

The right for justice in access to treatment is highly influenced by various outside factors and include issues related to "age, place of residence, social status, ethnic background, culture, sexual preferences, disability, legal capacity, hospital budgets, insurance cover and prognosis" (*Alzheimer Europe*, 2009, October, p. 21; Velasquez et al., 1990).

One such situation of questioned justice relates to the explosion of the prevalence of dementia with its associated costs and dilemmas faced by society (Purtilo, 2010), a situation that raises heated arguments on how to distribute resources in a fair and just manner. There are various reasons why persons with dementia and their caregivers are at increased risk of being vulnerable to injustice, these are considered in Table 28.

One limitation that tends to redefine the role of justice in care is the conflict that often results between the *ethics of justice* and the *ethics of care*. This dispute leads often to conflict between clinicians (Botes, 2000). In fact, the ethics of justice gives attention to the ethical rules of fairness and equity in the treatment of all people; on the other hand, ethics of care considers a needs-centred approach to the person in care.

5. Quality-of-Life v. Sanctity-of-life: An ongoing Debate in End-of-Life Care

A. Sanctity-of-life.

Vitalism sees life as a supreme value that must not be curtailed in any way (Keown, 2015). Therefore, vitalism promotes the view that wherever there is human life, whatever the condition of the person concerned - being comatose, disabled, or in suffering - such life has to be preserved (Hollinger, 2003; Keyserlingk, 1979). To this end, respect for life cannot be calculated on issues of practicality, performance or effectiveness.

In this expression of respect for human life, vitalism opposes QOL considerations that argue whether life is worth preserving or not (Keyserlingk, 1979). To this point, Sulmasy (2011) argued against a QOL approach, as life cannot be seen solely as a quality and thus cannot be calculated based on burdens or benefits. Thus vitalism helps to obliterate arguments to terminate life, where according to vitalistic thinking the giving and taking of life belongs exclusively to God.

However in his interpretation of vitalism, McCormick (1978) remarked that mere life in itself, as a vital metabolism, does not constitute on its own a value in itself. To this opinion, some proponents do also argue that vitalism is false, as in the balance of life in humans through a utilitarian approach, being a person finds more meaning than just being biologically alive (Fletcher, 1988).

Sanctity-of-life finds its origin in theological studies, the Bible and philosophy (Keyserlingk, 1979). It thus forms the “foundation of moral civilization” (Hollinger, 2003, p. 1402) that finds meaning in the protection of the vulnerable and weak. Therefore, sanctity-of-life protects human life and is an over-arching ethical principle that overrides all other principles (Jewell, 2005) that forms the basis for prohibition of euthanasia (see also Chapter 2, Section 9).

The Roman Catholic Church looks at sanctity-of-life as life that cannot be curtailed, it being the creative act of God, where “the person is to be affirmed as a person, possessing dignity” (Hollinger, 2003, p. 1403). To this end, through sanctity-of-life, the dignity and worth of the person are to be respected even in the EOL (McCormick, 1978), as there exists a natural cycle for life that has to be recognised - thus showing acceptance to “allowing to die” through a compassionate approach to dignity in palliation and hospice care (Hollinger, p. 1405).

In medical situations of life and death, the centrality of sanctity-of-life involves arguments related to patient wishes and welfare (Jewell, 2005), where patient-centred care gives importance to the notion of autonomy and relief of suffering.

In the EOL, bioethical and legal arguments strive to promote a co-existence between sanctity-of-life and QOL arguments, particularly if in the quest to acknowledge QOL considerations, efforts are made to clarify better what constitutes sanctity-of-life (Keyserlingk, 1979). Kohl (1974) argued, however, that sanctity-of-life cannot be bent to accommodate benevolent euthanasia.

One of the main themes that help define sanctity-of-life is that “man’s dignity, worth and sanctity are from God and not due to some quality or ability in man” (Keyserlingk, 1979, p. 11; see also Jewell, 2005; Hollinger, 2003). Thus the majestic will of God demands respect of man for life, and the union of body and soul is a gift in the trust where “man is not the absolute master of his own life and body” (Keyserlingk, p. 11; Ramsey, 1978).

It is argued that beyond religious beliefs, sanctity-of-life is deemed to be a pledge to commitment (Blackford, 2009) to a superior concept of life. Keyserlingk, (1979) pointed out that although sanctity-of-life is ascribed to theological origins, in truth, such religious beliefs find similar meaning in medicine through ingrained intuitive moral patterns of actions in clinicians.

Religion plays a firm hold on the decision process concerning care in the EOL, particularly as the issue of the "sanctity-of-life is often associated with religion" (*RCP*, 2010, p. 44). It should be acknowledged that of the Christian, Hindu, Jewish and Buddhist religious denominations "none are opposed to withdrawal or withholding of treatment under all circumstances" (*RCP*, p. 44). It is worthy to note that in Islam "life is sacred as God is its origin and its destiny" (*RCP*, p. 39; see also Sachedina, 2005) and according to Islamic teachings, nutritional support is considered basic care (Druml et al., 2016).

The *US Conference Catholic Bishops* (2009) remarked that "medically assisted nutrition and hydration becomes morally optional when they cannot reasonably be expected to prolong life" (article: 58), or when such medically assisted nutrition and hydration, would be "excessively burdensome for the patient or [would] cause significant physical discomfort, for example resulting from complications in the use of the means" (*Congregation Doctrine Faith*, 2007, commentary, 4, para: 3). Therefore the Catholic Church does include in the argumentation on the EOL the issue of discontinuing treatment that is "burdensome, dangerous, extraordinary or disproportionate to the expected outcome can be legitimate" (Druml et al., 2016, p. 9), with the understanding that tube feeding can be stopped in the last stages of dying when deemed futile (Amella, Lawrence, & Grezle, 2005; Singer & Kuhse, 1988). Such an approach makes it possible to create a bridge that synchronises sanctity-of-life arguments with those of QOL through an "overall reverence to life" (McCormick, 1978, p. 35). In the sense that, once sanctity-of-life does accept the need to preserve human dignity in EOL care (McCormick, 2008) such dignity-preserving care choices must be vetted through a QOL perspective. Such approach helps to clarify if such treatment is ordinary and acceptable to preserve life by respecting the dying process, or if it is extraordinary to the point that it may create excessive harm or is unbearable to the dying patient (Walter, 2003).

One of the problems of sanctity-of-life and its claimed origin from God is that it applies only to believers and is idolatrous (Hollinger, 2003). To this end, secular arguments do tend to challenge the idea that sanctity and dignity of man come entirely from God, and do argue that dignity and worth are inherent in man (Keyserlingk, 1979). Thus the imposition of life as a gift of God on a non-believer holds no worth, nor should a clinician believer impose his beliefs on patients with atheist ideas.

B. Quality-of-life.

The concept of *quality-of-life* in dementia finds its use in assessing health outcome measures (McKee et al., 2002), through addressing the effect of treatment, social services and care in residential care (Missotten et al., 2008). QOL does also find a place in the discernment of ethical dilemmas in dementia EOL care (Missotten et al.; Cantor, 2003), particularly in the prospect to apply sophisticated medical technology that has the potential to prolong life beyond what is naturally possible (Walter, 2003). To this end, QOL judgements do tend to influence treatment decision-making that relate to prolongation, termination, or the shortening of life. In so doing, Walter remarked that such QOL judgements do end up questioning the goals and limits of proposed medical choices, leading to difficult clinical choices that normatively question the value of life.

Schwartz and O’Sullivan Maillet (2013, p. 6) defined health-related QOL as “the value assigned to the duration of life as modified by the impairments, functional states, perceptions, and social opportunities that are influenced by disease, injury, treatment, or policy.”

Walter (2003, see also Reich, 1978) remarked that QOL could take two forms: either *evaluative* or *morally normative*. Evaluative approaches to QOL do assess the quality in stating, “What is it that we value about our physical lives?” (p. 1389). It is relevant to point out that wherever such an evaluative assessment of QOL takes a utilitarian view, persons with dementia would be deemed as lacking QOL.

Conversely, morally normative QOL ask more profound questions that include a moral judgement that asks, “Under which conditions should one protect life and preserve it?” (p. 1389). Walter (2003) remarked that in the presence of cognitive decline, normative appraisals of QOL are quite contentious as such patients cannot participate in decision-making.

In clinical situations leading to decisions in care, the quality of patient benefit forms a critical pillar that influences medical decision-making (Jonsen, 1994). Jonsen (see also Sulmasy, 2011) added that such clinical decision-making should incorporate QOL judgements that denote through assessment if the underlying pathology is of a transient remediable type or if it constitutes severe pathology with a bleak outcome. In practice in EOL care, clinicians at the bedside do not principally decide care management on QOL considerations. However, they do give importance to clinical futility and a therapeutic assessment of the helpfulness of treatment in that particular clinical situation. This approach gives more weight to decisions that address the appropriateness of management and analysis if the treatment constitutes ordinary or extraordinary care in that particular situation (Finnes, 1994).

It remains difficult, particularly in dementia to unearth personal views regarding one’s own QOL, with a proxy rating of QOL being prone to subjective bias. Moreover, Morreim (2003) remarked that cost-benefit analysis is in turn, notoriously prone to underestimate human suffering. For these reasons decisions to stop life-saving treatment based on QOL judgements that address personal values and choices should be restricted solely to persons who retain good cognitive faculties (Cantor, 2003) or be used in the presence of valid legally acceptable advance directives that express wishes on the matter in question.

Beauchamp and Childress (2013) remarked that calculating worth on quality-adjusted life-years [QALY's] does give importance to the "quantity and QOL" (p. 239). On the other hand, "health-adjusted life-years [HALY's] combine longevity with health status" (Beauchamp & Childress, p. 239; Miller, Robinson, & Lawrence, 2003) and thus give worth to QOL through health and prognosis. In the determination of QOL, all knowing that money is not unlimited; decision-makers are often put in a difficult situation to decide between costly eye-catching technology investments that serve a limited number of persons versus low-cost unremarkable care that serves the silent majority of patients (Morreim, 2003).

One QOL tool that has been applied in dementia care is the Alzheimer Disease Related QOL [ADRQL] (Missotten et al., 2008; see also Rabins & Kasper, 1997), which does measure by proxy, the following variables: "social interaction; awareness of self; feelings and mood; enjoyment of activities; response to surroundings" (Missotten et al., p. 1103). The ADRQL was utilised in a study on 357 Belgian persons with dementia against controls; emerging results showed that persons with dementia are more prone to having a poorer QOL against persons with mild cognitive impairment and cognitively preserved controls.

Jewell (2005) remarked that the ethics of euthanasia remains a complicated issue that requires interaction from philosophical ethics, an appraisal of the doctor-patient relationship, and statutory responsibility. Conversely, a QOL approach concerns value judgements that relate to "worth, usefulness or meaningfulness" (Keyserlingk, 1979, p. 21) of the life concerned in addition to a comparative account about relative worth. These considerations pave the way for reasoning that implies that benevolent euthanasia is a viable option to be contemplated, based on QOL concerns in terminal illness, including an assessment of unbearable pain and suffering in the EOL (Kohl, 1974).

Termination of life based on QOL concerns alone, do tend to give lee-way to arguments that certain persons would be "better off dead because their life is of no benefit or has no value" (Finnes, 1994, p. 38). On the other hand, Singer and Kushe (1985) gave a utilitarian meaning to the worth of life and termination of life, where lack of happiness, as inferred through severe mental and physical disability, are considered as predictable ways to judge reasons for termination of life. In a metaphysical view of the situation, Singer (1995) put the blame on the advances of medical technology for displacing the fine dividing line between life and death, leading to arguments that question the significance of brain death or not. He consequently pushed forward the argument that once this yardstick has changed, life and its continuation should start to be judged on whether it is liveable or not, on the terms of life quality, and based on assessment if life is worth living.

One of the limitations of weighing the appropriateness of aggressive treatment based on QOL judgements in the EOL rests on the fact that medical criteria, to determine suitability, are not objective enough to distinguish medical needs from moral evaluation (Beauchamp & Childress, 2013). Such a moral query brings into the equation the quest for justice by addressing resource allocation for frail older people, as opposed to younger folk who have more prolonged survival possibilities (Beachamp & Childress). Singer, McKie, Kuhse, and Richardson (1995) argued that such inequality in judgement condemns the disadvantaged ill / disabled to something akin to “double jeopardy” (p. 144).

Another limitation is when the appropriateness of treatment is based on a subjective evaluation of the level of unbearable suffering in the EOL, as this puts the clinician at risk of self-deception (Hughes & Dove, 2006). Also, when addressing the notion of futility as a measure to identify appropriate EOL care interventions, Hughes and Dove added that futility does not entirely correspond with the ethics of care as it does not consider “the principles of protective responsibility, narrative integrity and candour” (p. 48).

Therefore, QOL assessment needs to be strengthened (Beauchamp & Childress, 2013) and be supplemented by a risk/benefit assessment of the treatment considered, in an evaluation of what life the patient shall live after treatment. Beauchamp and Childress added that such benefit should also be weighed against suffering and pain, in a general analysis of the patient best interests, where “dignity and meaning of life” (p. 172) is given worth in association to an accurate appraisal of morbidity, medical diagnosis and prognosis.

C. The quality-of-life and sanctity-of-life debate in the management of swallowing difficulties in end-of-life dementia.

The debate between QOL and sanctity-of-life in clinical decision-making is a very controversial and complex ethical issue that has remained on the public and medical agenda for decades (Gilmore, 1984).

A QOL approach argues that human life gains value when the person concerned retains possession of relevant capacities, life experiences, and in the existence of a sound mental state that believes in the continuity of life itself (Davis, 1994). On the other hand, Davis (1994) remarked in a sanctity-of-life approach that human life does have primarily an intrinsic value as the human being has a right to life from “the moment of conception to the moment of brainstem death” (p. 630), even in the presence of cognitive decline. To this argumentation Sulmasy (2011) took a philosophical perspective on the intrinsic value of life as it, “must be understood as a value that is given, finite but nonetheless priceless, and transcendental” (pp. 187-188).

Quality-of-life arguments do not accept that life has inherent value and do not acknowledge equality of physical life to equality of the person (Walter, 2003). To this end, physical life holds only an instrumental value. Conversely, Walter argued that sanctity-of-life proponents refute this argument as they view physical life as “holding true value or good in itself” and this makes sanctity-of-life as being “far superior” (p. 1390) to QOL.

In addition, many QOL proponents view sanctity-of-life as being meaningless in favour of a QOL approach, based on arguments that sanctity-of-life is not only subject to various interpretations but also the continuation of life is also itself challenged (Keyserlingk, 1979). Counter arguments presented by those in favour of sanctity-of-life denote that it is a relatively stable concept, whilst on the other hand, QOL struggles as it is a “systematically ambiguous concept" (Gilmore, 1984, p. 180). These proponents stated that the quantification of physical, physiological, mental and spiritual QOL factors in EOL clinical decisions for individuals remain difficult.

For these contrasting reasons between QOL and sanctity-of-life, medicine must find its path on judgement and action that stays away from these extreme in views of care (Gilmore, 1984).

One must keep in mind that in the complex moral dilemmas regarding decisions to feed or not to feed a person in end-stage dementia, the scientific community has not as yet reached medical consensus, and the situation remains riddled with a diversity of opinion (van der Steen et al., 2014). At the same time, many voluntary organisations and professional bodies do favour decisions that go against tube feeding in end-stage dementia (*RCP*, 2010). In fact, Druml et al. (2016, statement 16) recommended that in "patients with advanced dementia, priority should be given to careful eating assistance through hand feeding" (p. 5).

In addition, judgement concern withholding and withdrawal of treatment, as is tube-feeding should always involve an analysis of the QOL of the person in care (Sulmasy, 2011). This is necessary, in an appraisal to determine if the proposed medical intervention is futile or not (Hollinger, 2003).

At the same time, it is challenging to identify the subjective QOL experience with regards to swallowing difficulties in end-stage dementia (Cervo et al., 2006). It is only through corollary data from cancer patients that one can hypothesise that hunger thirst and dry mouth do improve with the provision of small quantities of food, water, use of ice chips and mouth/lip lubrication. To this point, one must add that the sensation of thirst in dehydrated older adults is comparatively quiescent. On the other hand, tube-fed patients with dementia may suffer from additional discomfort, restraint, diminished social interaction and denial of the pleasures of the taste of food by mouth. Cervo et al. thus argued that these are significant points that show that tube feeding does adversely affect the QOL of affected persons with dementia and tends to increase EOL suffering. At the same time, Schwartz and O'Sullivan Maillet (2013) argued that as the EOL looms close, sub-optimal oral feeding does provide a better QOL than burdensome tube feeding.

The debate related to the morality of withdrawal and withholding of CANH has continued after the Schiavo case (Dresser, 2004) and a Papal Allocation (Shannon & Walter, 2004) and many are still seeking appropriate answers to this dilemma (Monturo, 2009). Use of tube feeding in patients with mental health problems is known to help sustain life and improve the QOL of some patients. This benefit loses its lustre when such cognitively impaired patients are close to their EOL (Amella et al., 2005). Such difficult decisions are, in turn, strongly influenced by local culture, religion and high costs of providing mealtime help (Amella et al.). In many societies, the drive to continue feeding is actively considered as a humane way to avoid starvation (Monturo) and is thus deemed to be life-sustaining treatment (*President's Commission*, 1983), even where the effectiveness of tube feeding is reduced (Amella et al.). Amella et al. added that in such situations advance directives to withhold tube feeding in the EOL do help sustain patient control and autonomy, but where such advance directives are absent, the result is that tube feeding is often prolonged beyond proportion to the terminal EOL.

One must remember that the prerequisite for starting CANH in dementia rests on the identification of a clinical indication for medical treatment and at this point, the clinician should ask if such treatment is "obligatory or optional" (Beauchamp & Childress, 2013, p. 172). In addition the treating "physician has to take the final decision and responsibility" (Druml et al., 2016, statement 1), after considering the benefits, risks and burden of treatment for or against CANH (Druml et al.). Furthermore, the physician must also keep in mind the relevance and appropriateness of the treatment choice (Rosin & Sonnenblick, 1998) as being in the patient's best interests (*BMA*, 2018).

Where death is imminent, the clinician should push forward those treatment interventions that are appropriate to the dying phase, while putting aside those treatment options that serve only to prolong death (Beauchamp & Childress, 2013). Such withdrawal of futile treatment should be carried out in a backdrop of appropriate palliative care measures to maximise comfort and QOL to the patient (Druml et al., 2016).

On the other side of the coin, respect for life relates to the problematic separation between killing and letting die (Beauchamp & Childress, 2013), which in euthanasia concerns deliberation for active euthanasia or the act to allow dying or passive euthanasia (Hughes & Dove, 2006). The argumentation on euthanasia and the implications in palliative care has been already dealt with in this thesis (see Chapter 2, Section 8) where the various arguments for and against euthanasia have been explored. In end-stage dementia, euthanasia does relate to involuntary euthanasia as mental competence in lost and does often relate to passive euthanasia as such persons are allowed to die as treatment is foregone (Hughes & Dove). One such example being denying the patient food and drink. Such denial of feeding brings up the difficulty to interpret arguments in “critical law, medicine and moral philosophy” (Beauchamp & Childress, p. 174) of what death is appropriate or inappropriate. One must point out that where jurisdiction allows, as in the Dutch Health system of care, euthanasia can be pushed to a higher level where a person with dementia is intentionally killed through euthanasia, on care based argumentation to relief the person from extreme suffering (Hughes & Dove). I here concur with the moral philosophical arguments written by Hughes and Dove who argued that virtue ethics in care is the road map of what a person believes is right or wrong, which characterises the clinicians’ moral beliefs to protect and assist the medical frail and vulnerable persons for whom we are responsible for caring. Hughes and Dove added that in the termination of the life of persons who lack mental capacity, where consent is lacking, this action changes the doctor/patient relationship to a new order and leaves its mark on the health professional. Hughes and Dove argued that the terminal of life of a person, “does not allow the sort of personal growth that caring for someone with dementia often allows” (pp. 51, 52).

Active stakeholders in EOL decisions in dementia, namely the family and clinicians do hold their personal beliefs (Gordon, 2002), and it is to be expected that the family and attending clinicians do not always agree on what constitutes appropriate management regarding EOL care (Hughes & Dove, 2006; see also Coetzee et al., 2003). Consequently, it is of importance to identify the values and beliefs of all stakeholders in the decision process. As doing otherwise in withdrawal or foregoing tube feeding, dissenting staff or relatives holding a conservative opinion, may presume such an act as euthanasia (Gordon). While others may deem aggressive tube feeding as a move to prolong suffering and unwarranted cruelty (Bowker et al., 2006). One must never overrule the seriousness of disregarding the beliefs of the caring personnel and professionals concerning conscientious objection (Druml et al., 2016) to stopping CANH in advance dementia, as such action may imply a “violation of their integrity” (Beauchamp & Childress, 2013, p. 41). Conscientious objection thus relates to a situation where compromise is difficult given integrity and personal moral issues, where the outcome does relate to either one of the following (Beauchamp & Childress) conclusions:

1. Either the clinician “sacrifices deep moral commitments” (Beauchamp & Childress, 2013, p. 41, see also DeGrazia & Rowan, 1991), or
2. The clinician withdraws from the care of the patient.

6. Addressing Ethical Dilemmas through Moral Theories

A. Rights theory.

Rights serve as a prime shield against “oppression, unequal treatment, intolerance, arbitrary invasion, and the like” (Beauchamp & Childress, 2013, p. 367). Beauchamp & Childress added that the expression of one’s rights is a legitimate claim for or against a situation necessary to ensure personal protection, safeguard dignity and respect.

Admittedly, rights are rule-based interventions which take the form of rules of morality, legal rules and institutional rules (Beauchamp & Childress, 2013). To this end, the ascertainment or denial of such rules leads to a positive or negative effect on rights. Many moral discussions imply the use of rights as “trump cards” (p. 369) in order to justify a particular position taken in the quest to safeguard the vulnerability of individuals or minority groups (Beauchamp & Childress).

Where mental capacity is lost, safeguarding of the rights of the person in care moves under the responsibility of the patient’s surrogate. Such involvement of the surrogate should - in the absence of a valid advance directive or living will - sustain the patient’s rights by upholding the patients expressed past wishes and values through substituted judgement or best interests judgement (*Alzheimer’s Association*, 2011). In such situations, the rights-bearer in exercising the obligation to protect those mentally vulnerable does leave the beneficiary not only in a passive position but also at the mercy on the other’s goodwill to administer the obligation (Beauchamp & Childress, 2013).

It is affirmed that the *European Charter Patients’ Rights* (2002, November) lists 14 patient rights (see Table 29) as a safeguard of the social model to help minimise society construed handicap on persons with disability. Furthermore, Beauchamp and Childress (2013) listed fundamental rights to be safeguarded in mentally incompetent persons:

- Even though an incompetent person cannot personally defend/ claim/ apprehend the right or exercise the right, he or she still holds justification of the right.
- Health professionals who are obliged to exercise rights to persons who are mentally incompetent to exercise/ claim/ apprehend such rights, they are still requested to exercise this right without due discrimination.

B. Virtue theory.

Beauchamp and Childress (2013) described virtue theory as “the most venerable type of moral theory” (p. 283) that finds its origin in the Ancient Greek tradition, where moral virtue was seen as a “moral anchor” (Day, 2006, p. 56). To this end, virtues act as the foundation for virtue-based ethical theories, and in so doing other normative ideas are grounded in them (Hursthouse & Pettigrove, 2018).

Moral teachers like Aristotle emphasised the idea of “excellence of character” (Beauchamp and Childress, 2013, p. 283) where humanity digs out the inner good as being the road to happiness (Vaughn, 2011). Aristotle’s reasoning on moral virtue finds expression in a life of moderation, on which Aristotle (n.d.) wrote that “virtue is the golden mean between two vices, the one of excess and the other of deficiency”. On the issue of moderation, Plato reasoned out that this concept finds meaning as a rule for sound ethical judgement (Day, 2006). One application of the “golden mean” is the process of avoiding over-treatment and under-treatment in end-stage dementia care (Hertogh, 2010, p. 273; Day, 2006).

Aristotle pointed out that in the application of moral virtue one should give importance to how honourable and virtuous is the decision process, or in other words how righteous are the means to reach an end (Day, 2006). On the other hand, Hume (1771) left his imprint on the relationship of virtue to “personal merit” (p. 217).

It is known that virtue is a solid starting point to justify excellent action (Vaughn, 2011). Vaughn added that virtue does lend its ways to coherence and common sense judgements and practical experience. Beauchamp and Childress (2013) remarked that virtue theory contains elements of intuition and sensibility, where virtuous persons do harbour “honesty, respect, fairness, just, and caring” (p. 377).

i. The virtue of care.

Caring is a fundamental element of virtue ethics, and the ethics of care is vital in moral life (Vaughn, 2011). The ethics of care gives importance to certain characteristics that relate to personal relationships that include “sympathy, compassion, fidelity, and love” (Beauchamp & Childress, 2013, p. 35; Vaughn). Beauchamp and Childress added that caring has an active cognitive component as it harbours various moral skills that need to be mastered; namely the appreciation of the patients' situations of care, needs, and feelings. Such habits of character give importance to responsibility and empathy, leading to quality care.

The work practices of medicine and health care are deeply rooted in moral virtues, in particular, the "virtue of care and caring" (Beauchamp & Childress, 2013, p. 34). The traditions of care practice and virtues do arise from the:

- Experiences of health care relationships (Beauchamp & Childress).
- Actions and practices in doctor/patient relationships (Bolsin et al., 2005).
- The virtues of "compassion, discernment, trustworthiness, integrity, conscientiousness, respectfulness, non-malevolence, benevolence, justice, truthfulness, and faithfulness" (Beauchamp & Childress, p. 33).

Also care-based ethics underpins the world's main religions, including "Judaism, Christianity, and Islam" (Day, 2006, p.57), and it is ingrained in the philosophical idea of reversibility namely the "golden rule: do unto others as you would have them do to you" (p. 57).

The practice of medicine gives stance to an ethically sound virtue based doctor/patient relationship, where the doctor gives importance to the provision of informed consent (Ogunbanjo & Knapp van Bogaert, 2014). However, Ogunbanjo and Knapp van Bogaert remarked that the doctor/patient therapeutic alliance is seriously ruptured in situations where balanced, prudent care practices are sidelined in favour of defensive medicine care practices.

C. Deontology theory.

The theory of Immanuel Kant or deontology theory is often termed as a *non-consequentialist* theory because the accent is mostly on acting according to moral duty or principle rather than the consequences, good or bad of an action (Day, 2006, p. 61). In his book *Grundlegung zur Metaphysik der Sitten* (1785), Kant as translated by Wood (2002), wrote that "the *categorical imperative* would be that one which represented an action as objectively necessary for itself, without any reference to another end" (p. 31). Therefore the categorical imperative forms the basis for the moral principle through its application to moral rules that are applied universally and thus gives meaning to safeguarding the dignity of the person and people in the universe (Day).

The practical application in dementia care is that non-consequentialism gives meaning to the duty of the physician to uphold patient interests when capacity is lost (*Mental Capacity Act,* 2005). Likewise, it does provide a solid argument for care professions and carers to continue the provision of care to persons in end-stage dementia as a moral obligation and duty to the frail person in care (Kitwood, 1997; *Nuffield Council Bioethics*, 2009).

Deontology theories are often termed as "absolutist" as their focus on "rules and commitment to duty" (Day, 2006, p. 62) does not leave lee-way for exceptions. In such situations, the "consistency of a maxim" (Beauchamp & Childress, 2013, p. 363), or person's reasoning to be morally valid, must pass the test of the categorical imperative to the point to pass the "*ought*" statement that underpins associated morality. The Kantian theory categorises the categorical imperative in 3 versions (Vaughn, 2011):

1. Where an act is right or wrong due mostly to its morality and consequence (Moreland & Geisler, 1996).
2. In dealing with persons, one must always treat them as having intrinsic worth (Moreland & Geisler).
3. The moral principle where the maxim is right as a moral law for all persons (Vaughn, 2011; Moreland & Geisler).

Furthermore, deontology ethics gives value to different social relationships and highlights the morality associated with special duties that arise in relationships including those encountered in doctor-patient relationships (Moreland & Geisler, 1996). Deontology also gives attention to moral worth, motives and values associated with an action resulting in convergence to moral obligation in a duty bound reasoning of morality (Moreland & Geisler).

Modern-day Kantian ethicists have re-evaluated Kantian moral theories, where Rawls (1999) worked on the development of the Kantian theories of "reason, autonomy, individual worth, self-respect, and equality" (Beauchamp & Childress, 2013, p. 364).

D. Utilitarian theory.

Utilitarian theory is termed as being a "means to an end" (Moreland & Giesler, 1996, p. 40), thus reference is made to *consequentialist* theories (Vaughn, 2011) of ethical judgement (Day, 2006). This view of utilitarianism finds possible meaning in public and institutional policies in the application of objective assessment, impartiality and general view to safeguarding everyone's interests (Beauchamp & Childress, 2013). In modern times, *teleological* or consequence based theories (Day) are prevalent.

In the nineteenth-century, the philosophers Jeremy Bentham and John Stuart Mill published their revolutionary ideas on consequentialism (Day, 2006). Bentham (1780) wrote that the principle of utility is a deed that "approves or disapproves of every action" (section II) and "tends to produce benefit, advantage, good or happiness" (section III). In his book *Utilitarianism*, Mill (1863) explained that there is nothing more desirable than happiness, if the pleasure does not supersede pain; such virtuous action would at the end of the day not be wanted. This *hedonist utilitarian theory* of maximising happiness or pleasure places the work of Bentham and Mill not only in the centre of consequentialist approaches but also finds meaning as being "welfarist, aggregative, maximising and impartial" (Beauchamp & Childress, 2013, p. 355). Such hedonist orientated approach can be measured in desirable values of well-being that include happiness, pleasure, welfare, preference satisfaction, freedom, and good health (Beauchamp & Childress).

Making reference to modern utilitarianists, termed *pluralistic* (Moreland & Geisler, 1996), such practitioners extended the set of total intrinsic values, to also include the values of “beauty, knowledge, success, understanding, enjoyment, deep personal relationships: (Beauchamp & Childress, 2013, p. 365). To these values, one must add “friendship, love, beauty, health, freedom, courage, and self-esteem” (Moreland & Geisler, p. 40).

One of the controversies that do surround the application of utilitarian theory and the computation of what is right or wrong in utility (Beauchamp & Childress, 2013), relates to whether this principle concerns only particular acts as *act utilitarianism*, or relates to rules as *rules utilitarianism*.

Referring to the work of Worthington Hooker in 1849, Beauchamp and Childress (2013) remarked that rule utilitarianism relates to truth-telling in medicine, where the harm rendered to the person far outweighs the benefits acquired through the use of deception in avoidance of diagnosis disclosure. On the other hand, act utilitarianism argues that truth-telling to patients does not always maximise the value of utility where “even a lie can give hope” (p. 358).

The application of utilitarianism theories in the care of a non-productive minority group, as is found in persons in end-stage dementia, puts them in a state of significant disadvantage (*RCP*, 2010). Persons with dementia can easily fall prey to market and consumerist forces and end up being deprived of mainstream care (ter Meulen, 2008). Also, utilitarian views could question if life in dementia is still worth fighting for (*RCP*).

7. Other Models of Moral Reasoning

A. Paternalism.

Paternalism can be defined as the act of “intentional overriding a person’s wishes or actions through coercion, deception, non-disclosure of information, or for the welfare of others” (Linzer, 2002, p. 27). In health care, clinicians act paternalistically through “deception, lying, manipulation of information, nondisclosure of information, coercion, or simple refusal to carry out another’s wishes” (Beauchamp & Childress, 2013, p. 215). Beauchamp and Childress remarked that one aspect of paternalism is the deception to hide from the patient the veracity of their diagnosis. In so doing the clinician aims, in terms of beneficence and non-maleficence, to provide a benefit or avoid from harm the person in care, even though this may mean undermining the autonomy of the vulnerable counterpart.

One must accept that paternalism is not justified in situations where the older person in care prefers to retain their right for self-determination, yet there exist situations where the aged do accept a paternalistic behaviour by their attending practitioners in care (Blasszauer, 1994). Gillon (1994) argued that the only form of paternalism that is acceptable to safeguard the respect of autonomy is when the person himself requests deception, as when the person in care expresses his or her wish not be given news related to a bad diagnosis.

On the other hand, as mental incapacity gets progressively worse, the natural consequence of loss of autonomy favours beneficence that gives leeway to justified paternalism (Beauchamp & Childress, 2013).

Nussbaum (2006) pointed out a clear distinction between *soft paternalism* and *hard paternalism*. In soft paternalism, the caregiver as a paternalistic agent interferes in the life of another individual, keeping in mind beneficence and non-maleficence to prevent or minimise non-voluntary behaviour (Beauchamp & Childress, 2013).

On the other hand, hard paternalism is an extreme form of unacceptable paternalism as it restricts information or overrides patient's informed choices (Beauchamp & Childress, 2013), leading to a grave affront to the dignity and autonomy of the person in care (Linzer, 2002).

Institutionalised persons with dementia are rendered vulnerable as this situation in care creates ethical dilemmas that challenge the autonomy, dignity, and beneficence. These are principles that come in confrontation to define what constitutes justified paternalism as opposed to sheer abusive care (Linzer, 2002).

An acceptable process to safeguard precedent autonomy in dementia is through the drawing up of advance directives (*Alzheimer Europe*, 2009b). However, failure on the part of health care professionals or proxies to respect and implement such expressed passed critical wishes, in favour of experiential interests of caregivers, do constitute "an unacceptable form of moral paternalism" (*Alzheimer Europe*, p. 14).

In providing appropriate patient-centred care, it should be remembered that one of the vices of health professionals in instilling a paternalistic approach to care is that they tend to refrain from giving a chance to patients with questionable capacity to participate in decisions regarding their care (Welie, 2010). What is ethically expected in such situations is that the physician should repeatedly attempt to uncover periods of lucidity in order to be able to identify personal wishes regarding care choices and thus preserve the respect of autonomy (Evans & Robinson, 2010).

B. Substituted judgement.

In dementia, where no advance directive is available, and the patient's past wishes and values are known, one petitions the use of substitute judgement (Torke, Alexander, & Lantos, 2008)

Substituted judgement is a model of decision-making that grants the power to the surrogate to decide for the patient, what the patient would have wanted for themselves had they remained mentally competent (Gordon & Baker, 2011), akin to "stepping in their shoes" (Welie, 2010, p. 164). In doing so, the surrogate has to uphold the patient's actual interests (*RCP*, 2010), values, attitudes, beliefs and past wishes (Gordon & Baker). In such situations, clinicians need to provide the family all necessary medical information regarding the patient's condition, prevailing illness and treatment options, to help the family decide in the context of substitute judgement (Chun-yan & Tao, 2004; Gordon & Baker).

Gordon and Baker (2011) remarked that the best way to achieve maximum results from substituted judgement decision-making is for the process to start early when the patient is still cognizant and retains insight. This gives the person with dementia the chance to explain his or her personal preferences in care with his designated surrogate. In the proper application of substituted judgement, the surrogate acts to safeguard the patient's autonomy, as ultimately, the decision belongs to the patient (Beauchamp & Childress, 2013).

One of the limitations of substitute judgement is that it tries to project to the present an interpretation by the surrogate of the past autonomy of a person who has lost decisional capacity (Torke et al., 2008). Furthermore substituted judgement risks the affront of paternalism and a violation of the person's dignity (Welie, 2010), as they are only an interpretation of the surrogate's assessment of what is in the patient's best interests.

C. Best interests judgement.

Best interests judgement forms part of the medical, ethical and legal clinical pathways that are utilised in the management of decision-making in persons who lack mental capacity (Hughes & Baldwin, 2006). In so doing, best interests decision-making regulate reasoning under the Maltese *Mental Health Act* (2012). Dekkers W.J.M (2010) argued that best interests judgement does define a better ethical defensible decision-making process than either advance directives or substituted judgement, as best interests approach does better safeguard patient dignity through the preservation of present personhood. Best interests judgement accepts the condition from which the patient is currently suffering and for the remainder of their life (Wellie, 2010) and it takes into account the patient's own experience of their condition.

The following is a list of variables that need to be considered to determine best interests judgement:

- "The person's past and present wishes and feelings.
- The beliefs and values that would be likely to influence his or her decision if he or she had the capacity.
- The other factors that the person would be likely to consider if he or she were able to do so" (Hughes & Baldwin, 2006, p. 65).

- Best interests should seek the best alternative that “allows most freedom for the person’s future” (Regnard & Huntley, 2006, p. 36).

Hughes and Baldwin (2006) remarked that in order for the clinician to determine patient’s best interests, an attempt should be made to make contact with all persons who had or have significant human contact with the patient, as a means to identify the patient’s values, preferences, and viewpoint.

Proper abilities of clinicians to endorse best interests of persons under their care should harbour care practices and treatment choices that “rely on interventions of proven benefit and acceptable risk” (Beauchamp & Childress, 2013, p. 331). Such balance of risk versus benefit should consider QOL but also keep in perspective what life will the patient be living after the intervention. Attaining best interests aims for the highest probable “net benefit among available options” (Beauchamp & Childress, p. 228). Consequently, best interests as a decision-making model in persons with cognitive decline does hold high esteem as it ultimately protects the welfare of persons who are vulnerable in their situation of care (Beauchamp & Childress).

Seeking the best interests of persons in care should not only seek to uphold the QOL of the patient alone, but also be attentive enough to also seek the best interests of the family who are often deeply engaged and involved in the care process of their elders (*President’s Commission*, 1983; see also Beauchamp & Childress, 2013).

The process of building up best interests judgement in dementia does include three considerations (Welie, 2010):

- *Diagnostics*.
- The *biography* of the person in care.
- *Perceptions* regarding the patient.

Many bioethicists criticise best interests judgement as being sheer “guessing and fantasising” what other people think or feel (*Nuffield Council Bioethics*, 2009, p. xxv).

Furthermore, the determination of best interests is also limited as it is depends on an empathic appraisal of the patient based on an unreliable subjective assessment of the person in care (Welie, 2010).

8. In Defence of Consensus-Building Approach

A. Defining a consensus-building approach.

Consensus-building can be defined as a decision-making process where stakeholders work together to reach agreement on an issue to find a mutually acceptable solution (“American Heart Association”, 2010; Hartnett, 2011). Consensus-building does not necessarily mean full agreement, or where all stakeholders attain their first choice decision. The ultimate aim of consensus methodology is to resolve different often complex ideation, arising from various participants, through discussion to draw up excellent recommendations (Wong, Brierley, & Brouwers, 2012; Downing & Larkin, 2009). Consensus strategy for problem-solving finds many uses, one of which is to determine the best choice of treatment in complex situations of care, (Murphy et al., 1998). The holistic approach in consensus-building approach finds increased meaning where mental capacity to decide is lost. It is known that complex EOL decision-making cannot be based on a balanced appraisal of autonomy preservation and beneficence alone (Yean & Anantham, 2015).

In general, when one refers to consensus decisions, one usually refers to the *formal consensus methods*, which are well-structured formats that are commonly utilised in clinical guideline development, and which facilitate a better-constructed consensus process than do *informal consensus methods* (Murphy et al., 1998). Formal consensus methods do relate mainly to the Delphi technique; the nominal-group technique; and the consensus-development conference (Murphy et al.) (see also Chapter 1, Section 4). Various authors have pointed out that hybrids of these formal consensus methods are frequently utilised in practice, in an attempt by proponents to adapt to the particular situation in question (NICE, 2006, March; Murphy et al.; Jones & Hunter, 1995). In fact, “American Heart Association”

(2010) argued that each consensus process is unique as different stakeholders set up a different flexible design process that best fits their situation under consideration.

It is necessary to point out that to reach consensus agreement in large groups of stakeholders; such groups do require the utilisation of formal forms of consensus methodology to help avoid group orientated limitations and avoid domination by a minority faction (Diehl & Stroebe, 1987; see also Murphy et al., 1998).

Wherever informal consensus methods are utilised, these do not use standardised structured procedures and do not necessarily revert to the use of a facilitator, yet they may still converge on specific characteristics of formal methods of consensus to reach group agreement in decisions (Murphy et al., 1998.). Murphy et al. added that in informal consensus methods, aggregation methodology is implicit where “freely interacting discussions” (p. 2) and decisions are taken consensually after a face-to-face confrontation that adapts to the situation in question.

Looking at examples of consensus-based processes in EOL decision-making in dementia, various researchers (Eggenberger & Nelms, 2004; Chun-yan & Tao, 2004; Karlawish et al., 1999) found that the use of informal consensus methodology turned out to be of benefit to structure a personalised dialogue and convergence to agreement between clinicians and the family (Jones & Hunter, 1995). This approach was not impaired by moral degradation or subservience of either party (Karlawish et al.; Jones & Hunter), and also never lost sight of the past wishes, values, best interests, and dignity preservation of the person in care (Chun-yan & Tao; Karlawish et al.). Consequently, the smaller number of stakeholders involved in EOL decision-making justified the move away from more formal consensus formats, which are of benefit in large groups (Murphy et al., 1998), as it is known that smaller groups of stakeholders in consensus may prove to be easier to reach unanimity (Hartnett, 2011). Still Murphy et al. remarked that when utilising informal consensus methodology, it is essential that certain principles are set up. For example, all participants need to be given the opportunity to air their views and not be criticised (Murphy et al.), and thus avoid dominance by one side over the other (Jones & Hunter). Also having an expert facilitator like the physician (Karlawish et al.) to guide the process of informal consensus decision-making, will help to ensure that the more important matters in question are targeted for deliberation to reach agreement, and thus help lead to more valid judgements (Murphy et al.), and better consensus outcomes (Wortman, Vinokur, & Sechrest, 1988; see also Murphy et al.)

Consensus methods are utilised in situations of conflict to help structure group communication leading to improved decision-making in clinical practice (Jones & Hunter, 1995). In seeking consensus, the problem in question should be analysed and compartmentalised in a way to seek "similarities rather than differences" (List, 2001, p. 277). In so doing consensus-building approach works better than a top-down decision-making process as in consensus all participants do give their input and are inclusive of the final decision (Hartnett, 2011).

The goals of consensus-building approach are (Hartnett, 1995):

- "Better decisions, as all participants are enabled to have a say in the final proposal.
- Better implementation as the fact that all stakeholders are involved leads to better compliance to implement the final decision.
- Better group relationships" (p. 2).

i. An ethical appraisal of consensus-building approach.

One advantage of consensus-building approach on other ethical models of decision-making in dementia is that consensus-building favours a dual ethical function. In execution of such duality, consensus-building not only provides a methodological process how all stakeholders participate together in a trusting relationship to reach a joint consensus decision (Chun-yan & Tao, 2004; Karlawish et al., 1999). However, also consensus-building approach does encompass a holistic approach to decision-making (Yean & Anantham, 2015), where ethical theories and principles are upheld and given value in the quest to resolve the ethical dilemmas at hand (Agius, 2010). In fact, through a consensus-building approach:

- The dignity of the person with dementia, despite profound vulnerability, is safeguarded as the consensus process respects the values and past preferences of the person with dementia (Agius, 2010; Volicer et al., 2002; Joy, 2013). Such an approach through consensus decision-making does also give allowance to how the patient in end-stage dementia reacts to treatment (Bowker et al., 2006).
- The family is given sufficient space and knowledge to participate with clinicians in the consensus process. Such family involvement helps them to come to an informed care choice while allaying the burden of decision-making (Karlawish et al., 1999; Kellett, 1998). In so doing the family can maintain its primary role, that, to bear witness to the values and past preferences of the person in care through substituted judgement (*EndCare Consensus,* 2018; Chun-yan & Tao, 2004).
- Consensus-building approach upholds most of the values inherent in virtue theory (Hartnett, 2011). These include the agency to take the right decision that is in good character, and the promotion of a trusting relationship between patients and their clinician. Such decisions are thus balanced and based on practical reasoning of the situation at hand.
- Consensus-building approach does also help sustain the deontological ideal of duty to vulnerable patients in care, by seeking to uphold their past wishes, best interests and dignity preservation throughout the decisional process (Chun-yan & Tao; Karlawish et al.).
- With concern to sustaining patient rights, consensus-building approach does give meaning to the process of upholding the rights of persons in care, while also giving importance to the views of the decisional makers involved in the process, namely the individual clinicians and the family (Yean & Anantham, 2015).

- Consensus-building approach does overcome the disadvantage that utilitarianism imposes on persons in end-stage dementia, as consensus-building strives to maintain person-centred care for vulnerable patients (Joy; *RCP,* 2010).
- Beneficence and non-maleficence are grounded ideas in consensus-building approach in EOL decision-making (Yean & Anantham5, p. 399; Agius) through decisions that safeguard the safety, dignity and values of the person in care while minimising suffering.
- Regarding justice in care, consensus-building approach gives close attention to the input of all stakeholders in care ("American Heart Association", 2010). At the same time, it bears justice to the needs of the person in care (Chun-yan & Tao; Karlawish et al.), mainly doing "justice to the dignity of the dying patient" (Agius, p. 2).
- In the face of ethical dilemmas created by paternalistic approaches in dementia, Chun-yan and Tao argued that consensus-building does respect all stakeholders in care including the patient and helps enable the building of care decisions based on trust.
- Consensus-building approach is a valid response to the management of complex scenarios regarding feeding difficulties, where conflicting ideas of QOL versus sanctity-of-life are often encountered. This is so as consensus-building helps resolve objections on EOL decisions through a team approach while respecting the values and beliefs of all concerned including the dignity of the patient in care (Chun-yan & Tao; *Swedish National Council*, 2008; Agius; Joy).
- In the process leading to consensus, clinicians should come to the medical decision by safeguarding patient solidarity and identity through affirming their values and wishes through patient best interests (Chun-yan & Tao). In such considerations, a consensus-building approach does help find resolution in medical decision-making and resolve the conflict between stakeholders (Yean & Anantham), leading to a general acceptable management plan (Agius). Agius argued that consensus-building approach works better than best interests

judgement in decision-making in dementia as such a process is a more inclusive and comprehensive process where the opinion of all stakeholders is given value.

The comprehensive input provided by consensus-building approach is an added safeguard to human dignity as it helps protect the patient lacking decisional capacity from “rushed decisions and hidden agendas” (Agius, 2010, p. 12) and keeps at bay subjective bias on the perceived QOL of the patient. Therefore consensus-building helps avoid erroneous judgements and inappropriate care delivery. It was also reported that a consensus-building approach does also help to resolve the conflict between family members themselves regarding treatment options for their elders (Yean & Ananthem, 2015), and helps shift treatment decisions in the management of EOL swallowing difficulties from cure to comfort care (Cervo et al., 2006).

The values that characterise a consensus-building approach in EOL decisions are inclusive of various issues that uphold care in end-stage dementia care (see Table 30).

ii. Consensus-building approach in decision-making in end-of-life dementia.

Decision-making in end-stage dementia does pose considerable difficulty between clinicians and family members, in their quest to attain the best care package for the patient in care (Karlawish et al., 1999). Such difficulty concerns issues that relate to values, preferences, and goals of treatment, which may all differ between the three stakeholders involved in decision-making namely: the clinicians; the patient’s legal representative or next of kin; and the past expressed wishes of the person with dementia (Karlawish et al.).

Chun-yan and Tao (2004) recommended that in the absence of advance directives, decision-making in end-stage dementia should follow a consensus decision-making model between clinicians and relatives, as it gives space for all parties to participate, but where the final decision remains a medical decision.

When consensus-building approach is utilised in the decision-process to manage feeding difficulties in end-stage dementia, attention should be given to:

1. “Dialogue between known proxy/family, and the clinical team” (Karlawish et al., 1999, p. 836). Such a multi-disciplinary team approach is the best way to manage such complex tasks (*RCP,* 2010).
2. “The objective is to reach consensus on diagnosis, prognosis, risks and benefits of treatment options.
3. All stakeholders should understand and agree on what is meant by “starvation, suffering, QOL, feeding and dying” (Karlawish et al., p. 836).
4. Decisions should give priority to patient preferences, weighing risks and benefit of each care option, with due attention being given to the management of suffering, comfort enhancement, safeguarding human dignity and QOL preservation (Karlawish et al.).
5. To set up an agreed management plan based on palliative principles, even where life-prolonging treatment is contemplated (Karlawish et al.).

Nelson and Nazareth (2013) referred to consensus-building approach as a means to resolve conflict in ideas regarding the withholding or withdrawal of futile EOL tube feeding. They remarked that for such consensus to be effective, the medical treatment proposal should be supplemented by a “moral space” (p. 23) where the family and clinicians are encouraged to “nurture shared decision-making” (p. 23). Such a moral approach includes an ethical reflection on the patient’s and family’s values and in so doing, enabling a better appraisal of care that honours the patient’s current perspective and lived values.

iii. The limitations of consensus-building approach.

Decision-making regarding feeding and hydration are notoriously tricky, and difficult to reach a balance of decisions between all stakeholders in care. *RCP* (2010) remarked there is “no ethical calculus that can determine what is right in some situations” (p. 47). *RCP* added that wherever consensus cannot be reached, it is recommended that the doctor must take the lead in decision-making to safeguard the best interests of the patient under his or her care.

Monturo (2009) remarked that lack of agreement, in stakeholders involved in decision-making to withhold or withdraw tube feeding, creates a chaotic situation to attain resolution, which has to seek judicial and bioethical levels of intervention beyond the bedside. Monturo added that in practice wherever court ruling is sought, clinicians do struggle in such situations, and legal decisions do end up granting little comfort to those concerned. Monturo concludes that the best way forward to resolve the disagreement on tube feeding treatment choices is to give more importance in discussions between those involved on the right “meaning, values and beliefs concerning food and artificial nutrition” (p. 212).

One of the problems of consensus-building approach in EOL care in dementia is that it is time-consuming (Karlawish et al., 1999), with no guarantee that consensus will be ever reached, and consequently urgent decisions are difficult to rely on consensus methodology.

An important asset that helps achieve better consensus is when all stakeholders are consistent and harbour similar values (*NICE*, 2006, March). In practice, such similarity in values is difficult when decisions concern the convergence of clinicians and family members in dementia care (Chun-yan & Tao, 2004; Linzer, 2002).

One common point of disagreement hindering consensus can arise when no consensus is reached on care management between clinicians and the family. Chun-yan and Tao (2004) remarked that in such situations, the past wishes and values of the person in care, as expressed through advance directives could often help to clarify which treatment option to be followed. At the same time, disagreement in reaching consensus between clinicians and the family can be minimised through “early, sensitive and proactive communication” (Agius, 2010, p. 9) where attention is focused on the goals of treatment, potential outcomes and the patient’s preferences and values.

Disagreement hindering consensus can also take the form of conflict regarding decisions within team members themselves. Such disagreement within the team emerges because professional values guide individual team members' values and ideologies (Sasson, 2000) (see also Chapter 3, Section 1.B).

For the consensus-building process to be effective there is the need for all stakeholders to be positively engaged and committed to the process, as one disagreeing member can stop the whole process from finding a consensus outcome ("Effective Decision-making", n.d.). To this end, the physician must be on the alert to identify and appreciate firmly held ideas by the family for aggressive management including tube feeding as such views are potentially consensus breaking differences in the planning of care (Karlawish et al., 1999). When such potential consensus blocking problems loom ahead, these conflicting views should be acknowledged by the clinician, negotiated and ultimately stakeholders should come to a compromise care plan, which in many instances may invoke a trial care agreement that usually lasts for a few weeks.

Black (1994; see also Murphy et al., 1998), remarked that there is limited methodological research within the health field. Also, the validity of consensus processes is highly dependent on the skills of the facilitator or expert in the field to direct the arguments related to the clinical dilemma in the right path, while ensuring that group discussions are not hijacked by a domineering minority group (Jones & Hunter, 1995). In reality, the facilitator is usually the physician (Karlawish et al., 1999) who does often rely only on "their own, possibly limited, experience" (Fink, Kosecoff, Chassin, & Brook, 1984, p. 981) in consensus-building practice. Consequently for consensus-building approach to attain a higher rate of success, the clinicians involved should receive training in the consensus process, communication, conflict resolution and team-work development (Nelson & Nazareth, 2013; Yean & Ananthem, 2015).

In dealing with opposition and significant disagreement, the facilitator must explore if the dissenting part is ready to be neutral to the proposed decision. If not, particularly where disagreement is significant and involves issues of strong beliefs, it would be best to "lay aside the issue for another time" ("American Heart Association", 2010, p. 3), whilst ensuring that the dissenting part is not put under undue coercion to agree to the proposal on the table. Another option proposed by Hartnett (2011) is to provide the dissenting party with the chance to promote an alternative solution for discussion.

Wherever disagreement seems to be insurmountable, and there is a persistent block in agreement, consensus methodology does allow levels of agreement termed consensus "minus one" or "minus two" (List, 2001, p. 277). Although acceptable, such a diminished level of agreement does redefine what is meant by consensus (List). Certain situations do require that group agreement is reached unanimously (Hartnett), one such situation where unanimity in consensus is encouraged relates to EOL decision-making between the family and clinicians for patients with dementia (Karlawish et al., 1999).

In their practice in a Kaiser Permanente Medical Center in Southern California (USA), Nelson and Nazareth (2013), explained that wherever there is conflict in decision-making regarding futile treatment in EOL care between the clinical team and the patient/family, they do follow a consensus-seeking framework between stakeholders. If consensus does not materialise after interaction of "quality conversation" (p. 23), a second physician is asked to intervene, followed if necessary by ethical review. The ethics board does then recommend either one of the following: where the ethics board's opinion differs from the physician's opinion, in such instances, the patient is offered to be transferred to the care of another consultant physician in the same hospital. On the other hand, if there is a persisting dispute with the patient/family, they are given a choice to either transfer the patient to another consultant in another hospital, or start legal proceedings. According to the findings of Nelson and Nazareth, this consensus-based approach resulted in a high-resolution rate (94%; n =146 cases).

Hartnett (2011) remarked that unanimity in consensus-building is favoured wherever: the list of stakeholders involved relates to a small group; where the purpose is clear and focused on a common objective; and also where there exists mutual trust between stakeholders involved. In my opinion, all these three variables that enable a better chance for consensus can potentially be met in dementia EOL clinical decision-making. This is because the interaction of the family with clinicians does usually boil down to a one to one interaction that should respect the person in care's wishes and values (Karlawish et al., 1999). Also, the setting of bed-side decision-making is grounded in mutual good-will between the clinician and family who interact together in a trusting relationship (Agius, 2010). Furthermore one believes that both the family and clinicians act on the basis of beneficence, as both have a common goal, that of achieving the patient's best interests (Beauchamp & Childress, 2013) in providing proper care for the person who is suffering from swallowing difficulties in end-stage dementia (Karlawish et al., 1999).

9. Concluding Reflections

In this literature review, I have discussed at length the complexity in decision-making related to the management of swallowing difficulties in end-stage dementia. This problematic situation does often create a severe divergence in opinion between stakeholders in decision-making that hinders agreement in the plan of care.

An ethical decision-making process that is agreeable to all stakeholders has to uphold the moral principle that constantly keeps in sight respect for dignity of vulnerable persons in end-stage dementia (Epp, 2003; Gastmans, 2016; Higgs & Gilleard, 2016). Therefore the emphasis should be to provide a person-centred approach in palliation that seeks to give value to the current needs of the person in care (*NICE*, 2006, November) in respect of past wishes, values and future consideration. In this approach, the family do play a fundamental role in upholding the values of their loved ones with dementia, while also their needs must be acknowledged (van der Riet et al., 2008). Clinicians must also work with relatives to manage this complex situation of care and ensure that care provision meets clinical standards while at the same time give leeway to decision-making that is inclusive of patient wishes and values as expressed through advance directives (Hughes & Baldwin, 2006).

The fundamental objective of this complicated situation is to find synergy in the decisional process between stakeholders that respects the dignity of the person in care (*GMC*, 2010). To this end, the application of ethical models of moral reasoning facilitates clinical decision-making (ten Have, 2010) by exploring the situation of care, with the added gain that forthcoming ethical judgments are defensible through a logical analysis of solid arguments (Ursery, 2005; Day, 2006)

While it would be ideal to identify one model to cover all decision-making situations in end-stage dementia care, in truth, such a perfect model does not exist (Keyserlingk, 1979). Consequently, the reasoning of the pros and cons of each ethical model would help to delineate which model best meets the needs of stakeholders to define a morally acceptable decision process that safeguards the dignity and interests of the person with dementia in care.

Virtue theory guides the moral compass of a virtuous agent (Hursthouse, 2000) where character highlights the right balance to support decision-making based on the “golden mean” (Vaughn, 2011, chapter 7) reasoning by Aristotle. This helps to avoid extremes of over-treatment and under-treatment in end-stage dementia care (Hertogh, 2010). The limitations of virtue theory is that virtue alone gives limited guidance on how to define a clear decisional procedure to resolve dilemmas or other conflicts (Beauchamp & Childress, 2013), and thus usefulness on its own is poor (Vaughn).

Deontology theory gives centrality to rules and moral duty (Day, 2006), where the categorical imperative is an absolute moral law where the validity of the concept does not depend on ulterior motives (Wood, 2002). Such rules-based approach finds an example in the management of confused patients, mainly where it concerns minimisation of restraint and provision of tube feeding, as long as the benefit of CANH exceeds harm (Moreland & Geisler, 1996). The limitation of deontological theory is that it does not allow for exceptions to the absolute approach (Day) as moral intuitive judgement is left out (Moreland & Geisler). Therefore deontology approach is marred from attaining the capacity to find moral resolution of inconsistencies logically (Chonko, 2012).

Human rights theory transmits a valid theory to address moral opinion and thus helps to avoid improper conduct. Beauchamp and Childress (2013) added that requesting respect for human rights does find meaning in mentally competent persons who feel that they are being treated with injustice. However, in persons with dementia, these are left out cold in a vulnerable passive position, where safeguarding rights rests at the mercy of their carers (Beauchamp & Childress).

Utilitarian theory gives importance to the consequences of an action with an imprint on objective assessment, impartiality and general view overseeing everyone's interest (Beauchamp & Childress, 2013). Utilitarianism promotes the good intention to produce benefit and happiness to the community (Bentham, 1780, section III). However, in the distribution of resources and associated decision-making, a utilitarian approach does not give additional value to the weak and vulnerable (Day, 2006) in violation of human rights and dignity. Therefore utilitarianism tends to forget the special obligations and moral duties of society to those who are vulnerable, to the point that they are deprived of mainstream care and prime resource allocation (ter Meulen, 2008),

Principlism theory concerns the principles of autonomy, beneficence, non-maleficence, and justice (Strech, Mertz, Knupperl, Neitzke, & Schmidhuber, 2013). These principles are fundamental in the evaluation of ethical decision (Gordon, 2002) yet on their own are found lacking in the definition of suitable models of decision-making in swallowing difficulties in dementia (Arries & Cur, 2005).

Respect for autonomy underpins modern ethical ideals (Welie, 2010) in granting the right to patients to keep control on their lives through informed care choices (Sasson, 2000) including EOL care (ten Have, 2010). Nonetheless, while acknowledging the importance of respect for precedent autonomy through advance directives, in practice one does find autonomy to be ineffective in decision-making in dementia, as the capacity of the patient to decide for themselves is lost (Welie).

Beneficence and non-maleficence are fundamental principles that by doing good and avoiding harm, underpin good standards of EOL management (Beauchamp & Childress, 2013). However, one major limitation of beneficence is that in enforcing a management plan that avoids risks, it might lead to an insult on the dignity of the person, as self-determination is over-ridden by risk limitation (Tuckett, 2006). Pantilat (2008) argued that the patient should decide such decisions through informed consent, a decision that is not possible in end-stage dementia.

The principle of justice rests on safeguarding equality (Velasquez et al., 1990) and justice in health care entitlement while separating itself from discrimination that undermines the vulnerability experienced in end-stage dementia (Agius, 2010; *Alzheimer Europe*, 2009, October). Justice also gives value to the input of caregivers who do often assist at high personal expense (Purtilo, 2010). Nevertheless, in complex decision-making, the principle of justice is limited in its reasoning as it gives more importance to related moral request for rights and social welfare (Velasquez et al.) but gives less importance to other ethical principles and theories that need to be considered in decision-making (Summers, 2009).

The "step in their shoes" (Welie, 2010, p. 164) concept of substituted judgement does warrant attention in decision-making in dementia, where the family or other surrogates decide on the assumption that they know the patient's past wishes, beliefs and values. Therefore, decisions are taken according to the patient's past preferences and values, as a safeguard of autonomy. In reality, such information is not always present and is often challenged in medico-legal fora as happened in the Eluana Englaro case (*Corte D'Appello Milano*, 2008, July 09). Furthermore, one is never sure that the family through substituted judgement are genuinely seeking to testify the patient's wishes in violation of the person's dignity (Welie).

Best interests judgement finds favour in medico-legal and ethical pathways of decision-making (Hughes & Baldwin, 2006), where they do safeguard patient dignity (Dekkers, W.J.M. 2010), and accept the current patient's condition in dementia with swallowing difficulties (Wellie, 2010, Polden, 1989; *GMC*, 2010). Best interests bring together the clinical judgement of clinicians and the family views (Polden), while they do respect the patient's wishes, feelings, beliefs, and values (Hughes & Baldwin). The limitations of best interests judgement is that in dementia they do tend to disregard past patient wishes (Wellie), whilst many bioethicists argue that best interests is nothing more than guessing and fantasising (*Nuffield Council Bioethics,* 2009), as such analysis is a subjective and unreliable assessment of patient care needs (Wellie).

Vitalism indicates that life should be supported even where persons are comatose, disabled or in suffering (Keyserlingk, 1979). On the other hand, the sanctity-of-life principle is a normative concept that denotes that respect for life is a basic norm where life has inherent dignity, since it is a gift of God. Therefore man's worth, dignity, and sanctity should be maintained (Jewell, 2005). Critics of sanctity-of-life argued that it is an abstract concept that finds difficulty to be applied as the prime model for decision-making at a grade higher than actual patient wishes (Jewell; Keyserlingk). Furthermore, Macklin (2003) argued against the centrality of human dignity in its application to qualify what is appropriate EOL care, as dignity is too vague a concept that has a profound religious connotation.

Quality-of-life considerations in decision-making do help to denote "worth, usefulness or meaningfulness" (Keyserlingk, 1979, p. 5) of life and subsequent interventions in care. Public policy makers do also give a relativistic economic value of the effect of the intervention on human life where the calculation of worth is done through quality-adjusted life-years and value to health (HALY's) and prognosis. The problem with QOL is that it is quite challenging to quantify physical, physiological, spiritual and mental QOL judgement at the very EOL, as it is strongly influenced by subjective judgement (Gilmore, 1984).

Consequently, critical EOL decisions cannot be taken on QOL considerations alone (Keyserlingk). Furthermore, QOL considerations in EOL care do try to weigh suffering versus happiness (Jewell, 2005) and thus such arguments tend to lead to claims in favour of benevolent euthanasia where life is deemed of no benefit or value (Finnes, 1994). Also, QOL decision-making finds difficulty to balance clinical with moral ideals (Beauchamp & Childress, 2013), and this limits QOL as a measure to guide decision-making in the EOL.

Paternalism in decision-making is an intervention by a clinician to act for the patient's good in a situation where such action either goes against the patient's wishes or where the patient is not involved in the decision taken and thus is denied informed consent (Beauchamp & Childress, 2013). To this end, paternalism is seen as opposing the fundamental principle of patient autonomy (Sasson, 2000).

In the Introduction to this thesis, I have expressed the opinion that consensus-building approach could be a possible solution as a model of ethical reasoning to underpin morally acceptable decisions in the management of swallowing difficulties in end-stage dementia. Even though consensus-building approach has some notable limitations as there is no guarantee that a consensus between parties will ever be reached (Monturo, 2009). The fact that most often the decision process in the EOL faces a limited number of stakeholders, this renders the situation less difficult to reach consensus given the involvement of a relatively small group of stakeholders (Hartnett, 2011). Wherever there is lingering conflict, such dispute is most often overcome through further discussions with the family, where such communication aims to explain better the true "meaning, values and beliefs concerning food and artificial nutrition" (Monturo, p. 212; see also Karlawish et al., 1999). Furthermore, the achievement of agreement through consensus between stakeholders does overcome ideas of distrust, suspicion, and claims of mismanagement, which lay out a fertile ground for legal litigation, from which nobody ends up as being the victor (Monturo).

What makes consensus-building approach so appealing is that is beneficial in finding agreement in complicated situations of care (Wong, 2012; Downing & Larkin, 2009) leading to unanimity on the best choice to follow in treatment decisions (Murphy et al., 1998) particularly in relation to complex EOL decision-making in dementia (Yean & Anantham, 2015; Chun-yan & Tao, 2004). To this end, informal consensus processes are flexible enough to help reach a solution to a clinical dilemma between stakeholders creating a situation of trust (Murphy et al., 1998; Agius, 2010) where all feel participatory in the decision taken (Hartnett, 2011). It is essential to point out that consensus-building approach does also safeguard the past wishes, values, best interests, and dignity of the person in care (Chun-yan & Tao; Karlawish et al., 1999), whilst appropriate follow-up of the process does give due opportunity to assess how the patient responds to the treatment provided (Karlawish et al.) leaving sufficient lee-way for revision of care.

My concluding remarks based on literature review and my personal experience in the caring for persons in end-stage dementia firmly attest that consensus-building approach is indicative of being a better ethical model of decision-making model than all other models studied.

10. Conclusion

In this chapter, I have considered the ethical implications of dementia EOL decision-making, with particular attention being given to the moral deliberation related to decisions regarding swallowing difficulties in end-stage dementia. Of note is that I have reviewed the ethical implications that concern respect for dignity preservation and an exploration of the vulnerability that most often is associated with persons who have lost decisional capacity due to dementia. Also, an appraisal was given regarding the moral issues that are experienced by other stakeholders involved in EOL decision process, namely family members and clinicians involved in care. Lastly, a critical account has been given to the moral theories and ethical principles that are implied in this complex EOL decisional process. I finished off with a detailed appraisal of what makes, in my opinion, consensus-building methodology the best format of decision-making given its inclusivity of all stakeholders while safeguarding the human dignity and interests of the person in care.

Having addressed the literature review, the next chapter will concern the methodology used to address the research question.

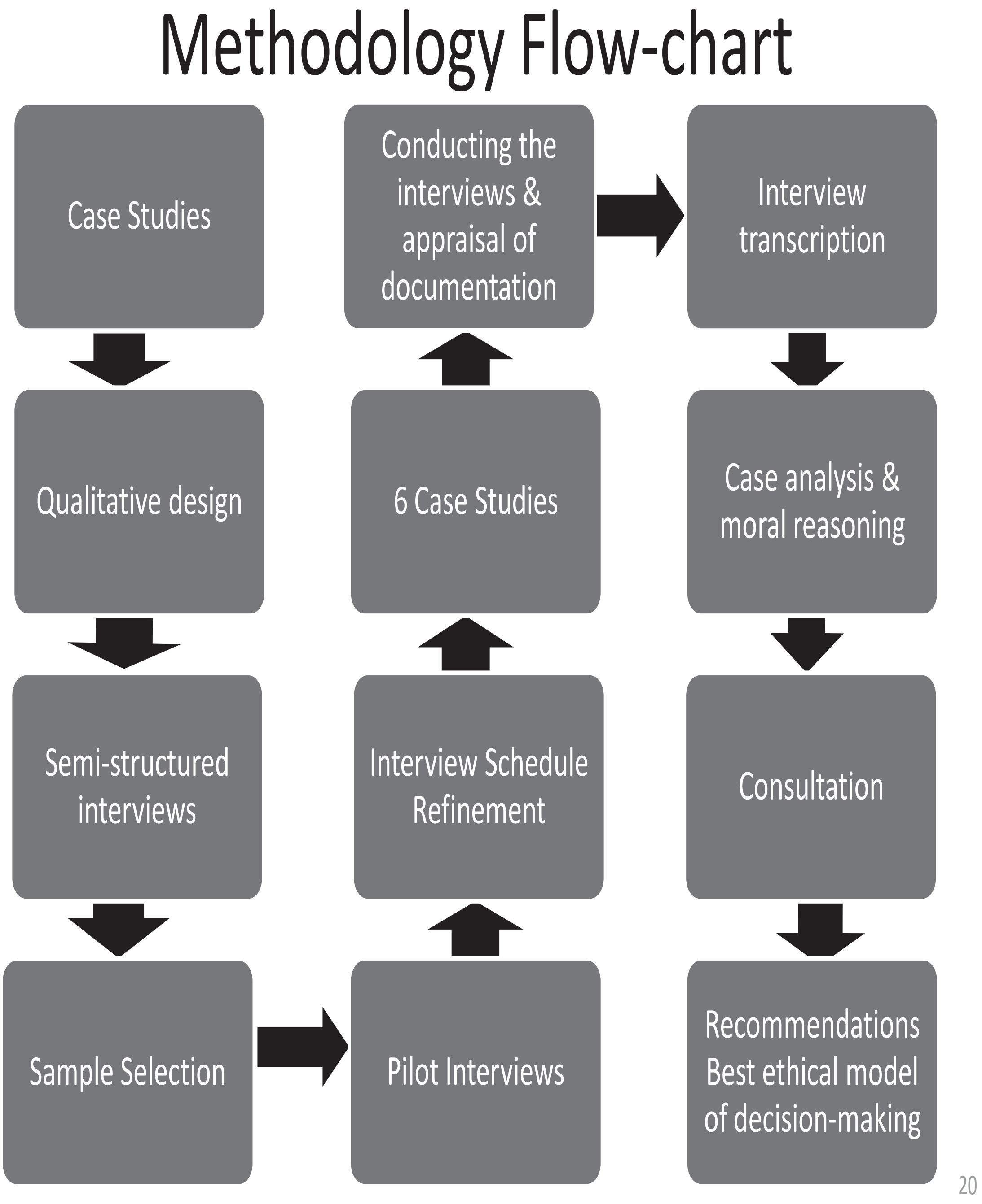
Chapter 4: Methodology, Results and Analysis of Data

This chapter describes the methodology used to address the research question (see Figure 1). A rationale is first provided for the use of qualitative research design, while a discussion of the methodological arguments about attitude measurement in complex situations of shared decision-making follows. An appraisal is also included on the reasoning behind the choice of case studies for this empirical research and its application in the site of study chosen.

1. The Rationale underlying the Design of the Study

Healthcare decision-making is often reported to be a complicated process necessitating input from “ill-structured, uncertain, and potentially conflicting information from various sources” (Kushniruk, 2002, p. 365; see also Pope, van Royen & Baker, 2002). Sampson et al. (2009) remarked that team decision-making in swallowing difficulties in end-stage dementia is one such example of medical and ethical complexity. In defining the central dilemma arising from this situation, Hanson et al. (2011) argued that decision-makers need to decide on a fundamental choice “between tube feeding or assisted oral feeding” (p. 2), which are respectively profoundly rooted in the domains of curative versus palliative management.

Figure 1
Methodology flow chart



Making a decision to tube feed or not to tube feed a patient creates a situation of uncertainty where it remains to be determined who decides what (*RCP,* 2010) in a scenario where attitudes, values, beliefs and wishes play a firm hold on decision-makers (*Measuring Shared Decisions*, 2012; Elwyn et al., 2012). To further complicate matters, the decision between curative care versus palliation is not always a one-time clear-cut event, as such a decision is not necessarily taken at one point. Moreover, Dunlop et al. (1995) pointed out that decisions regarding the management of swallowing difficulties in end-stage dementia are complicated by the existence of possible intermediate interventions between the two ends of the scale.

In such a clinical scenario, *RCP* (2010) highlighted the fact that decision-making on swallowing difficulties in the EOL bears strong emotional meaning and imparts conflicting views in clinical management. In this complex scenario, the application of ethical models of moral reasoning is an asset to help facilitate morally acceptable clinical decisions (ten Have, 2010). This study aimed to shed light on what is happening in clinical decisions taken at the bedside, in the quest to promote an ethical approach to EOL care where the person with dementia is valued as an individual in the decision process (*Nuffield Council Bioethics,* 2009). Therefore, the research question addressed the following query, namely.

"What ethical models, if any, are being used and underpin the decisions of clinical teams and other stakeholders in relation to swallowing difficulties in end-stage dementia?"

In order to understand the decision-making process, the research used multiple case studies with an embedded case study design (Yin, 2014, 2009; "Emerald Publishing", 2019), where the unit of analysis was to study the phenomenon of ethical models of decision-making through six case studies.

2. Use of a Naturalistic Decision-Making Framework

The study addressed the complex clinical situations that are frequently researched through descriptive case study methodology. To this end, a naturalistic approach was identified as being capable of addressing the details in complex clinical situations (Keen & Packwood, 1995), in an approach that aims to safeguard against interference by the observer. To better address this complexity, this study also utilised retrospective qualitative case studies, as they do afford a detached evaluation of the process and outcome of policy implementation (Keen & Packwood).

Naturalistic decision-making is a methodology utilised in practical situations that helps to address the issue of the study of cognitive function in decisions that are often complex (Klein, 2015). To this end, the adoption of a qualitative approach in research enabled a holistic and in-depth analysis of the complex cognitive processes involved in team decision-making (Keen & Packwood, 1995; Scholz & Zimmer, 1997). A qualitative approach also helped to clarify and theorise why in many situations of care there is experienced significant differences in views between clinicians and the family of how to manage swallowing difficulties in end-stage dementia (Hughes & Dove, 2006). In so doing, qualitative research helped to give a voice to stakeholders in care who are often excluded in the decision process (Ruggunan, 2014). Klien remarked that a naturalistic approach does also serve well in situations where many participants are involved who are experienced or are experts in their respective fields. Such naturalistic based research found scope in my area of study as the decisional process invoked an element of intuition in ill-structured uncertain situations and where objectives change and compete with high-risk outcomes (Elstein, 2011). Ultimately Elstein remarked that such naturalistic approach does help to analyse mistakes and may help to identify organisational factors that adversely affect performance.

Elstein (2011) pointed out that naturalistic decisional model acts profitably in situations where research is non-quantitative. In appreciation of the above, this study followed a qualitative research method to help unearth the lived and care experience of the patient, relatives and clinicians involved in the decisional process. In so doing, a naturalistic approach helped to explain the events and situations in dementia wherein the person in care experiences a high level of vulnerability (Gastmans, 2016).

Also, qualitative research gives the depth necessary to come to the root of what differentiates between deep moral disagreements that may arise between stakeholders involved in the decisional process (Richardson, 2009). Qualitative research helps to provide a "humane side to the issue that is often contradictory in behaviours, beliefs, opinions, emotions and relationships of individuals" (Kolbe & Boos, 2009, p. 1; see also Mack, Woodsong, MacQueen & Namey, 2011). Moreover, a qualitative approach helped to promote a flexible, iterative approach to explore phenomena in natural settings and explain relationships in groups, thus leading to an in-depth understanding of individual behavioural experiences (Pope et al., 2002). In so doing, the application of in-depth interviews through flexible, broad, open-ended general questions, do help participants to express in their own words, true-life personal perspectives of their own experiences of what they think about the phenomenon under study (Pope et al.; Mack et al.). To this end, the researcher must listen carefully and apply probe questions with due sensitivity, to unveil what is of importance for the participants, while giving allowance to "individual personalities and styles" (Mack et al., p. 4). Such an approach would help to reveal *what* is happening and the *how* and *why* that highlights the quality of the service, leading to a dense description of the processes and outcomes that underpin the decision-process (Pope et al.; Mack et al.; Creswell & Plano Clark, 2004). To this end, a qualitative approach allows the researcher to understand better the quality of the service by providing a real-life multidimensional experience of the complexity of the care experience (Pope et al.).

Furthermore, a qualitative approach does help provide the meaning of actions and value judgements and unravel how caregivers process complex EOL decisions on ethical issues in dementia (Hughes, Hope, et al., 2002). Hughes et al. added that qualitative methodology could help enlighten issues that relate to dignity, respect, consideration of the human being, best interests, euthanasia, medication, confidentiality, carer's needs, and the ethos of institutional care, moral beliefs and EOL care decisions. Moreover, the application of qualitative methodology in the study of caregivers in dementia helps to unveil decisional conflicts to "negative choices" (Hughes et al., p. 38, see also Wilson, 1989). These include the conflict and balance concerning needs of the person with dementia as compared to the needs of the carer, the losses to the self in view of communication difficulties, support needs, moral duty; and religious beliefs (Wilson, 1989).

In a critique of qualitative research, Mays and Pope (1995) pointed out that health-related research is deeply rooted in the tradition of biomedical research that tends to use "conventional, quantitative and often experimental methods" (p. 109). Mays and Pope also perceived a number of limitations related to qualitative research as:

- Lacking scientific rigour.
- Merely a collection of personal ideas.
- Prone to researcher bias.
- Lacks reproducibility and generalisability.
- Generates mountains of data from a limited number of study points.

Consequently, Mays and Pope (1995) remarked that qualitative research faces a more significant challenge to ensure the validity of research findings. Mays and Pope added that to help address this limitation in qualitative methodology; the researcher should ensure that "rigour in qualitative research is systematic and self-conscious in research design, data collection, interpretation, and communication" (p. 110). They also suggested that the researcher must ensure reproducibility of method and data so that another researcher would come to the same conclusions, and thus be able to describe in precise detail the phenomenon under study.

On the other hand, quantitative research, contrary to qualitative methodology, is of a more rigid style with highly structured methods of data collection that is mainly aimed to be utilised to confirm hypotheses or phenomena (Kolbe & Boos, 2009). Furthermore, the fact that quantitative research follows a structured enquiry, it does lack the flexibility in the analysis of complex situations that only qualitative methodology can provide (Mays & Pope, 1995; Scholz & Zimmer, 1997).

Based on the above arguments and knowing that decision-making in swallowing difficulties in end-stage dementia is a complex health issue with strong and varied undercurrents, I decided in favour of the utilisation of a qualitative approach to the empirical research in question. I also used multiple case studies since this provides the required qualitative data for the study in a very practical manner, in the quest to help unearth the complexity of decision-making in dementia (Wackerbarth, 1999).

A. Case study research.

Case study research has gained considerable popularity in social research (Hammersley & Gomm, 2011). A case is defined as “a phenomenon for which we report and interpret only a single measure on any pertinent variable” (Hammersley & Gomm, p. 10). To this end, case study research is of use in all stages of a research enquiry. Case study methodology has been used in various situations that relate to “individual, group, organisational, social, political and related phenomena” (Yin, 2014, p. 4). Amongst the many applications of use, case studies have found favour in empirical studies in the fields of psychology, sociology, education, nursing and community care planning. In such situations, case studies are used to unearth knowledge on the processes of how outcomes are reached (Becker, 2011) in complex social phenomena, in a “holistic and real-world perspective” (Hammersley & Gomm, p. 4). One such application is enhancing the knowledge and understanding of small-group behaviour.

McCleod (2008) reported that case studies are “in-depth investigations of a single person, group, event or community” (p. 1). Thus case dimensions do concentrate on a limited number of cases with an emphasis of detailed assessment in each situation of research enquiry (Hammersley & Gomm, 2011). Yin (2014) developed an operational definition of what constitutes case study research; this definition affirms that empirical case studies are characterised by an in-depth analysis of a contemporary real-world phenomenon (the case), where the margins between the phenomenon and the situation are not distinguishable. In addition Yin declared that case study enquiry is also characterised by the presence of "many more variables of interest than data points" (p. 17). Furthermore, case study research is dependent on many sources of input as a means to maintain adequate triangulation that would ideally be backed by pre-determined "theoretical propositions to guide data collection and analysis" (p. 17). In so doing, the main objective of case study research is to understand, describe and explain in-depth, a large number of features related to the case under study (Hammersley & Gomm, 2011).

Consequently, case study methodology does strive to "capture the unique character" (Hammersley & Gomm, p. 6) of a situation in an authentic manner, by giving value to the unique voice of the everyday experience of those who are often "unknown, neglected or suppressed" (p. 7). As there exist various pathways involved in a process, Hammersley and Gomm remarked that it is relevant to give value to the narrative of the situation (see also Becker, 2011). The process of case study method thus enables the researcher to build up thick implied knowledge (Hammersley & Gomm), which helps in the setting up of a "theoretical structure, behaviour, and interaction of phenomena" (p. 10), to ease the progression towards "naturalistic generalization" (Stake, 2011, p. 19). Such "naturalistic generalisation" in case study research enables a vicarious experience of in-depth knowledge in other situations that show similarities.

It is worthwhile mentioning that case study methodology does help promote the process for "naturalistic generalisation" and helps in the transferability of findings based on "fit" from one situation to the other (Hammersley & Gomm, 2011, p. 5; see also Lincoln & Guba, 2011).

Also, case study evaluation uses a qualitative method that has found favour in medicine in situations that exhibit particular complex circumstances in real life situations in health care (Keen & Packwood, 1995; Yin, 2014). In other words case studies do present an empirical study to address qualitative judgments that include policy, in the sense of identifying whether "outputs and outcomes of interventions are justified by their inputs and processes" (Keen & Packwood, p. 2). At the same time, case studies are a valuable tool to study social phenomena in the real world, where the behaviours in questions cannot be manipulated (Yin, 2014). Therefore, qualitative case studies do end up converging on the evaluation of exploratory questions that relate to the *why* and *how* the particular intervention finds a positive or negative outcome. It has to be pointed out that research questions can also be exploratory, a situation which fits the circumstances surrounding my research question (Yin, 1994).

Therefore in appreciation of this knowledge, this thesis not only aimed to reveal what ethical models were in place in the management of swallowing difficulties in end-stage dementia but also addressed how decisions were taken in swallowing difficulties in end-stage dementia by all stakeholders. Furthermore, this research clarified what was the role of the respective stakeholders in decision-process; this in addition to addressing how such decisions were taken about accepted clinical practices, the culture of the institution, beliefs, values and preferences in EOL care.

Yin (2014) added that to address such questions in case studies, the researcher should evaluate document information, artefacts, carry out interviews and involve observations. Yin added that in addressing these questions, the researcher has the additional option to perform multi-case studies.

Gustafsson (2017) stated that *multiple case studies* increased the possibility of unearthing more new information that can be obtained through a single case study. In so doing, a researcher could thus obtain data for analysis from single case studies and compare them across the different cases in the research and thus being able to unearth “similarities and differences” (p. 11) across cases, thus rendering results more valid and reliable. The multiple inputs of comparative data also give a broader perspective of the situation, particularly where the area of study has been poorly researched (leading to limited available information), while at the same time “allowing a wider discovery of theoretical evolution and research questions” (p. 11). Also Lincoln and Guba (2011) remarked that full descriptions arising from multiple case studies do help provide the necessary information of how different cases fit together to the point to bring forward a possible working hypothesis that helps better understand cases under enquiry. At the same time, multiple case studies can help to unearth “a general explanation that fits each individual case” (Yin, 2014, p. 148.

In practice, case studies do at times end up utilising multiple methods, namely both qualitative and quantitative measures, which approach is a particular asset in the facilitation of increasing validation and triangulation of findings (Keen & Packwood, 1995; Yin, 2014). It is relevant to point out that in the empirical research in this thesis, I utilised only qualitative methodology. Therefore reference was made to alternative modes of validation, which do not necessarily arise through quantitative triangulation. To this end, Yin remarked that validity in case study research is very dependent on the application of a rigorous methodological procedure, where case studies utilise an organised way of observing, collecting and analysis of real-life events from various viewpoints, as a means to provide sufficient triangulation to produce more credible results (“Case Studies”, n. d.)

Yin (2014), pointed out that both single-case studies and multiple-case studies can have units of analysis at one or more levels. To this end, “*embedded case study design”* (Yin, p. 56) relates to multiple units of analysis in the case (“Emerald Group”, 2019), on the other hand, “*holistic case study design*” (Yin, p. 56) looks at a global nature of what is being studied. The advantage of embedded case study is that by incorporating sub-units of analysis, this provides the study with “significant opportunity for extensive analysis” (Yin, p. 56)

Keen and Packwood (1995) pointed out that research questions in case study methodology do usually take either one of the following two strategies:

1. The first option is more *deductive* where precise questions are utilised at the beginning of the research, and therefore collected data and subsequent analysis do aim to answer such questions. This format often utilises a mixture of qualitative and quantitative data where semi-structured interviews help enable this process. This method is often utilised to compare results between sites or between different approaches.
2. The second option is more *inductive* and delves in a broader approach, with broad, open-ended questions being utilised at the beginning of data collection, allowing the determination of findings to be more grounded in the data. This method is often utilised in addressing the assignment of resources and is of help to develop a framework which enlists the essential features in resource allocation. Methodologies of data collection in this second option do include interviews, non-participant observation and document analysis.

Critics of case-study research declare that it does not lead to a universal scientific generalisation (Stake, 2011) as it is challenging to measure all factors that have an influence in the matter under investigation (Lieberson, 2011). On the hand, comparative analysis in case studies helps to derive a causal relationship that addresses what is in agreement or differs, via the process of analytic induction (Hammersley Gomm & Fraser, 2011; see also Mill, 1843; Skocpol, 1979). For this to occur, full, accurate descriptions are needed, (Hammersley et al.) in order to identify what is similar, not only within a case but also across cases (Donmoyer, 2011). Hammersley et al. remarked that generalisability in case study research remains fraught with difficulty and creates the risk of leading to “misleading conclusions” (p. 10). Contributing to this uncertainty is the fact that comparative case analysis validity remains with notable limitations, and thus, similar conclusions remain at best “probabilistic” (Lieberson, p. 12).

3. Attitude Measurement in Complex Decision-Making

An *attitude* is defined as “the effect for or against a psychological object” (Miller & Wolf, n. d., p. 1; see also Thurstone, 1931). Therefore an attitude is a mental state in individuals that paves the way to how one perceives and responds to an environment. Milf and Wolf added that attitude involves consistency in behaviour and is usually directional, and not easily changed. An analysis of the components of attitudes relates to three elements, namely: a cognitive component; an affective component and an action component (Kumar, Aaker, & Day, 2009).

Rurup, Onwuteaka-Philipsen, Pasman, Ribbe, & van der Wal (2006) pointed out that participant *behaviour* is a way in which one acts and is essential in research, mainly where situations involve complex decisions that relate to the various views, values and beliefs of the participants involved in the decision process.

Rurup et al. (2006) added that an understanding of the different attitudes and behaviours of clinicians and relatives in decision-making does help improve the understanding between all those involved.

Monger (2013) pointed out that various techniques could be utilised to measure attitudes. These range from direct to indirect techniques; and also from physiological to verbal techniques. One method to gather feedback on attitudes from respondents is to ask them to “perform a task such as ranking (scaling), rating, sorting or making a choice or comparison” (Monger, slide 6). Likert scales are the most popular format of attitude measurement (Miller & Wolf, n. d.), and have been utilised in a study on nursing home clinicians and relatives, to define attitudes to EOL care in dementia (Rurup et al., 2006).

Despite the above, I have taken a methodological decision to follow more closely a qualitative approach, rather than a quantitative process. Such a decision was made to better address the underlying phenomena in decision-making in end-stage dementia. In so doing, it was envisaged that qualitative methodology helps unearth a more profound analysis of the processes involved in decision-making (Creswell, et al., 2004) with particular attention being given to the study of variance in behaviours between different professions and family members, where consideration is given to reveal individual differences in views, beliefs, values and feelings (Kolbe & Boos, 2009).

4. Addressing Shared Decision-Making

It has been reported that it is challenging methodologically to measure clinicians' performance in shared decision-making (Barr & Elwyn, 2015). At the same time, various tools are available to look at the process from the standpoint of the patient. Barr and Elwyn added that the validity and reliability of patient-reported measures could be extracted from the response instructions and options that are acknowledged by the patients' answers.

Barr and Elwyn (2015), and "Measuring Shared Decisions", (2012) both referred to various published instruments that measure the process and outcome of shared decision-making, usually from the standpoint of the patient in care (Sepucha & Scholl, 2014). However, the person with dementia cannot, by definition, grant real-life feedback on the shared decision process that affects them personally. Thus, the best way to gain feedback on the real-life experience and relationships between stakeholders involved in decision-making in end-stage dementia, was through qualitative data on their approach to decision-making (Mack et al., 2011; Creswell et al., 2004). Qualitative data thus provided access to the subjective meaning, personal beliefs, values, preferences and opinions that related to the process and outcome of the decision-making under study (Pope et al., 2002).

5. Aims of the Study

The study aimed to discover how clinical decisions were being made by all stakeholders to deal with swallowing difficulties in end-stage dementia in a Maltese institution for older people. Such focus on how decisions were executed was done by identifying what models of moral reasoning, if any, were being utilised during the decision process to manage swallowing difficulties in end-stage dementia. Particular attention was given to uncover models of practice that utilise:

a. Human dignity-preserving approaches.

b. Human rights preserving approaches.

c. Principlism with due attention being given to beneficence, non-maleficence, autonomy and justice.

d. Vitalism, sanctity-of-life and quality-of-life.

e. Substituted judgment.

f. Paternalism.

g. Stakeholders excluded from the decision-making process (forgotten stakeholders).

h. Deontological approach.

i. Utilitarianism.

j. Virtue theory.

k. Best interests judgments.

l. Consensus-building and its relationship to the shared team decision process.

m. Any other factors which might seem pertinent from an ethical perspective (Copp, 2007).

6. Site and Participants

The study was carried out at St. Vincent de Paul LTC Facility (SVP). This was because SVP is Malta's largest institution for older people (Department of Health, 2013), with over 1,100 beds. St Vincent de Paul has thirty-three nursing wards, two of which are purpose-built dementia units. This institution also harbours a robust geriatric team approach with 24-hour nursing and 24 hours on-site medical cover (Fiorini, 2015).

Apart from the above, the resident population at SVP shows a soaring concentration of high dependency residents with a high prevalence of dementia, medical frailty and need for EOL care; where family involvement in the care of their elders is frequently present

(*Admission Policy SVP*, October 2015). Finally, from my personal past observation at SVP, practically all cases that present with swallowing difficulties in end-stage dementia are managed in house, and thus it is infrequent that such patients are hospitalised solely for the management of swallowing difficulties.

At the time of the study, residents fell under the care of one out of ten consultant geriatricians and eight resident specialists. Each ward had a charge nurse and deputy charge nurse and a varying number of registered nurses plus trained carers. At that time, SVP had eight SLP's and one clinical nutrition nurse whom all did duties on site.

The study identified for the patients under study their:

a. Demographic characteristics.

b. Date of admission to SVP.

c. The severity of swallowing difficulties before at the point of decision-making (risk/life threatening / persisting / food and liquid consistency as a measure of severity/choking and/or aspiration as complications).

d. Current active medical diagnoses including evidence of episodes of recent aspiration pneumonia and/or evidence of severe renal infection/sepsis/ deep pressure sores / severe loss of weight in the previous year.

e. Date of subsequent death, to determine the time frame between the date when the decision was taken to manage swallowing difficulties and the date when death eventually occurred.

On the other hand, concerning relatives / legally-appointed representatives, the study identified what nature of relationship they had with the patient under study, namely if:

- They were the first contact family member.
- They were proxy holders of a general power of attorney/advance directive.
- They were the patient's guardian / legal curator /legally authorised representative.
- Their frequency of attendance to visit the patient in care in the past three months.

In addition, through questioning the relatives / legal representative, the study tried to identify if the diagnosis of dementia was ever disclosed to the patient under study in the early stages of the disease, and if yes, if any form of advance care planning with respect to EOL care in dementia was ever discussed with the patient/relatives. Such query also searched if at the time when the patient still retained mental capacity in the past, whether or not they did ever talk of what they would have wanted to be done for their EOL care.

Moreover, the interview with the relatives / legal representative helped to unveil their personal views and values about the management of swallowing difficulties in end-stage dementia, in other words, what they would want to be done for themselves if in future they were to be found in the same circumstances of care needs as their elders.

The relatives / legal representatives were also asked to explain if they had received support for decision-making regarding the management of swallowing difficulties, including exposure to patient decisional aids. At the same time, an enquiry was done of the relatives' / legal representatives' satisfaction concerning the shared decision-process underlying the management of swallowing difficulties in end-stage dementia.

The individual clinicians involved in the decision-process were asked individually if a team meeting ever occurred to discuss the management of swallowing difficulties for the person under study. Where such meetings were held, clinicians were also asked who of the participants in the study (clinicians and relatives / other proxies) were invited to attend for such a meeting. Also, they were asked to what extent was each team member granted an active role in the decision process and given a chance to express the values, beliefs, and wishes of the patient in care. Also, the individual clinicians were interviewed to assess their knowledge regarding advance care planning and also to define their attitudes and behaviour to palliative approaches to swallowing difficulties in end-stage dementia.

Other information was collected from the patient’s medical file documentation. The patient’s medical file was analysed to assess if, before the decision-making, any of the following was carried out:

a. Was the patient investigated before decision-making?

b. If cognitive and functional grading tools were recorded in the file?

c. Was bed-side monitoring of swallowing difficulties being carried out?

d. Was the list of medicines administered to the patient reviewed?

e. If any food/hydration corrective measures were utilised?

f. Was specialist care intervention involved?

g. Was the decision taken to manage swallowing difficulties in end-stage dementia recorded in the file?

h. Was a consent form filled out by a relative/legal representative in those situations where tube feeding was started?

All clinicians and relatives / legal representatives involved in the decision-process under study were separately asked if they were involved or not in the decision process, with the latter sub-group being further asked if they would have preferred to be involved and their views on the decision taken. All such stakeholders were also asked to give their views regarding a team approach to decision-making and to what level they give importance to reaching agreement and inclusion of all ideas in a consensus-building approach.

Through expressing their views regarding consensus, those interviewed where asked if they gave value to the opinion of other clinicians and relatives, and also if they gave due respect in the decision process to the past wishes and values of the patient in care.

Also, all clinicians and relatives / legal representatives were interviewed to assess their attitudes, values and beliefs in the decision process concerning decision-making in end-stage dementia, with a particular focus on how such decisions related to palliation/terminal care as opposed to aggressive/curative care. At the same time, these stakeholders were asked to share their views/fears/ suggestions on the decision-making process, with particular attention being given to the ethical models involved in decision-making.

7. Sampling

Consecutive sampling was utilised to identify six case studies that first met inclusion criteria for incorporation in the study after the pre-defined start date (Bhat, 2019). Each of these six case studies originated from the list of patients that fell under the care of six different consultants. It is relevant to point out that the pool of consultants and their patients who had the potential for inclusion in the study was made up of nine consultant firms, as the 10th consultant and his patients was the researcher himself, and thus excluded from the study.

Sampling was based on the following criteria: any member of the team, namely: doctors, nurses, SLP or clinical nutrition nurse were invited to forward a case for study. The first six cases, each from six different consultant teams that met the inclusion/exclusion criteria, after a specific start date, were included in the study.

8. Inclusion / Exclusion Criteria

The following selection criteria for case study inclusion were adhered to, namely:

a. The person in care had to be in the end-stage of dementia, i.e. 7c or worse on the FAST score (Reisberg, 1988). This spelt out in a situation where cognition was lost, the patient was chair-bound, there was loss of language skills being able to state one word only, was dependent in activities of daily living [ADL], and was dually incontinent. These manifestations of end-stage dementia (FAST 7c or worse), plus the presence of specific manifestations of medical frailty (listed hereunder under a.i and/or a.ii) pointed for an increased propensity for six-months mortality (Mitchell et al., 2010):

    i. Severe infection/s (chest or urine) in the past year &/or.
    ii. Multiple deep pressure sores ≥ stage 3.

b. A primary family contact / legal representative had to be identified as regularly attending (at least once a month) to visit the resident in care in the past three months.

c. A decision was taken in the previous seven days to address severe + potentially life-threatening swallowing difficulties, where swallowing difficulties related to at least one of the following (Hanson et al., 2011):

   i. Severe eating/drinking problems because of swallowing difficulties and thus "no longer takes enough food and drink to survive" (Rurup et al., 2006, p. 1) and therefore was labelled as life-threatening.

   ii. Presence of dysphagia defined for the study "as difficulty in swallowing, choking in food or liquid" (Rurup et al. p. 1); leading to a risk of inanition, dehydration, or aspiration.

Exclusion criteria about patients in care concerned residents who were observed to be aged less than 65 years of age (Mitchell & Lawson, 1999). Excluded from the study were also patients who already had a feeding tube when the decision was taken (Hanson et al., 2011); or had weight loss associated with diuresis; or had died [within a week] after the decision was taken to manage swallowing difficulties (Hanson et al.)

Exclusion criteria for clinicians related to members of staff who had less than six months of experience in institutional geriatric practice (Lopez et al., 2010a).

Exclusion criteria for relatives / legal representatives related to proxies who visited their kin in care less than once a month in the previous three months. Moreover, wherever a person held guardianship, all other relatives were excluded from consideration in the study.

Given the difficulty to surrender to memory the above inclusion/exclusion criteria, a user-friendly check-list was drawn up (see Table 31) to facilitate identification of patients for inclusion in the study; this check-list was distributed personally to all clinicians who had the potential for inclusion in the study.

Furthermore, in order to better describe the nature of the study and selection process, six meetings were organised with doctors (2), nurses (2), SLP's (1) and the clinical nutrition nurse (1), during which the study rationale and check-list questions were explained.

9. Interview Schedule and Data Collection

Qualitative data was collected through individual interviews from physicians; nurses; SLP; the clinical nutrition nurse; and relatives, as they were the principal stakeholders in decision-making in end-stage dementia (6 case studies totalling 30 interviews). In drawing up "the case study instrument" (Yin, 2014, p. 89), the interview questions were set in such a way to answer what was expected from the research question. In practice, one interview schedule was dedicated to all clinicians through a common framework, while another interview schedule was set up expressly for relatives.

It is relevant to point out that data collection, directly from the patients in care was technically not possible in this study, as by definition, persons in end-stage dementia do suffer from maximal cognitive decline and are thus unable to reason and communicate in a meaningful way (Dekkers, W.J.M., 2010). For such reasons, patient-related data was collected from interviews with relatives, clinicians and personal documentation. All audio-taped interviews were transcribed verbatim.

The inclusion criteria denoted that different teams, and thus, different clinicians and relatives were to be involved in the six different cases under study. Such separation of stakeholders was possible in all (doctor, nurse, SLP, and family members) except where it concerned the involvement of the clinical nutrition nurse, as at the time of the study, there was only one such certified professional working at SVP, who was thus covering all wards. To this end, the nutrition nurse was exposed to six separate interviews, one for each case. The six interviews with the nutrition nurse were purposely held on six different days, spanning a period of five weeks. Such an approach was made to minimise replication error. It was observed that the differences between each of the six cases helped to minimise annoying repetitions of common concepts between the six cases studied.

The data obtained from the interviews were not only used to assess the decisional models utilised but also helped to address the stakeholders' respective values, attitudes and beliefs on EOL decision-making in dementia (Rurup et al., 2006), this in addition to addressing their respective roles in the decision-making process.

As it was envisaged that the number of professionals involved in each case study was very small, it was not possible to utilise focus groups, thus the option to perform individualised interviews. In four situations, a second interview was held with certain clinicians under study to help clarify and deepen certain points of interest originating from the first interview. In addition to information gathered from stakeholders through the interviews, additional data was collected from the patients' medical file. Such information from patient documentation helped to unearth details regarding the decision process that was taken; the cognitive and functional severity; and the presence of co-morbidities.

Data consisted of retrospective semi-structured interviews with each member of the team and relatives who participated or was entitled to participate in the decision. Retrospective investigation of decision-making is an acceptable form of study design used in a cognitive approach to address complex issues in health care (Kushniruk, 2002). Such an approach allowed flexibility in responses while at the same time, still retaining the ability to compare responses between participants (Yin, 2014). The data collected included information related to health, social, legal and ethical issues. All questionnaires had both a Maltese and an English version depending on the preference of participants. Backward translation was carried out to ensure conceptual similarity between both versions.

It was anticipated that in each decisional situation, not all relevant stakeholders would be involved and not necessarily all to the same extent. To this aim, two sets of questionnaires were drawn up:

- One questionnaire (labelled Form: A, see Appendix Section) was addressed to those involved in the centrality of the decision process with the intent to identify how and why the decision was taken.

- On the other hand, for those stakeholders who were not involved in the decision, another set of questions (labelled Form: B, see Appendix Section) was drawn up to identify their views of what was decided and at the same time how, in the hypothetical sense, they would have taken such a decision, if they were involved in the decision process.

It is relevant to point out that at the planning phase of the interview schedules each question was drawn up in such a way to make way for the depth of information about what ethical models of decision-making were involved in the management of swallowing difficulties in end-stage dementia. To this end, it was expected that the interview questions would overlap as they related to the emerging relationships in the eight themes (see Table 32).

Before the data collection, a pilot study was performed to assess the clarity of the chosen interview schedules. In the quest to align mortality prediction with accepted international standards, the FAST (Reisberg, 1988) was utilised on all patient participants in the study. Permission was obtained from the respective author for the use of the tool as it is covered by copyright (see Appendix 4)

10. Ethical Considerations

Permission to perform this study was obtained from the relevant authorities, namely the:

1. The Director, elderly and community care department.
2. The Chief Executive Officer and Medical Superintendent, SVP.
3. The six Consultants.
4. The Manager Nursing Services SVP.
5. The Head: Speech-language pathology department.
6. The Clinical Nutrition Nurse.

Consent was also obtained from the University of Malta Ethics Committee before starting the study (FREC and UREC).

Once a patient was singled out for inclusion in the study, consent was first sought from the proxy holding legal representation/guardianship. In all six cases under study none had documented such legal representation/guardianship. Consequently consent was obtained from the family member who visited the patient on a regular basis. Additional consent was obtained from the respective ward charge nurse; the nutrition nurse and SLP responsible for the patient in care. Personal data was not disclosed to third parties and could only be requested by the University of Malta or assigned Supervisors for verification purposes.

Also, any recorded data/text that identified the patient was deleted or concealed through referral to individual patients by a fictitious name. At the same time, clinicians were given a generic orientation title (e.g. referring to “the doctor” instead of the actual name of the physician involved). Furthermore, wherever I deduced that the recorded interviews were particularly sensitive, the concealment was taken to a deeper level by referring to the originator in a generic “a clinician” or “a relative” rather than denoting the specific professional denomination or relationship to a particular patient. All effort was done, so that confidentiality, dignity preservation of vulnerable persons and personal choices was safeguarded throughout.

11. Analysis

Data collection arising from case study research led to the formation of an analytic framework to help better organise and evaluate data. An advantage of resorting to multiple case studies was the ability to perform cross-case analysis of specific emerging themes and hence being able to derive common cross-case conclusions (Yin, 2014). At the same time “cross-case syntheses” (p. 167) helped to delineate emerging differences between the various cases under study. The arising data was then reasoned out and judged in a manner to interpret findings with maximum confidence leading to theory development (Yin).

However, one known limitation of case study analysis is that this is not always possible, consequently, in situations where results pointed to different interpretations and conclusions, value judgments were reasoned out based on all data available (Keen & Packwood, 1995).

The following four principles were given particular attention to deriving high-quality analysis arising from case study research (Yin, 2014, p. 168):

- The analysis gave “attention to all the evidence.”
- Analysis “addressed all plausible rival interpretations.”
- The analysis addressed the “most significant aspects of the case studies.”
- Use of “personal prior, expert knowledge.”

The analytic method of *thematic analysis* was utilised in the analysis of this thesis research as it allows “an accessible and theoretically-flexible approach to analysing qualitative data” (Braun & Clarke, 2006, p. 77). Thematic analysis is a methodological analysis that helps to identify, analyse and bring forward patterns/meanings known as themes that emerge from the data set (Braun & Clarke; Ruggunan, 2014), which in my study concerned individualised interviews to stakeholders involved in the decision-making process.

It is relevant to clarify that this study involved a theoretical and an inductive approach, as the interview questions were theoretically framed from the literature (Braun & Clarke, 2006; “About Thematic Analysis”, 2006), whilst the analysis of data was primarily inductive through open coding, with the arising themes being “data-driven” (Braun & Clarke, pp. 83-84).

The thematic analysis utilised in this study followed the six-step framework, drawn up by Braun and Clarke (2006), as follows:

1. “Familiarising yourself with your data.
2. Generating initial codes.
3. Searching for themes.
4. Reviewing themes.
5. Defining and naming themes.

6. Producing the report” (p. 35).

Data analysis utilised a mixture of NVIVO 11 software and a manual method to deal with text and build relationships into codes & themes. Where necessary, the results of the study were processed with the help of my thesis Supervisors. The study results were presented and discussed with stakeholders, including regulatory and institutional officials, health professionals and academics.

Critical thinking was utilised in the analysis of alternative options of EOL decision-making models for the management of swallowing difficulties. At the same time, moral reasoning was utilised in the face of uncertainty in moral decisions (Ursery, 2005) to help identify if consensus-building approach could be justified to be selected as the preferred model by all stakeholders for decision-making in swallowing difficulties in end-stage dementia. The resolution of this moral dilemma was unearthed following an analysis of the qualitative data arising from input from the interested parties involved in the study. Such analysis included:

a. Stating the facts of each case study.

b. Input and effects of various models on the various stakeholders involved.

c. An assessment of the values, obligations and effects of each option.

d. Clarifying the moral dilemma for each case study.

e. Choosing the best ethical model of decision-making through the use of a critical thinking process of reasons that favour the best option.

f. Also, the Office of the Mental Health Commissioner was consulted on what legal / care delivery standards exist in Malta to regulate decision-making in mental incapacity, and their views on alternative options and eventual revision.

g. The best-identified model of EOL decision-making in end-stage dementia be brought forward to the relevant authorities for further discussion and promoted for inclusion in a revision of EOL care services in dementia.

12. Triangulation

Yin (2014) pointed out that case study research is characterised by multiple sources of input that do help address and maintain adequate triangulation of findings. Yin added that such input should ideally be backed by pre-determined “theoretical propositions to guide data collection and analysis” (p. 17), and should include “logic of design, data collection techniques, and specific approaches to data analysis” (p. 17)

In this study, triangulation was sought through comparison of interviews, interview notes and analysis of documentation. One must point out that all case scenarios did arise from the same institution, and thus were liable to give similar results following “replication logic” (Zucker, 2009, p. 5). Furthermore, the fact that the study design involved the use of multiple case studies helped to improve the triangulation of findings (Yin, 2014), where the individual viewpoint of each stakeholder in their particular clinical situation helped triangulation of observed findings. In fact the six case studies all had six separate sets of family members, in a scenario of six different wards with six different medical teams (made up of six different doctors, six nurses and six SLP’s, but one common nutrition nurse).

13. Limitations of the Study

The limitations encountered in the study (see also Chapter 7) did include issues related to the methodological shortcomings of multiple case study research. One limitation of case study research is that of comparative advantage, in the sense that case studies in comparison to other research methods are unable to reveal the results of real experimentation as obtained by randomised controlled trials (Yinn, 2014). However, it is accepted that case study research is an ideal research methodology to offer better answers in situations where *how* and *why* are central points in the research (Yin).

Furthermore, multiple case study research suffers from claims of lack of vigour, thus rendering such research at risk of being perceived as poor quality research (Yinn, 2014). This problem was anticipated and reflected upon during the planning and collection of data, with particular attention being given to planning good design during the pilot phase of the research collection. All efforts were made during the planning process to derive research questions and study objectives based on a carefully crafted literature review. Also, due attention was given to develop a good study design to help support a valid replication plan in the six case studies.

Additional limitations encountered in this study did also concern the difficulty to define a decision point when a case could be selected for participation. This concern did relate to the situation when a patient became qualified to be suffering from *severe* and *life-threatening* swallowing difficulties. Achieving such requirements was methodologically tricky, mainly as such evaluation was often found to be subjective. This cognitive element of subjectivity bias (Pannucci & Wilkins, 2010), was minimised by addressing all cases myself, as single assessor and by distributing of an inclusion criteria check-list to all clinicians before case selection (see Table 31). Also, the selection was based on a clear definition of the severity and life-threatening components of swallowing difficulties as derived from the literature.

Selecting patients in end-stage dementia as having less than six months of survival was challenging to capture, as prognostic tools lack sufficient specificity (van der Steen et al., 2014). Knowing this, the FAST 7c (Reisberg, 1988) + co-morbidities yardstick was utilised in view of its widespread use in the USA (“Hospice Eligibility Criteria”, 2008), even though accuracy of determination of six months mortality only amounted to 71% of cases when FAST 7c score was evaluated (Mitchell et al., 2004b; Hanrahan et al., 1999). After appropriate follow-up, the study findings did show similar inaccuracy to define six-month survival, as while five cases passed away within the six-month time frame, in the case of Katarin (fictitious name) she passed away seven months post clinical decision to manage swallowing difficulties. Still, the closeness to the six-month time frame and similar clinical/social/ethical circumstances to the other cases under study warranted that Katarin be subject to study review in a general phenomenon (Yin, 2014) of a person in end-stage dementia who was close to dying.

Also, the FAST score was explicitly designed for staging progression in Alzheimer's disease (Reisberg, 1988). The inclusion criteria in this study, while delineating a 7c score on the FAST as the cut-off entry point, did not make a distinction for entry between patients with Alzheimer's disease and other formats of dementia including the mixed type of disease presentation. To this end, prognostic estimation of six months mortality in non-Alzheimer's disease cases including in the study (two of the six cases had non-Alzheimer's disease pathology: one had multi-infact dementia and one was documented as probable Lewy-Body dementia), were prone to influences on staging and prognosis beyond the estimated limitations of the FAST score.

One of the selection criteria listed in this chapter (see Section 8) was that patients that were already tube-fed at the time when the decision was taken to manage swallowing difficulties should be excluded from the study. Such exclusion criteria were never intended to mean that patients who previously had a tube should be excluded from the study. In fact, three out of the six cases identified had a previous episode in their lives when they were tube-fed. While Gina's and Rosa's previous episode of tube feeding was months before the decision-point in this study, Berta's previous episode of tube feeding, which was stopped as it was deemed to be inappropriate, was only two days before the decision point. The fact that the time frame between previous tube feeding and the current decision was not included as a specific criterion for exclusion from the study, I decided to include Berta's case to be one of the six case studies chosen, as to my reasoning this case still satisfied a similar replication design (Yin, 2014) to the other cases under study. It is relevant to point out that this decision to include Berta's case, introduced a strong reflection in her case regarding concerns on withdrawal and withholding of tube feeding, which were less present in the other five cases. Consequently, the recent withdrawal of tube-feeding led Berta's case to offer a richer account of the ethical models involved and helped to give better definition to the tensions involved in the interaction between clinicians and family members in the decision-making process.

The empirical research in this thesis aimed to evaluate six case studies. Such pre-set limitation in sample size (based on a consecutive sampling technique depending on who first met criteria for inclusion), might have given an incomplete picture of the variance in what ethical models underpin the practices of all nine consultant teams who were eligible for inclusion (Bhat, 2019). Counter-arguments to this rested on the fact that the choice of six cases out of a total of nine potential consultants meant that in such a small population it was “hard to sample” (Kirkendall, & White, 2018, p. 92).

Another limitation of case study research is that it cannot be interpreted as being reflective of what happens in the universe (Gomm, Hammersely & Foster, 2011) and is, in fact, generalised only to ethical theory regarding end-stage dementia decision-making. Consequently, the unique circumstances that were underpinning the case studies could not be representative of what is happening in other Maltese nursing homes. Nonetheless, the results of this case study research have helped to unravel an as yet undetermined theory on EOL decision-making in dementia and the associated ethical dilemmas that arise in Maltese care settings.

It is also relevant to point out that although it was necessary, for accuracy purposes, to carry out the interviews within one week after the decision-making was taken to manage swallowing difficulties in end-stage dementia; this was humanly impossible in some situations. Also, the rigidity to perform interview schedules in a short period did also create an inherently difficult methodological problem to ascertain that the cases did choose a long-term management plan to deal with swallowing difficulties. In fact, in some interviews, it was appreciated that decision-making in swallowing difficulties in end-stage dementia was quite often a works in progress and decisions taken were often subject to revision at an undefined future time, depending on patient response and whether or not the objectives listed at the decision point were reached in due time.

Another limitation of qualitative review was that I am myself one of the consultant geriatricians doing duties at SVP. Therefore in this study, I brought in my, “own data-making role in reflexivity…introducing my biases, interests and areas of ignorance” (Richards, 2015, p. 53). One such potential bias is my interpretation during the analytic phase of the interviews, leading to narrative analysis bias (Gomm et al., 2011). My clinical practice has always been based on the promotion of a team approach, where my convictions have guided me to promote a dignity orientated approach in the management of persons in end-stage dementia. In the knowledge of my beliefs, although all efforts were made on my part to remain objective and dissociated from the cases under study, the bias of personal conviction could not be excluded from my findings.

It is important to clarify that the patients under my care were excluded from the study. However, it is relevant to point out that my thirty-three year history of uninterrupted medical duties at SVP, might have influenced the decision-making in clinicians participating in the study, who, once they became aware that they were involved in this research, may have been exposed to a broad Hawthorne effect, leading to re-consideration of orders for tube feeding (Hanson et al., 2011).

Additionally, at the planning phase of the study, consideration was given for me, as the researcher, to observe the feeding process. It is in fact known that case study method includes input derived from observation of the case/s in question (Yin, 2014). However, my position as consultant geriatrician in the place of study, made it practically impossible for me to sustain an unobtrusive presence (“Unobtrusive Measures”, 2006) in observing how nurses, carers and family members did feed their patients, and the risk was that those feeding the patients would, “alter their behavior in order to look good in the eyes of the researcher” (p.

1). Consequently, such observation was withdrawn prior to commencement of the collection of data.

Furthermore, performing this research from the standpoint of an active staff member in the institution under study did require additional tact and attention on my part on how to present sensitive findings that may bear witness to what may seemingly appear to be negligent or inappropriate behaviour of colleagues and / or the institution's administration approach to care of vulnerable patients in care.

14. The Conclusion to the Chapter

Drawing up a precise methodology is the foundation of successful research. The need to achieve such accuracy is particularly real in exploratory research, where case studies are utilised. This study followed a qualitative approach in order to gain depth from the responses of participants in question. A reasoned build up of methodological process has been meticulously developed and applied to practice. Also multiple case studies were carried out in a specific site of care that permits the inclusion of all potential stakeholders that have a say as study participants in the identification of what ethical models were utilised in swallowing difficulties in end-stage dementia.

Following the above account on the methodology of the study, the following chapter does deal with an in-depth appraisal of the research findings as arising from the field work.

Chapter 5: Research Findings

1. Introduction

This chapter gives an account of the ethical models that were found to be involved in decision-making to manage swallowing difficulties in end-stage dementia. At the same time attention is given to how stakeholders interacted together in decision-making. The chapter opens with a brief overview of the six case studies. Henceforth the chapter expands on the ethical values and theories involved in decision-making. In addition, attention is given to how emerging ethical models involved in the decision-process influenced the human dignity and interests of the person in care.

A. The decision-making context: main features of the six case studies.

The six persons with dementia in the study, which happened to be all female, were given fictitious names to ensure confidentiality. The six case studies originated from six separate and distinct teams comprising the attending consultant/resident specialist, ward charge nurse/senior nurse on duty, the SLP, and the involved relatives, while one clinical nutrition nurse served all teams. Consequently, six different relatives and nineteen different professionals were interviewed, while the clinical nutrition nurse was interviewed six times. Therefore, data consisted of a total of thirty interviews.

All case studies were referred for inclusion in the study by the attending clinicians, namely, two from their consultants; one from the ward nurse manager, and three from the SLP’s. All interviews were commenced within one week after the decision was taken to manage swallowing difficulties, and all interviews were finalised within eighteen days post-decisional date.

In hindsight, one can consider that all six cases presented end-stage situations in that they all passed away within seven months after the decision-making point to manage swallowing difficulties in end-stage dementia.

Before starting the cross-case analysis, it is relevant to delineate background information of individual case studies (Yin, 2014) that should help the reader to get a realistic appraisal of the scenario surrounding the clinical situation and decision process for each case study (see also Table 33).

CASE STUDY 1: *Berta* was an 84-year-old widow who was admitted to SVP from MDH four days before the decision to manage swallowing difficulties was taken. Her primary diagnosis was end-stage dementia. She was in an emaciated state with contractures and multiple deep infected pressure sores with associated low-grade fever. Berta was admitted to SVP with an NG tube for feeding that had been inserted initially at MDH. On the night of the first-day post admission to SVP, her NG tube was dislodged, and the duty resident doctor decided against tube re-insertion, given her poor condition, and started the patient on an intravenous drip and intravenous antibiotics. This scenario was considered the zero point to satisfy the selection criteria in the study, that of a patient without tube feeding and having a problem with swallowing difficulties to be acted upon. In fact, an SLP review carried out the next day (day two) confirmed she was unsafe to swallow. Post SLP review, she was seen by the ward resident doctor who questioned the aggressive management and consequently opted for a palliative EOL approach by not re-introducing tube feeding and initiating comfort oral feeding and pain management including morphine. Drip hydration and antibiotics were continued. The consultant was informed by telephone with this management plan and agreed with this decision. When on the fourth-day post admission, the son and his partner came to know about this decision to treat palliatively, they strongly objected as their values supported the continuation of proper nutrition to prolong life. Following further discussion between the relatives and the consultant/resident specialist, tube feeding was restarted. In this decision to restart tube feeding, the ward nurse and the SLP were marginally involved while the nutrition nurse was not involved.

The ethical models of decision-making used in this case were beneficence, non-maleficence, withdrawal and withholding of care, QOL, and deontology. Berta passed away six weeks after the decision was taken to manage her swallowing difficulties.

CASE 2: *Gina* was a 68-year-old married woman who was admitted to SVP, eighteen months before the decision taken to manage swallowing difficulties. Gina was suffering from two primary active diagnoses, namely end-stage dementia and advanced Parkinson’s disease, both contributing to progressive swallowing deterioration. Earlier on in life when faced with swallowing difficulties, she had expressed her wish to pursue oral feeding but was totally against the use of food thickener. Also, the relatives claimed that they had past verbal instructions from the patient of her wish to avoid tube feeding. At the time of the decision re-swallowing management, she was emaciated with contractures, and her problem with swallowing was associated with recurring episodes of chest infection. Attempts to revise her anti-Parkinson’s medication to improve swallowing proved unsuccessful. The resident specialist wanted to start NG tube feeding to avoid the patient from starving, to prolong life, and to administer medication for her Parkinson’s disease, something the husband and the patient’s daughters objected. At this point, the clinical impression was that the patient still showed an interest in food but could not swallow it safely. A case conference was held with the relatives to decide the way forward, leading to a decision to start tube feeding. In this decision, the SLP was involved peripherally, while the nutrition nurse was not involved.

The ethical models of decision-making used in this case were respect for human life and vitalism, virtue theory, QOL, beneficence, autonomy, substituted judgement and a deontological approach to decision-making. Gina passed away seven weeks after the decision was taken to manage her swallowing difficulties.

CASE 3: *Katarin* was a 97-year-old single lady who was admitted to SVP four years previously. She had a history of controlled schizo-affective disorder and progressive dementia and had now entered its end-stage with associated episodes of recurrent chest infection, weight loss and functional dependency. She had reached a stage where she was wheel-chair bound with minimal communication abilities. For years she had problems with swallowing difficulties, and in the earlier phases when she could still express her wishes, she had always resisted the ingestion of altered food, preferring solid food especially crusty bread and dry cakes. Two years previously, at a team conference in the presence of the sister-in-law, consensus was reached to provide varied safe to swallow food choices with the help of the relatives. Input from the psychiatrist showed that the patient was incapable of deciding for herself. Various nephews and nieces expressed conflicting values in views on how to manage swallowing problems and this reflected in some food choices being administered by the relatives in a format that was deemed unsafe for swallowing. Two days before the decision, the patient became very lethargic, started to choke with her food, and was refusing all food and drink. The ward nurse manager consulted with the SLP to assess alternative forms of feeding and a decision was taken to increase the level of food thickener consistency. The consultant/resident doctor, relatives and the nutrition nurse were not involved in this decision.

The ethical models of decision-making used in this case were autonomy, QOL, deontology, substituted judgement, beneficence, and non-maleficence. Katarin passed away twenty-eight weeks after the decision was taken to manage her swallowing difficulties.

CASE 4: *Lorenza* was an 82-year-old widow who was admitted eight years previously to a dementia ward (SVP) for patients with challenging behaviour. Ten days before the decision date, she was transferred from a dementia ward to a general ward as she was now immobile with normalisation of her challenging behaviour. Lorenza had a history of end-stage dementia, old stroke, and recurrent chest infection. She was in an emaciated state with severe kyphosis, contractures and pressure sores. Following transfer to a general ward, the relatives reported that Lorenza started to refuse to eat and drink, at which point the resident specialist started the patient with subcutaneous fluids to maintain hydration. At one point, a team conference was organised that involved the patient's daughter and her husband, the ward nurse manager and the resident specialist. During this meeting, the resident specialist left it in the hands of the relatives to decide what management plan of swallowing difficulties to follow for Lorenza. The decision taken was to proceed with subcutaneous hydration and comfort feeding in respect to the patient's past wishes and values. In this decision process, the SLP and nutrition nurse were marginally involved.

The ethical models of decision-making used in this case were substituted judgment, beneficence, consensus-building approach, QOL, sanctity-of-life and the patient's best interests. Lorenza passed away seven weeks after the decision was taken to manage her swallowing difficulties.

CASE 5: *Pina* was an 84-year-old widow who was admitted to SVP, two years previously. She had a history of end-stage dementia with contractures, severe weight loss, and recurrent chest infection. Furthermore, clinicians had recently noted that she had started to deteriorate, which situation was ascribed to hypercalcaemia secondary to a newly diagnosed multiple myeloma. In this clinical picture, the consultant in care decided for transfer of the patient to MDH for management of high blood calcium levels. On returning to the ward at SVP, she was noted to be semi-lethargic and not able to eat or drink. The consultant called a team conference involving the patient's children and the senior ward nurse on duty. A decision was taken to start tube feeding to be able to provide the necessary medication to treat the multiple myeloma and to provide adequate nutrition. The nutrition nurse and the SLP were marginally involved.

The ethical models of decision-making used in this case were virtue theory, beneficence, substituted judgement, sanctity-of-life, consensus-building approach, best interests, and deontological approach to decision-making. Pina passed away thirteen weeks after the decision was taken to manage her swallowing difficulties.

CASE 6: *Rosa* was an 89-year-old widow who was admitted to SVP three years previously. She had a history of end-stage dementia, recurrent aspiration pneumonia and fractured hip. Rosa showed signs of severe progressive weight-loss, long-standing intermittent swallowing difficulties, and contractures in a functional state where she was dependent and bed-ridden. The patient's son always claimed that his mother was able to eat a full plate of food whenever he was feeding her, even though his feeding technique was found to be questionable by the nurses. Over a short period of days, the patient started to choke incessantly on eating and drink. A preliminary decision was taken by the consultant, with the involvement of the SLP and the ward nurse manager, to revise the food consistency before considering other aggressive methods of feeding. A second level of consultation and decision-making also involved the relatives, at which point this decision was confirmed (the relative left it in the hands of the clinicians) to provide comfort feeding at a consistency that was values-led as being the safest possible to swallow. The son was offered to have his feeding sessions with his mother supervised by a nurse to ensure safety in feeding. The nutrition nurse was not involved in decision-making.

The ethical models of decision-making used in this case were beneficence, non-maleficence, best interests, virtue theory, consensus-building approach, and deontology. Rosa passed away eight weeks after the decision was taken to manage her swallowing difficulties.

2. An Overview of the Eight Themes

Thematic analysis (Braun & Clarke, 2006) of the interviews sought to answer the research question, "*What ethical models, if any, are being used and underpin the decisions of clinical teams and other stakeholders in relation to swallowing difficulties in end-stage dementia?*"

The data showed that the practical circumstances of the patients' situation and whoever was involved in the decision had an impact on what was decided. However, no decision was haphazard and was found to reflect one or a combination of ethical principles. From a clinical point of view, the priority for decision-making varied between *prolonging life* versus *dying with dignity*. The interchange between these two clinical strategies depended on personal and professional values as they related to an appreciation of the proximity to the EOL.

An overview framework of the ethical models that were used in the six cases of decision-making in end-stage dementia is visualised in Figure 2; Table 34 shows how the initial hundred categories of ethical issues identified in the data were grouped into the following eight main themes:

1. The challenge of safeguarding human dignity in end-stage dementia.
2. Substituted judgement.
3. Principlism.
4. The debate between sanctity-of-life and quality-of-life.
5. Virtue ethics as an ethical framework to promote optimal care.
6. Paternalism and Deontology.
7. Patient's best interests judgement.
8. Consensus-building approach.

3. Theme 1: The Challenge of Safeguarding Human Dignity in End-Stage Dementia

This theme concerns how clinical issues, cultural factors and care attitudes influenced the respect for human dignity in the management of swallowing difficulties in dementia.

A. Respect for human dignity.

i. The complexity of decision-making in the management of swallowing difficulties in end-stage dementia.

A number of interview responses affirmed that the progression of dementia to its advanced stages led to the loss of autonomous decisional capacity. Katarin's nurse remarked, "It is the fault of dementia… she lacks the insight into what is right or wrong."

There was a general acceptance of the advanced frailty of the person in end-stage dementia, which included swallowing difficulties. Gina's husband summed up the bleak situation, "She is finished, she is now very frail and in poor condition. She does not move; she does not speak, all the time staring blankly in front of her, she cannot swallow."

Many clinicians remarked that in end-stage dementia the difficulty in swallowing and feeding created severe health risks to sustain life: "In dementia the amount eaten will with time get less and less, which eventually will lead to problems of life sustainability." (Pina's SLP)

The complicated situation of swallowing difficulties in a picture of severe frailty created a decisional dilemma in caring staff to determine what would constitute a suitable programme of care. Katarin's nurse was alarmed, "Her swallowing problem suddenly worsened, she started choking. …we came to a dilemma, 'What are we going to do now?'"

The presence of active co-morbidities in association to end-stage dementia held a strong influence on the decision strategy taken, leading to an aggressive approach to care. The presence of Parkinson's disease in Gina's case and a diagnosis of multiple myeloma in Pina's clinical scenario did relegate late-stage dementia care to a lower level of importance. For instance, Pina's doctor said, "As this associated medical problem (multiple myeloma) was potentially reversible and the patient was not eating or drinking at all, we decided to insert a nasogastric tube." While Gina's doctor approached the relatives and pushed forward the argument with them for tube feeding by stating, “She has those medicines to take and all (i.e. meaning food). I went to them and told them that we need to introduce a nasogastric tube."

Another factor that clinicians commented on was the lack of precise estimation of the survival time in end-stage dementia. Such lack of clarity of estimation of survival time raised the dilemma of when would be the proper time to start EOL care. Rosa’s SLP stated, “One is amazed on how the body compensates and copes. You might think she is coming to an end and then she is sort of like restored again.”

The central recurring theme observed in the interview responses was the decisional dilemma faced by stakeholders, where in swallowing difficulties in end-stage dementia, the decision concerned the choice between two ethically based strategies of care:

- To promote *dying with dignity*, through a QOL approach that favoured comfort feeding and avoiding burdensome futile care.
- To *prolong life* by pushing for safety in swallowing and proper nutrition. Given the dire clinical circumstances in end-stage dementia, this often led to starting tube feeding.

On the decisional dilemma between these two clinical strategies, Rosa’s SLP highlighted the difficulty by stating,

> Nursing staff expressed concern regarding her overall intake, and they asked, ‘Is she having enough?’ Presently she has lost weight. We are also trying to find a balance, to keep her comfortable in her EOL… No one has a crystal ball! I do not think that she would benefit from a nasogastric tube.

These conflicts and uncertainties were epitomised in the difficulty that some stakeholders faced when they were asked to state their personal preference for EOL management if in a hypothetical future they were faced by a similar situation in care. For many relatives, the dilemma seemed quite difficulty and did not want to answer: “Oh my God! What a difficult question, I find great difficulty to answer.” (Katarin’s sister-in-law)

Figure 2: The relationship between the various ethical models (in green boxes) used in decision-making to manage swallowing difficulties in end-stage dementia. The blue balloons indicate the process leading to a decision, between either one of the two clinical strategies (red boxes) that prevailed in the case studies.

On the other hand, it was observed that some clinicians wished a different care strategy for themselves as compared to what they had decided for their patients. Such variance suggests different challenges to those holding the status of a health provider versus being yourself the patient. After supporting the team's decision for tube feeding, Gina's SLP wondered why she preferred a palliative strategy for herself, "I would choose [for myself] feed at risk. Wait! Now you are putting me in a personal dilemma! Why did I choose NG tube feeding for my patient now that she is doing so poorly?"

A threat to human dignity arose from the conditions of care in institutions that seriously challenged the patient's identity as a person in end-stage dementia:

> After some two years following her diagnosis, her liveliness had gone, her beautiful dresses were no longer available, and she was being dressed in baggy dull clothes…. People here are all dressed practically the same. The loss of that personal touch did put her in a sad state, and I believe she lost her identity. (Lorenza's daughter)

ii. Cultural issues as they impinge on patient participation in dementia decision-making.

Clinicians understood that one of the mainstays of dignity-preserving decision-making in dementia is that persons in early dementia should be allowed to express their wishes for their future care. For this to materialise, persons in early dementia need to be given the truth about their diagnosis and the necessary knowledge on progression and care options to help them come to an informed care choice: "Ultimately this is your body, and you should decide for it, but you need to know beforehand what could possibly happen in your future disease, prior to losing mental capacity to express wishes." (Gina's nurse)

However not all clinicians were in favour of divulging an informed diagnosis of dementia to patients in its early stages: "There are doctors who prefer to tell the person even a bad diagnosis, which makes them very sad. It is better to give the message to the relatives." (Rosa's nurse.)

Indeed, Maltese older adults valued the doctor-patient relationship by showing a high level of trust in their attending physician. Gina's doctor pointed out, "We have a culture, that if the doctor tells you to stand upside down, especially this elderly generation, they do it."

Similarly, some relatives showed such trust to leave care decisions entirely in the hands of the caring professions: "Whenever they asked me, I always answered, 'Whatever is best for her, do it!'" (Gina's husband)

Another cultural drawback was that Maltese patients had a restricted view of their health concerns and concentrated their attention solely on meeting their current needs: "I do not think it is part of our culture really to think that far ahead." (Rosa's SLP)

Maybe these cultural attitudes where older people don't give importance to involve themselves in planning their future care, was one of the possible reasons why in end-stage dementia, clinicians were unaware of the patient's past wishes. This threatened the patient's dignity for control on their EOL: "I have no idea what were the patient's past wishes, the relatives have never told me or told the team, nor is it in the file …this is common you know!" (Rosa's SLP)

B. Safeguarding human dignity in end-stage dementia.

i. Safeguarding personhood in dementia care.

Despite the above challenges, many respondents expressed their commitment to safeguarding the human dignity of persons in dementia: "You see the patient as a person. To ensure my personal safety, I would go for an NG tube, but no, many patients do not tolerate it …there is their dignity." (Lorenza's SLP)

The relatives acknowledged the clinicians' approach to safeguarding the patient's dignity as they felt that the patient's values were respected: "Yes I believe our Christian values are being respected in decisions, I cannot say anything wrong about the staff." (Katarin's sister-in-law)

Secondly, the relatives themselves gave importance to the patient's dignity by showing appreciation to the patient's humanity and life experience: "My mother was a stylish person, she was very colourful in her dresses… and she never wanted to tell how old she was!" (Lorenza's daughter)

ii. Consideration given to the patient's past wishes.

Family members seemed to understand the concept that a patient retaining mental capacity had the right to hold ownership of decisions about their health: "When she could still talk, if I were to take such a decision I wouldn't have taken it, the decision would have been hers." (Gina's husband)

Clinicians understood that to safeguard human dignity in end-stage dementia; measures should be taken early in dementia to involve the patient in their future care planning:

> Our intention as professionals is that we are there to help the person express her past wishes … [starting] at the very early signs of dementia, such wishes should be sought and documented. (Katarin's doctor)

Safeguarding dignity was also acknowledged in giving a chance to patients in early dementia to participate in future care planning regarding tube feeding: "In deciding to insert or not a feeding tube. In such a case, one should provide all the information; explain the risks for each option; and the possible outcome and prognosis for each possible decision." (Pina's doctor)

Consequently, preserving human dignity in dementia, valued the patient's involvement in advance care planning:

> Through advance care planning, once you know the possible trajectory of the disease, you can plan with the relatives how to meet this challenge. Actually, such

> planning should start early with the diagnosis of dementia so that the person with dementia would be given the possibility to take her own decisions. (Pina's SLP)

C. Was human dignity being safeguarded?

The data indicated that clinicians did not at times respect the patient's known past wishes regarding the management of swallowing difficulties in dementia, and this seemingly challenged the respect for the patient's dignity:

> I know of cases, where there were patients who had expressed their past wishes re management of swallowing difficulties and such preferences were known, and still when it came to taking the clinical decision, what was decided went in the opposite direction of what the patient would have wanted. (Pina's SLP)

A number of clinicians did mention some reasons why at SVP, the patient's past preferences regarding future care lacked primacy in care. One reason was the lack of a legal framework to regulate past wishes in end-stage dementia care (see in Chapter, Section 5.B.ii). The second reason mentioned the lack of a standard procedure to follow in such cases: "If we had a format to document past wishes, and all know this, it would guide us in the decision-making particularly in such complicated situations." (Gina's nurse)

D. Safeguarding patient dignity by giving due attention to what patients in end-stage dementia are telling us.

In order to meet dignity concerns regarding the patient's experience in their current illness, clinicians gave value to what the patient was experiencing at the time in the actual context of a compromised autonomy. In so doing, the influence of the present illness was given prime value over what had possibly been expressed by patients earlier on in life (see in Chapter, Section 3.B.ii): "When you decide earlier on in life against aggressive treatment, you are still healthy, you have in your mind your current style of life. It could be that when you become more disabled, your preferences and views change." (Pina's doctor)

In some situations, despite end-stage dementia limitations, patients could still somehow show a reaction to the care given; such expressions were given value by clinicians. Lorenza's nurse related to memory the story of a past patient,

> As she didn't want to eat, I remember telling her …'Let us eat a little bit or else I will pass you a tube to eat'. Whenever I said this, she used to look at me with those wide pity eyes of hers, giving me the message, 'Do not dare do me such a thing!'

In conclusion to this section, one can deduce from the interview responses that threats to safeguarding human dignity in decision-making to manage swallowing difficulties in end-stage dementia arose out of the inherent multi-factorial vulnerability that patients in the late stages of dementia do suffer. The lack of decisional capacity in dementia was a prime difficulty coupled with uncertainty about the patient's prognosis and practices that gave little value to the past wishes in end-stage dementia decision-making.

The next theme will consider the role of the relatives in the decision-making process, with particular attention being given to concerns regarding the utilisation of substituted judgement in decision-making to manage swallowing difficulties in end-stage dementia.

4. Theme 2: Substituted Judgement

This theme considers the role of the relatives in the decision-making process to manage swallowing difficulties in end-stage dementia. Particular attention is given to the impact of *substituted judgement* on the decision process.

A. The relatives in decision-making.

Most family members valued their involvement in the care and decision-making for their relatives with swallowing difficulties in dementia. Rosa's son stated, "I have been attending here for three years, always feeding her myself… I feel it is of priority to involve the relatives when they decide to revise her management of swallowing difficulties."

Clinicians valued the importance of involving relatives. Katarin's doctor said, "When the patient is in end-stage dementia …you need to talk more with their children, to decide care."

In so doing, clinicians were aware that involving the relatives was an asset to ascertain patients' preferences in feeding. Katarin's nutrition nurse's commented, "I know what she can eat, but I do not know what she likes. The relatives can tell you what she likes."

Family members themselves were often aware of the preferences of their elders regarding CANH. Rosa's son remembered, "Some months ago, [my mother] had some intra-venous tubes, and she pulled them out; they had to restrain her hands; I was sure 100 per cent she would pull the feeding tube out."

i. Substituted judgement.

Clinicians were often observed to be at a loss to direct care to respect the patients' needs and wishes for care. Rosa's doctor explained, "She doesn't take the required full amount of nutritional intake orally, and the question was: 'What are we going to do about it?'"

When in end-stage dementia there is no available knowledge regarding the patient's EOL wishes for care, clinicians do turn to family members to decide in such a way that mirror's the patient's wishes, akin to stepping "in their shoes". However, the data showed that the concept of decision-making by relatives through substituted judgement was not consciously sought out by clinicians. Lorenza's doctor explained, "There is nowhere documented what her past wishes were, nor was this argument brought up during a discussion with the relatives."

The lack of appreciation of the patients' wishes regarding EOL care, led many family members to decide care based on their personal preferences for care. For instance, Berta's son remarked, "For us [her relatives] feeding was important …I never talked with my mum about this [her wishes for care]."

On the other hand, there were a few instances where the relatives decided care for their elders based on the patient’s past preferences and values. In these cases, substituted judgement appeared to have left the respective family members more at peace and convinced that the decision taken was the right one: “Yes she at times brought up the argument; she expressed the wish to let her die in peace…Yes, it helped me personally to decide with more conviction, as that was her wish.” (Lorenza’s daughter)

ii. The decisional burden on the relatives.

Various interview responses showed that the relatives’ role in dementia decision-making was not an easy one. In this situation, Maltese cultural traits of firm family bondage rendered EOL decision-making more problematic. Berta’s nurse argued,

> The relatives will be those who will be losing the most …we must not forget that many Maltese persons have a very strong bond with their relatives. So it is not easy to mention palliative care for them to let go.

Many interview responses indicated that family members felt conflicted and emotionally challenged to let go and accept that the end was near. Lorenza’s daughter said, “It is very difficult… to either let go or fight for life, a continued war inside your mind, a war where for my egoism I want my mother to live, so where is right or wrong?”

Furthermore, the struggle to come to terms with the poor health status of their loved ones rendered relatives quite emotional and fragile to cope. Gina’s husband pointed out,

> Her legs are so contracted that they are fixed up to her chest; she does not speak... So she simply exists, not living. When I come here and see that she is in such a poor state with a pity face, she makes me cry.

Many relatives seemed to be already bereaving their relatives with dementia. Gina’s husband cried out, “I have no life any more, my life is here; we used to go out together when she was still healthy, but now what life do I have?”

The responses evidenced that the needs of family members were considerable. Lorenza's daughter sobbed in apparent emotional turmoil:

> Do we need support? A lot! As soon as your mother is admitted to a home, you immediately feel the need for support. It would be better if professionals here do give more information about what is happening, the reasons why some things are being done, the future, discussions with us of the problems as they crop up.

Clinicians did appreciate the plight of family members and accepted the concept to support the relatives and include them in the decision-making process. Berta's nurse remarked, "Regarding the provision of palliative care or aggressive care choices, it is important to make detailed communication with the relatives…you have to give enough time to prepare the relatives."

Some clinicians promoted the need to consider the family's interests on a broader appreciation of the decision-making process. For instance, Rosa's doctor declared, "You must review how the team is feeling, how the patient is feeling, and how the relatives are feeling."

Furthermore, some clinicians believed that more efforts need to be done to educate the family on the manifestations that characterise all the stages of dementia and consequently have the opportunity to learn and adapt accordingly. On this Pina's SLP said, "The people out there think that dementia is solely loss of memory! I believe it is extremely important to give information about the progression and eventuality of dementia."

In conclusion to this theme, it was clear from the responses that relatives of persons in end-stage dementia suffered a double burden, namely: the issue of dealing with the physical and mental losses in end-stage dementia; and also the burden involved in deciding life or death issues regarding the management of swallowing difficulties. On the other hand, it was also clear that clinicians themselves have not as yet appreciated the importance of helping relatives to adopt decision-making in end-stage dementia based on substituted judgement.

The next theme will give an account of how the ethical models inherent in principlism influence decision-making in the management of swallowing difficulties in end-stage dementia.

5. Theme 3: Principlism

This theme considers the evidence for the application of ethical principles represented in *principlism* theory. Principlism refers to the use of ethical principles in care decision-making, namely the respect of autonomy, beneficence, non-maleficence and justice.

The study findings showed that the main pillars of clinical decision-making fell between two distinct yet interlinked clinical strategies, which involved on various levels the principles and values of beneficence, non-maleficence, vitalism, sanctity-of-life and QOL. The two care strategies were, to either give value to *prolong life* or else to promote *dying with dignity*. The considerations regarding vitalism, sanctity-of-life and QOL are considered in detail in Theme 6 (see in Chapter, Section 8).

A. Beneficence.

i. The provision of good care.

Many clinicians gave consideration to *beneficence* by promoting the provision of good care in the face of severe swallowing difficulties. For instance, Rosa’s SLP remarked, “This patient would not be here if it wasn’t for the care that the nursing and care staff are giving her; she has quite severe dysphagia you know!”

The findings indicated that the provision of benevolent care in swallowing difficulties concerned the choice between two separate yet interlinked care strategies. Namely the provision of safe nutrition to prolong life, as opposed to the provision of dying with dignity in consideration of QOL concerns: “The aim should be that the patient is comfortable, nourished as far as possible with all the limitations of the case, taking in consideration safety.” (Katarin’s SLP)

In deciding between these different care options, clinicians promoted a patient-centred approach. Rosa's nurse manager highlighted, "I always ask the question 'will the patient benefit?'"

Furthermore, the provision of a variation in food choices was given importance as it led to better patient compliance. "If you have a patient on a soft diet and the only option is an omelette, he will very soon get fed up. Eventually, he will say: 'Give me something different from omelette even though it will kill me!" (Katarin's nutrition nurse)

Family members valued a benevolent approach in the face of swallowing difficulties. Lorenza's daughter proudly remarked, "The fact that she was seeing our faces, her relatives, helped her to eat more. She felt more relaxed, more trusting in me, and she ate it."

Family members did also act, in terms of beneficence, by providing kindness and commitment to their dying relative in care. Gina's husband summed it up, "From our end, we have never abandoned her, we love her"

In the face of swallowing difficulties, most clinicians and relatives did favour oral feeding as a benevolent act to respect the humanity of the person in care. For instance, Rosa's nutrition nurse said, "Because you do understand that food by mouth is by mouth, the normal feeding process… patients always prefer oral than tube feeding… It is the humane way how to do it."

To this end, in the presence of swallowing difficulties in dementia, careful hand feeding satisfied the ideals of good care, thus keeping the patient in satiety and comfortable. Katarin's nurse observed, "On her good days, we are still giving her liquidised food… and so the patient does not remain hungry, and she could also have a comfortable night's sleep."

ii. Giving value to safety in swallowing during oral feeding.

When faced by swallowing difficulties in end-stage dementia, a common strategy that was often reverted to in terms of beneficence, was the provision of food of altered consistency, which thus provided a safer solution in oral feeding. Lorenza's daughter was content to say, “They suggested feeding her with a thickener. At that point, she was doing well.”

Wherever hydration was an issue in conjunction with swallowing difficulties, most doctors opted in favour of setting up of a subcutaneous drip: “She had hydration problems, but we managed adequate hydration with a subcutaneous drip.” (Rosa’s doctor)

In practice, the situation was often complicated by secondary variables which rendered management more complicated.

One such dilemma in decision-making related to finding the right balance in care in swallowing difficulties, namely to either promote careful oral feeding at the cost of suboptimal nutrition, versus pushing oral feeding to sustain adequate nutrition at the increased risk of aspiration. This dilemma in virtue theory seemed to expose a possible conflict in the principles of beneficence and non-maleficence. Rosa’s SLP remarked,

> Such patients have problems with the rate of feeding, and if you were to feed them as often as they open their mouth in response to a spoon, you would probably give them aspiration…pushing her to feed to the point where she might develop a chest infection.

Despite the preference for oral feeding, this was sometimes insufficient to meet needs. Gina’s SLP stated, “If I spent all day with her, she would not be taking the required nutrients for the day, because her swallowing was so slow.”

iii. Prolonging life and safeguarding patient dignity by giving due consideration for tube feeding.

Clinicians’ application of the principle of beneficence included a reference to cultural norms. Some clinicians made general remarks about the Maltese and their strong values that favour the provision of sustenance throughout the life course. For instance, Pina’s SLP remarked,

> There is a mentality in general amongst relatives that the more a patient eats, the healthier you would be, I cannot understand it…. We know that with advancing dementia, automatically the patient will lose their appetite and will diminish in the quantity of food eaten.

The quest to provide benevolent care to define solutions to allay starvation and hunger led to considerations for starting tube feeding: “The doctor told us about the need for passing a nasal tube… if a person does not eat, you know what happens!” (Pina’s daughter)

This Maltese mentality for giving substantial importance to feeding in end-stage dementia did reflect in action taken by some clinicians who argued that tube feeding was not a futile measure in end-stage dementia. For instance, a clinician said, “We the Maltese have the tendency that if the patient is not terminally ill… we do go for tube feeding, as we do not consider it as an extraordinary measure.”

Likewise, the decision to go for tube feeding related to the concern in clinicians to improve nutrition, particularly where swallowing difficulties were associated with frailty and weight loss. Gina’s doctor pondered the decision,

> In decision-making I considered her level of frailty; she is rather frail and wasted with disuse atrophy… I also considered the report of the SLP who said she cannot take anything by mouth even stage 5, so to feed she needs tube feeding.

Some doctors pushed for enteral tube insertion as a convenient means of access to administer oral medication. Pina’s doctor argued, “The nasogastric tube was inserted for nutritional purposes and also for drug administration as the multiple myeloma was amenable to treatment.”

At the same time, consideration to start tube feeding gained strength when such decisions considered the patient’s dignity, by giving attention to support their past choices and values in care. Pina’s daughter argued in favour of tube feeding, “My mother loves life so much that she would definitely tell me yes!”

Once a decision was taken in favour of commencing tube feeding, the next query to answer related to the choice of which tube option to utilise. This decision considered various tube formats in terms of beneficence, non-maleficence and QOL. Gina's nurse remarked,

> We all know what the problems are in nasogastric tube-feeding. It is uncomfortable; it is painful; you cannot breathe normally; you cannot talk properly; you cannot turn… Referring older people for a RIG or PEG would spell wonders for their QOL.

iv. Considerations that favour a palliative approach.

The above two sections gave prominence to those interview responses that valued the strategy in care to prolong life and favoured methods of adequate nutrition, both oral and tube feeding. Other clinicians and some family members felt at odds with this approach and expressed their views against tube feeding in end-stage dementia in favour of a palliative approach to promote dying with dignity. Lorenza's doctor pondered these two care strategies,

> The main aim of the medical profession is that the patient does not suffer... This includes the avoidance of interventions that cause suffering, one of which is nasogastric tube feeding….Also of importance is to avoid where possible an inadequate diet and nutrition. These two aspects are often at odds with each other and finding a happy medium is not always possible.

In terms of beneficence and non-maleficence, many clinicians decided to avoid tube feeding, and instead followed a palliative approach to maximise EOL comfort. Berta's doctor argued,

> In such situations in dementia, tube or not tube feeding will not make any difference for the patients. What is important is to keep comfortable, no pain, with a tube she would not be comfortable. Why insert a nasogastric tube in their EOL?

A similar sentiment to avoid tube feeding and avoid aggressive futile intervention was also reported in other professions. Lorenza's nutrition nurse summed it up by saying, "In this case, I would go for non-intervention palliative care - I do not see the scope for aggressive management. So basically go for … comfort feeding.”

In Gina’s case, family members wanted avoidance of suffering in end-stage dementia by avoiding burdensome aggressive measures as is tube feeding. In this approach, these relatives went against decisions favoured by clinicians to medicalise the EOL through provision of tube feeding. Gina’s husband stated, “They told us they were going to insert a tube. I asked him why? He [the doctor] told me that for example, instead of dying in 1 month; she would die in two months. For us this would be additional torture on her.”

A palliative strategy in the management of swallowing difficulties favours comfort feeding. However, through such an approach, clinicians were conscious that there would always be an associated element of risk in swallowing through choking hazard. Gina’s SLP pondered on this issue, “The patient is now doing so poorly…..I tend to go a lot on the feed by mouth at risk.”

B. Non-maleficence.

Many interview responses indicated a common appreciation to avoid forcing the patient to eat, as this would counteract the principle of *non-maleficence*. For instance, Pina’s SLP remarked, “If you are going to force feed, such food is going nowhere, and this food will lead to aspiration and chest infection.”

In consideration to avoid harm created by aspiration, one alternative that was considered was to keep the patient *nil by mouth*. Gina’s nurse noted, “I asked for an SLP assessment. She came to see her … but she remained unsafe, so she advised nil by mouth.” The same nurse subsequently expressed her worries regarding such management, as in deontological duty for care, keeping the patient nil by mouth could lead to problems of viability, thus the consideration for tube-feeding: “She was losing weight, and she still was giving us indication of hunger, looking at you with puppy eyes. We couldn’t leave her in this condition!” (Gina’s nurse)

i. Withholding or withdrawing tube feeding.

Many clinicians appreciated that a palliative strategy involves withholding futile and burdensome treatment as a means to curtail suffering. Rosa's doctor remarked, "The nasogastric tube was decided against because I don't think it would increase either patient longevity or patient comfort."

The timing close to the EOL when feeding should be withdrawn was an argument that was given importance by some clinicians:

> There is a distinction between those that are terminally ill, from those who are still physically robust, even though frail at times, and have swallowing difficulties….In the terminally ill, we at times do stop the feeds, as it is stressing the body more. (Gina's doctor)

One of the practical difficulties related to tube feeding was that once inserted; it would be tough for the relatives to accept its withdrawal even if now deemed futile. Referring to a patient of hers not in the study, Lorenza's nurse remarked on the difficulty to withdraw tube feeding, "Now no, it is too late! It is quite difficult. One of the sisters does at times mention half a word about it to stop tube feeding, but for the others, it is quite difficult."

The difficulty for family members to accept the withdrawal of tube feeding was observed in Berta's case when on admission to SVP this was done as it was considered futile in a dying patient. Bert's son argued against the withdrawal of tube feeding based on values conflict,

> Of course, it made us worried! At one point she was ok, and soon afterwards you are going to tell me that you have stopped everything for her so that she will die off slowly… While for us feeding was important, for the staff it wasn't!

ii. Structured care guidelines and training initiatives.

Many clinicians felt insecure to forego tube feeding, particularly as practice guidelines were non-existent in end-stage dementia care. A clinician in Gina's case said,

> However, we cannot do this and stop feeding via tube! … We do not have any form of guidelines available to help regulate practice in EOL…. As we stand now, you may be accused that you left her to die of hunger!

Other clinicians pointed out the need to set up standards of practice in the form of a paradigm to help regulate EOL care in dementia. Katarin’s nutrition nurse highlighted this issue, “One aspect is to have guidelines, a structured process to aid how to go about the management of swallowing difficulties in dementia.”

Another consequence of the absence of EOL care guidelines was the observation that different teams in the case studies opted to use different care strategies for the management of swallowing difficulties in end-stage dementia. Some teams favoured a quality EOL approach to avoid burdensome futile care. Rosa’s Doctor said, “Letting the patient feed as much as she can by mouth, with some risk of aspiration, was for me a very valid option, because it is a palliative approach that best suits the case.” On the other hand, other clinical teams gave value to prolong life by avoiding starvation. Gina’s nurse explained their decision why NG tube feeding was started, “Time was passing, the patient was not getting any better; she developed some bed sores; she was losing weight, and she was still giving us an indication of hunger….We could not leave her in this condition!”

Having evidence-based practice guidelines that cover sensitive and complex issues in the care of vulnerable people was found helpful in decision-making: “It is evidence-based because you try to give them the best care.” (Rosa’s SLP)

Furthermore, one clinician pointed out the issue that clinicians require formal training in communication skills to be better able to interact with patients and their relatives. Berta’s nutrition nurse stated, “Health professionals are not confident to communicate with the relatives …we do much training on various things but not on communication skills.”

Most clinicians remarked on the need for palliative care training in dementia. Such education should also concern the relatives in order for them to better grasp the problems at hand in care choices in the EOL. Katarin's nurse said, "I believe in a better education regarding palliative care. This is needy even more for the relatives who are not knowledgeable enough on care for those who are near to dying."

iii. Institutional factors.

The data showed that institutional factors / ward care practices held an important influence on decision-making to manage swallowing difficulties in end-stage dementia.

Proper staff levels of experienced carers were deemed of fundamental importance in managing oral feeding in swallowing difficulties. Rosa's nurse pointed out, "You need good staffing levels and having staff that is competent, because if you do not have enough staff, how can you in such absence provide good feeding for persons who need additional time to be fed?"

One of the points that came to attention was the impression that not enough care time was being provided at the bed-side to patients to permit adequate safe oral intake in the face of swallowing difficulties. Such lack of sufficient attention during feeding time was one factor that could tilt the balance for or against tube feeding. Lorenza's daughter remarked, "They have a lot of patients to take care of; they do not have enough time to dedicate for feeding." Possibly consequential to the above, this daughter had to face the decisional burden to decide regarding tube feeding, "He [the Doctor] wanted from us the decision… of whether we wanted to start tube feeding or not."

The continuity in day to day care was valued as being of importance to develop a good caring bond between individual carers and their patients with dementia. Lorenza's SLP affirmed, "Always using the same staff does help to enable better communication and observation of the patient. If they are able to communicate with the patient's mother tongue, it is even better."

For such reasons, the transfer of patients with end-stage dementia from one ward to another created its problems in continuity of care. Thus Lorenza's daughter argued against the transfer of her mother from a dementia ward to a general ward,

> I noticed a lot of difference between how she was faring in the dementia ward and here, for us and her, the differences were a shock! In fact, in the other ward, she used to know who the others were, their faces - so she was more responsive to her environment…since she came here, she is totally lost.

C. Autonomy.

i. Respecting the patient's past wishes.

Many clinicians gave value to the patient's past wishes for care as an expression to support *autonomy* and control on future care. For instance, Pina's doctor stated, "I believe it is right to consider the past wishes of the patient."

At the same time, clinicians expressed concern that the Maltese legal framework was silent regarding advance directives. Consequently, clinicians felt unsupported to focus care decisions based on the patient's past preferences. Katarin's SLP argued,

> Regarding the past wishes of the patient*?* …They are not legally binding …So we, as professionals, do not feel comfortable to discuss a difficult argument in the absence of a legal framework that could be used as a guide.

At the same time, many clinicians commented on the need for regulation of advance directives in Malta: "For advance directives to work, we need good legal backing to ensure that when the professionals decide to respect the patient's wishes, they are not challenged … by someone else who prefers a different decision." (Pina's SLP)

Some clinicians recommended that all stakeholders should be involved in advance care planning (see also in Chapter, Section 3). Rosa's nutrition nurse remarked, "I always prefer working inside the framework of a team, where you involve all the stakeholders from the very beginning, including advance care planning."

ii. Guardianship.

Clinicians valued the inclusion in the decision-making process of the legally-appointed patient representative to decide on the patient's behalf. However, clinicians reported that most family members steered away from starting proceedings for guardianship. A possible reason behind such disinterest related to in-family conflict: "Guardianship has not gained the necessary application in practice; relatives seem to be afraid to take up the legal role of guardianship, at times because of a dispute between siblings." (Katarin's nutrition nurse)

Also, the process to appoint a guardianship was observed to be a lengthy process and thus ineffective when you need an immediate response from the legally appointed representative. For instance, Berta's doctor said, "The guardianship process takes too long."

D. Justice and rights.

Many clinicians indicated that persons in care retained the right to be provided with the necessary care to meet their current needs. Rosa's SLP commented, "It is very important that the clients have the right care at every stage of dementia."

Some clinicians pointed out that in safeguarding the principle of *justice,* patients with swallowing difficulties should receive a better allocation of resources for them to benefit from proper care during feeding time. Rosa's SLP argued,

> I can't understand why people don't realise why a patient with problem swallowing, needs more time to feed than a normal person without dysphagia….Feeding in persons with dysphagia is a life-threatening situation too. What is the point of spending millions on an MRI scanner if then you cannot feed the person properly?

Another point in terms of justice was brought up by a clinician who pointed out that nasogastric tube feeding causes much discomfort in patients needing tube feeding: "Nasogastric tube seriously affects the lifestyle of the person in care. It is aesthetically ugly…

it causes discomfort and embarrassment." (Katarin's nutrition nurse) However, older people in institutions are given low priority in the waiting list to insert a more comfortable PEG tube, to thus do away from the discomfort created by a nasogastric tube. Gina's nurse argued, "What I would want is that if she were given priority of urgency to insert a PEG …If they give our patients waiting for a PEG an early appointment, it will spell wonders for their QOL."

In conclusion, the principles of beneficence, non-maleficence, autonomy and justice have been observed to give a significant contribution as ethical models in the decision-making process to manage swallowing difficulties in end-stage dementia. However, in the face of the complex difficulties experienced in end-stage dementia care, it was clear that these principles were often seen to be involved in decision-making with other ethical theories and principles, which also needed due consideration and reflection. Furthermore, respondents themselves pointed out the need for a revision of care attitudes and legal constraints concerning these principles, to better safeguard patient dignity and interests in care.

The next theme will consider how the values and principles of sanctity-of-life and QOL interact in the decision-making process to manage swallowing difficulties in end-stage dementia.

6. Theme 4: The debate between sanctity-of-life and quality-of-life

This theme considers the influence of vitalism, sanctity-of-life, and QOL, on the decision-making process to manage swallowing difficulties in end-stage dementia. As mentioned in Theme 3, vitalism, sanctity-of-life and QOL were observed to be ethical models that were closely involved in the deliberation between the two care strategies involved in decision-making, namely prolonging life as opposed to dying with dignity. Furthermore, although the practice of euthanasia is not legal in Malta, this section also considers the influence of euthanasia on the decision-making practices in end-stage dementia.

A. Vitalism.

The insistence on preserving life as an absolute value was noted in the interview responses of both family members and clinicians. Some family members expressed their beliefs that CANH should be provided even in the terminal EOL. Berta's son was adamant about saying, "Feeding was very important, for us food is life! ...They wanted to remove the tube, everything, they wanted to let her die!"

Similarly, one clinician stated their personal belief, which favoured the absolute value of life. Such belief in *vitalism* was reflected in this clinician's management of patients under their care:

> If I were to be in this situation of end-stage dementia, I would say I want to remain alive and praise the Lord ….I would be ready to suffer in bed, but not be ready to kill myself. For me what I do for others, I want for myself.

These absolute ideals for preserving life were found to be related to fears that failing to do so would constitute euthanasia. This same clinician added, "For me doing so [not striving to prolong life] would be choosing euthanasia."

Undercurrents to vitalism seemed to be also rooted in considerations to prevent hunger and avoid starvation based on the conviction that tube feeding constitutes basic care. Katarin's sister-in-law affirmed, "I would agree regarding this tube through the nose, as you cannot let her die without food."

The arguments that favoured life-prolonging measures were also rooted in the fear of death. Berta's nurse noted that, "Everybody is afraid of death."

On the other hand, prolongation of life at all costs was based on the belief that the clinician cannot play God. Berta's SLP remarked, "I would have tried all alternative routes possible for feeding… who am I to decide to stop?"

B. Sanctity-of-life.

What emerged from the interview responses was that in showing respect for human dignity, the decisional framework chosen in respect of sanctity-of-life seemed to vary, and such variance, depended on the perceived closeness of the patient to death.

Such variation in management, depending on the perceived survival that is left, was observed in one of the case studies where the patient was deemed to be stable and not close to dying. In this situation, the dignity-preserving intervention inherent in the principle of sanctity-of-life did support a decision for tube feeding, but with the proviso that this does not incur dignity concerns involving additional burden and suffering:

> There was a chance she might improve. We all wanted her to live longer. However, importantly, we did not want her to suffer, because we didn’t want to prolong her life with the loss of dignity. (Pina’s daughter)

On the other hand, in other situations where the patient was observed to be close to dying, considerations that favoured sanctity-of-life opted for the avoidance of burdensome disproportionate tube feeding intervention and favoured dignity conserving comfort feeding in the EOL. Lorenza’s daughter opted for comfort feeding,

> We the relatives all agreed to let her go with the minimal intervention possible. She cannot communicate at all; in 2 to 3 weeks, she has continued to deteriorate so markedly. We decided that we shouldn’t prolong her suffering just for our egoistic needs to keep her alive, to keep her suffering…. We want her to live and die a peaceful death with dignity, where we let nature take its course.

C. Where sanctity-of-life and quality-of-life interact synergistically together.

In the preservation of dignity in the last phase of life, QOL plays an essential role on the broader perspective to sustain the sanctity-of-life: “You have to avoid using treatments which are futile, burdensome, and which do not contribute to patient well-being ….as I believe in patient comfort and patient dignity.” (Rosa’s doctor)

With the conscious appreciation of the proximity to death, many clinicians followed the principle of sanctity-of-life, where dying with dignity was sustained by giving due consideration to QOL concerns. In such situations, patient vulnerability, poor prognosis, and severe frailty, were given importance to withdraw and avoid futile, burdensome tube feeding in the management of swallowing difficulties. Berta's nutrition nurse remarked,

> I would prefer to leave her in peace and avoid intervention, particularly as her condition is not very good… to show this patient respect in her weak condition. First of all, I do not want to start a very uncomfortable intervention [tube feeding], it is invasive and uncomfortable.

D. Quality-of-life.

Individual clinicians were observed to push forward *quality-of-life* ideals as a primary decisional factor that guided decision-making. One such conviction came from Pina's SLP: "Geriatrics is about QOL!"

From a QOL perspective, tube feeding was believed to be an extraordinary burdensome measure in the EOL. Berta's doctor argued, "[If the tube] is causing a lot of undue discomfort - there it becomes an extraordinary measure - so ethically you can stop such tube feeding."

One of the situations where QOL was used as a yardstick to guide decision-making in end-stage dementia was when certain clinicians argued whether or not life was worth preserving. Pina's nurse argued, "She is now only on NG feeds and water - that are keeping her alive, you might say. What QOL is this? Fed via an NG tube when the patient is unaware of what is happening around her?"

The focus on QOL concerns was also brought up by certain family members as they felt that their kin in care should be spared from unnecessary suffering in their EOL and should instead be left to die in peace without tube feeding. Gina's husband said, "What is the QOL here? … Why live a longer life that has nothing more to offer than more suffering? There is no other argument."

Wherever tube options were deemed inappropriate and also where even thickened food could not ameliorate comfort in swallowing, this left the clinician with very meagre options in management. One possible consideration mentioned in such situations was the administration of fluids through subcutaneous or intravenous drip hydration. However, such parenteral hydration itself created a QOL concern in some clinicians as it only led to prolongation of the dying process. Gina's doctor said, "If it depended on the children, she would have finished with a subcutaneous drip 24 hourly, and in that case, she would have died slowly."

E. When patients refuse to eat in end-of-life care.

One QOL concern considered was where patients showed no interest in food. This was a value question that found conflict between the provision of food as basic care, versus the patient's autonomy in refusing to eat. On this issue, Rosa's SLP pondered such an argument in a hypothetical situation in care. "At the EOL... if they are not hungry, they are not interested in food, and they are having difficulty in eating, and you are so like trying to feed a reluctant person. Why would you want to do that?"

F. Concerns regarding euthanasia.

Respect for life was in some cases, reinforced by deeply held beliefs against euthanasia. Rosa's nurse argued, "The biggest insult to humanity is when a person terminates his life."

A few clinicians commented on the prevalent older generation's beliefs against termination of life and how such beliefs were interpreted in lieu of the management of swallowing difficulties in end-stage dementia. Berta's doctor said, "Today's elderly wouldn't draw up an advance directive stating that if they suffer from dementia and have swallowing problems, they would wish to starve themselves … doing so for them would be choosing euthanasia."

All knowing the lack of EOL practice guidelines in Malta, particularly the lack of regulation to govern withdrawal and withholding feeding, many clinicians expressed a sense of fear in their practice that such action could be interpreted as euthanasia (see also in Chapter, Section 5.B). Katarin's doctor was concerned, "We need EOL guidelines…What are our borders in order not to fall in the trap of euthanasia."

In conclusion, the data showed that the eternal debate between sanctity-of-life and QOL was strongly felt in the six case studies. It was also observed that in some responses vitalism was given centrality in decision-making. While none of the respondents expressed themselves openly in favour of euthanasia, maybe because it is not legal in Malta, at the same time it was observed that some clinicians felt fearful of practising in its shadow, particularly as clinical practice was still lacking clear EOL guidelines in end-stage dementia care.

The next theme will consider virtue theory as utilised by clinicians and family members in decision-making, in a drive to provide the person with dementia with optimal care.

7. Theme 5: Virtue Ethics as an Ethical Framework to promote Optimal Care

This theme of *virtue* ethics brings to light what attitudes and dispositions were valued by clinicians and family members to help promote optimal care to patients suffering from swallowing difficulties in end-stage dementia. To this aim, persons in care are thus spared from being exposed to extremes in care: be it burdensome futile treatment in one extreme view, as opposed to letting go, without consideration for life and dying with dignity, at the other extreme of the spectrum.

A. Ethical virtues involved in the decision-making process.

Clinicians were observed to be making use of several virtues that led to an ethically sound decision. These virtues included prudence, compassion, wisdom, courage, patience, humility, character and care.

Prudence is a virtue in decision-making that had profound meaning in decision-making, and in so doing dignity was safeguarded: "It has been a long time since I have seen a patient tied up and restrained so as not to be able to pull out the nasogastric tube." (Katarin's SLP)

The virtue of prudence also promoted a practice of trying to do what was right for the patient at that moment in time.

When the patient in dementia was not in the terminal phase of life and prognosis was not bad, wherever swallowing was severely affected, tube feeding was considered as a viable invasive alternative that helped meet the patient's nutritional needs and promote recovery. Pina's consultant said, "This patient had problems with unsafe swallowing difficulties … if you decide to insert a nasogastric tube for nutrition purposes, in such instances, the patient is being subjected to this invasive intervention only if she has the chance to improve."

On the other hand, where the situation of the patient in end-stage dementia was considered poor and close to the EOL, the virtue of prudence favoured the avoidance of futile, burdensome treatment. Berta's nurse concluded, "The patient's condition was very poor…we who saw the state of the patient saw that she would not gain [from tube feeding] in this state, in other words, what aggressive input we do, is futile."

Compassionate care at the EOL gave value towards maintaining patient comfort in acceptance of an element of some risk in oral feeding. Gina's SLP showed *character* by saying that in the EOL,

> Many prefer feeding at risk because if you tell them not to feed as it is risky, for them, it does not make sense to avoid food altogether. Even my professional opinion is to go for oral feeding in the EOL.

To this end, the use of *wisdom*, in giving attention to experience, knowledge, and good judgement, helped ensure that care was of benefit to meet the patient's current needs: "Every case has its ins and outs. Moreover, this is a question of experience and wisdom." (Rosa's doctor)

In the application of the virtue of *courage,* some stakeholders stood up to make known their diverse beliefs on management as they contrasted with the views of the rest of the multidisciplinary team: "When we discussed the issue between the professionals I expressed my personal views to avoid aggressive care in view of her poor condition." (A clinician in Gina's care)

The virtue of *patience* was observed to be widely applied in the case studies. This was because giving time for treatment to work is symptomatic of good medical care. For instance, Rosa's doctor said, "The problem has culminated recently following the development of a chest infection…it was decided that she cannot take anything orally. So then we decided to wait to see if this was a temporary or long-term situation."

In other situations, the virtue of *humility* helped to define realistic objectives: "Dysphagia is commonly a first line marker that you are coming to a terminal stage…part of my role is to walk hand in hand with nature I cannot stop it, even if I wanted to. I am just trying to make sure that the person has a sort of more comfortable journey" (Rosa's SLP)

On the other hand, upholding the virtue of *care* and *character* in end-stage dementia favoured clinical practice that enabled the administration of optimal care to meet the patient's current needs:

> We gave the patient the attention, the importance she merited from the outset. So we didn't leave her long without a decision or nil by mouth for long, she

> recuperated earlier on… what you are doing is being done for the benefit of the patient. (Lorenza's nurse)

B. Virtue theory and finding a balance in care decision-making.

Conflicting care strategies and disputed values burdened management of swallowing difficulties in end-stage dementia. In order to understand this diversity in care approaches, there is the need to carry out a clinical and ethical appraisal of what constitutes proper balanced care. For instance, Gina's nutrition nurse remarked, "The dilemma is, where do you stop and where do you proceed, where do you withhold the tube, and where do you insert it?"

A balanced approach to care necessitated an intervention where the focus was to meet the patient's true needs, and an appreciation of the patient's reaction to treatment to avoid excessive burden. Pina's doctor remarked.

> If we decide to insert a nasogastric tube for nutrition purposes and administration of medications; we would then be doing this for the primary aim to improve the patient's situation….now if the patient were to start to repeatedly try to forcefully remove the tube, I suggested that we should revise the treatment strategy.

The importance of inclusion of all concerned to address treatment options and analyse together all possible outcomes was one issue that helped find a balanced decision: "I would always promote that such decisions regarding the management of swallowing difficulties should be taken by all involved and the relatives properly informed." (Pina's SLP)

The development of a *trusting* relationship between clinicians and family members depended on the exchange of views and ideas between all parties. Katarin's sister-in-law reasoned out, "They do tell me some things about her, I tell them you know what to do, I am not knowledgeable you know…I trust the staff a lot."

In those instances where different stakeholders held strong contrasting views of what should constitute proper care, a disposition for all to agree on a trial plan of care helped in the development of an agreed plan of care: “At times even doing a trial period of intervention can be of help to get the relatives on board.” (Pina’s nutrition nurse)

Moreover, in the presence of doubt regarding care, it was observed that better management related to taking decisions in favour of care options that invoked the least risk for the patient. Berta’s nutrition nurse argued,

> For me to insert a nasogastric tube involves risk, I would probably have gone first to wait for the patient to improve so I would leave her temporarily on subcutaneous or intravenous hydration and later on go for a RIG or PEG, an option which has less risk once it is done.

The application of the virtue of wisdom and experience in care helped clinicians to move away from a rigid technical decision, to instead follow a more flexible approach to care. For instance, Katarin’s SLP recalled, “When I started working at SVP, I used to take the safest option, but with time I started to get to know better my patients, and I started to risk a bit more.”

In conclusion to this chapter, it was evident that in many instances the attitudes and dispositions of character that were observed in clinicians and family members strongly influenced the decision-process towards a balanced decision that safeguarded human dignity and interests in care. These dispositions and values are captured in virtue theory.

The next theme will consider the involvement of paternalism and deontology in the decision-making process to manage swallowing difficulties in end-stage dementia.

8. Theme 6: Paternalism and Deontology

This theme considers the influence of paternalism and a deontological approach in team decision-making in end-stage dementia.

A. Paternalism.

The study findings indicated a common situation where a *paternalistic* approach left a significant deleterious impact upon the patient’s autonomy to sustain control on their EOL, in the sense that in early dementia, patients were denied the veracity of their diagnosis and thus could not declare their care preferences for their EOL. For instance, Berta's son stated, "I never talked with my mum about this" (see also in Chapter, Section 3.A.ii).

In isolated situations, doctors admitted that they took decisions in end-stage dementia in a paternalistic manner without consulting family members. Gina's doctor said, "This patient was due for surgical intervention in the form of a PEG … At that time, we didn't discuss the issue with the children, I admit we were a bit paternalistic in this."

In such situations, the said doctors made it clear that such paternalistic decisions were taken in the patient's best interests. Gina's doctor stated, "I try to put the interests of the patient first."

One consequence of paternalistic approaches was that the decision-making process ended up leaving out other stakeholders (including other clinicians and family members) from being involved in the decision process. The phenomenon of *forgotten stakeholders* adversely affected the decision-making process, leading to frustration and fragmentation in the decision taken. Faced by such exclusion, Berta's nutrition nurse remarked,

> When you meet the relatives all stakeholders should be involved, so that at least you avoid double work, as you avoid going back to revise a decision once again through another grand meeting involving all those persons.

Such frustration arising from paternalistic approaches was also appreciated in relatives who were excluded from the decision taken, leading to avoidable friction. Berta's nurse recalled,

> The ward doctor decided that it would be best not to insert a nasogastric tube ... [Later] a relative came to see the patient who asked, 'Why?' … She was not very happy with the decision that was taken.

At the same time, many clinicians were aware of the problems created by a paternalistic attitude and to this end, explained their views how to promote shared decision-making process involving all stakeholders. For instance, Rosa's consultant remarked, "I feel that my role in the decision process is not to be paternalistic, I think my role ….in this case as the lead person is to guide the process and help lay the cards on the table for all in the multidisciplinary team."

B. Deontology.

Deontological theory is a model of decision-making that denotes a way of providing care that is based on duty, in conformity of a set of rules (see also in Chapter, Sections 3 & 5).

A number of responses indicated the obligation in care to avoid suffering and promote dignity in the EOL. Pina's daughter stated, "We did not want her to suffer, because we did not want to prolong her life with the loss of dignity."

The provision of good conduct through proper care in the management of swallowing difficulties did most often concern the issue of safety. Such concern for safety was particularly observed in responses originating from the speech therapists' profession. Berta's SLP highlighted, "Always the safety of the patient wins."

On the other hand, it was evident that the nurses felt a profound responsibility to provide comfort and nutrition to their patients. Pina's nurse stated, "You try to keep them comfortable, even though in patients like this, they do not know what is happening around them, and they might not even appreciate the issue of hunger in this state, we still try to feed them."

In a deontological approach, many clinicians and family members appreciated the moral duty to safeguard the patients' preferences for care. Katarin's nurse remarked,

> When she was at times lucid, she always wanted food that she used to eat at home … I gave out orders that during the night absolutely no bread is given, but during the day yes (we do give it) as she is in a sitting position, more safe and less risk to aspirate.

One limitation in the provision of a deontological approach was that in obeying rigid institutional rules, this left little leeway to adapt care to meet the patient’s needs in their EOL. A clinician in Gina’s care remarked,

> The aim is to prolong life, despite suffering, no other way to go about it. Once she is in an institution, you have to follow the institution’s rules, and if you do not do it, you are inviting trouble. At present, the guiding line is to continue till the end, if necessary, pass another tube, and another tube….this to me is not life.

In some cases, it was observed that doing one’s duty in care took a restricted profession orientated view-point to care. The interviews indicated that this often followed a pattern of a duality that characteristically took the form of somebody giving orders in decision-making, at times paternalistically; while on the other hand, others obeyed these same orders through a deontology duty bound perspective. Pina’s SLP had this to say regarding this phenomenon,

> Our role as SLP is to assess safety in swallowing. In my opinion, the decision regarding the commencement of enteral feeding …should fall in the responsibility of the medical profession.

Similar reasoning regarding a duty-bound approach to obeying orders in the decision-making process was also noted in nurses. Rosa’s nurse manager said regarding the decision for or against tube feeding the patient, “We the nurses would not even bring this argument forward for consideration, as the decision is that of the consultant and speech therapist between them. Still, wherever I feel that I need to pass a comment, I do so.”

Such compartmentalisation and fragmentation in decision-making led to a situation where certain stakeholders in the team felt alienated from a holistic approach to the decision-making process:

> Our aim as SLP’s is not to promote tube feeding as a first choice but to enable where possible the patient to restart feeding by mouth. So honestly I was not very

> happy when they told me that the patient was going to be fed via a nasogastric tube… If I was involved, I could have brought forward certain issues that could have been included in the discussion. (Pina's SLP)

Furthermore, fragmentation in team decision-making may have sidelined attention away from considerations that related to values and beliefs conflict within the team and / or relatives. Consequently, considerations of conscientious objection seemed to have remained unaddressed during the decision-making process. A clinician remarked,

> I am going to tell you the truth. We are supposed to be there to help improve QOL and extend life; there is no QOL here! This, to me, is not life. But, we cannot do this and stop feeding via a tube. However, this is personal and something else.

In conclusion to this theme, it was evident that in some of the case studies, deontology and paternalism were present and at times linked in the mechanics of team decision-making. One of the problems faced in a deontological approach, as opposed to consensus-building approach (see in Chapter, Section 10), was the compartmentalisation of duties which seemed to hinder interaction between stakeholders in seeking agreement as a team in decision-making. The fact that in many case studies, the phenomenon of the forgotten stakeholder was a common finding, this in itself served to significantly impair the quest for agreement in decision-making, leading to frustration and unbalanced decisions.

The next theme highlights the use of another ethical model of decision-making, namely that of the patient's best interests, which holds a high legal esteem in the face of the vulnerability caused by cognitive decline. However, this patient vulnerability, in the face of deficient regulation of care in end-stage dementia (see in Chapter, Section 5), did seem to expose the patient to different interpretations of what constitutes best interests.

9. Theme 7: Patient's Best interests judgement

This theme considers those interview responses that promoted *best interests judgement*. Reflection is given to what motivated family members and clinicians to seemingly challenge the centrality of the patient in best interests decision-making.

A. The centrality of the patient in best interests decision-making.

Safeguarding patient's best interests required that the person in care be put in the centre of the decision-making process. Lorenza's nurse said in terms of beneficence and non-maleficence, "When we take a decision we agree together to take it in the best interests of the patient, we don't decide the easiest way out, pass a tube with all the subsequent consequences, operation etc."

Relatives also considered patient's best interests judgement as a fundamental decision-making process. Rosa's son claimed that, "In the decision taken, the best way for my mother prevails."

At the same time, family members did promote patients' best interests decision-making by bearing witness to the patients' dignity in respect of their values, beliefs and past expressed preferences for care. For example, Lorenza's daughter shared this knowledge with clinicians by stating, "Yes she did express the wish to die, especially when she was admitted her, you know in the past my mother was a vain person… We want her to live and die peacefully, die a peaceful death with dignity."

Furthermore, a constant reappraisal of the patient's needs was kept in progress to safeguard the patient's ongoing best interests. Katarin's SLP remarked, "We followed up the feeding recommendations to see what is best for her."

At the same time, decisions taken to safeguard the patient's best interests involved all stakeholders in consideration of the risks and benefits of care options. For instance, Lorenza's doctor pointed out, "We decided to involve her relatives in the decision regarding the options to either go for comfort feeding or else go for a nasogastric tube or another form of enteral feeding like a PEG or RIG."

In so doing, many stakeholders did appreciate that patient's best interests in end-stage dementia amounted to a palliative approach. Lorenza's daughter stated, "With the doctor, we all agreed, to let her go with the minimal intervention possible …we decided that we shouldn't prolong her suffering."

B. Challenges to a patient-centred approach.

It is an accepted ethical concept that best interests in decision-making seek out to define the best course of action for the person in care, and in so doing, the patient's dignity is safeguarded. However, in addressing the application of a best interests approach in the patients involved in this research, the fundamental ethical query that needed reflection was if the patients' best interests retained central consideration in the decisional process? Gina's nutrition nurse remarked, "When we speak of what is best, the question is, what is best for whom? It could be we are not seeking the best for our patients but what is best for us, where for us I mean the staff or the relatives."

i. Different interpretations of best interests by clinicians and relatives.

The relatives' responses in the interviews showed that the close bond to their family members in care was so strong that at times, it seemed to distort the centrality of the patient in the decision-making process. Such emotional expression led to decisions that challenged the concept of patient's best interests judgement.

One such example was that in end-stage dementia, instead of promoting a plan for a dignified death, relatives' intervention, out of love, fear of loss, and in a desperate measure to prolong life, pushed care decision-making in favour of the administration of tube-feeding. A move which many consider as being disproportionate care in the EOL (see also in Chapter, Sections 3, 4, 5.A, 5.B & 6). Pina's daughter remarked, "If I know that I would enjoy her more in my life by keeping her alive with tube feeding, I would suggest to a friend to give consent for it….in all this when you face disaster you try to grasp to anything that could offer hope!” Subsequently, at the end of the interview, Pina’s daughter said with a tear in her eye, “If she passes away, I wouldn’t be able to tell her I love her!”

Another challenge to the centrality of the patient in best interests judgement related to values-dispute between family members and clinicians on what constitutes proper management of swallowing difficulties in end-stage dementia. Such confrontation related to situations where family members insisted on feeding their relatives with dementia unsafe-to-swallow, yet pleasurable to ingest, food/liquid formats. Such food choices however placed involved patients at increased risk of choking hazard and aspiration. In such divergence of opinion regarding what constituted proper managmeent, one queried what could stand out to be a virtuous balanced approach to care that sustains the centrality of the patient’s true current needs and values in a best interests approach to care?

Looking at reasons behind such divergence in what constitutes proper managment, it was observed that at the root of such dispute in care, between family members and clinicians, was a different perception of how close was the patient to their EOL.

When the patient was close to dying, such dispute was observed to be non-existent. In fact, clinicians in terminal care were more accepting of a QOL approach in the management of swallowing difficulties; this led clinicians to be more lenient regarding food consistency choices in the EOL. Katarin’s nutrition nurse remarked, “When the patient’s condition is not so good, sincerely, I do not like to make a crusade about it [safety].”

The problem became controversial when relatively stable patients with swallowing difficulties were fed by relatives unsafe-to-swallow formats of food/liquid consistency. Rosa’s SLP pointed out, “You do not want to create an aspiration that will perhaps create a situation where breathing becomes more difficult. … Wherever aspiration occurs, it increases the risk of her step-wise deterioration.”

In such situations where the patient was stable and not close to dying, clinicians considered that it was in the best interests of their patients, to provide food that was safe to swallow. Berta's SLP said, "My concern remains always the safety of the patient…I look at the relative's needs, but safety always wins, because that is always the patient's best interests."

However, at times, this became problematic to the patient's response, as the patients themselves were not always compliant to abide to eat only safe to swallow food/liquids. Such lack of patient compliance created an ethical dilemma to decide between, abiding with the patient's current wishes in a situation where their judgement and insight was poor in view of dementia, as opposed to measures in terms of non-maleficence to avoid food of a consistency that was unsafe to swallow. Katarin's SLP said in the patient's best interests, "She becomes at times somewhat agitated insisting for bread, this creates an increased risk of coughing, and she could also choke. So I had decided that it would be best for her that she takes puree type food consistency for safety reasons."

In situations of conflict of ideas for feeding in relatively stable patients, a number of clinicians lamented that despite approaching relatives to bring food to the patient that is safe to swallow, they at times encountered family members who defied expert SLP opinion and instead fed patients food that put them at increased risk of choking or aspiration. This approach of divergence of opinion between clinicians and family members regarding food choices and consistency was witnessed in many patients at SVP by the nutrition nurse who pointed out, "[After explaining the situation], relatives continue forcefully to give her [the patient] whatever she wants saying, '*Miskina* [poor lady], what life does she have left!'" According to Katarin's nutrition nurse, "This is a common situation of care at SVP."

Clinicians recognised that such unsafe behaviour in feeding by certain relatives did involve conflicting ethical interpretation of what constitutes patient's best interests. In fact, whilst clinicians gave stronger appreciation of diminution of risk and the promotion of safety in feeding; this contrasted with the patient's /relatives' wishes to pursue pleasurable food choices. Such values dispute involved conflicting ethical consideration in terms of beneficence and non-maleficence in carers, as opposed to autonomy, beneficence and QOL in patients and relatives. All in a situation where relatives were often poorly informed of the patient's situation:

> We do often meet with situations where relatives insist on feeding the patient with swallowing difficulties, whichever food they bring from home… Some do it out of inadequate knowledge or ignorance … maybe they are thinking that by so doing they are improving the QOL of their relative, while at the same time, they do not appreciate the risk. (Pina's SLP)

In some situations, there was also evidence of conflicting values of what constitutes patient's best interests among the relatives themselves (see also in Chapter, Section 4):

> At times I notice that the relatives do seem to be considering more their interests rather than those of the patient. This is particularly evident when there is litigation between the siblings of the patient in care… [In such situations] the patient's best interests suffers. (Rosa's nutrition nurse)

Further to the above, wherever there was lacking an identifiable legally appointed surrogate, the situation became even more complicated as in such situations clinicians were bombarded by conflicting ideas from different family members, who all wanted to have a say in decision-making. Katarin's sister-in-law remarked,

> I informed all her close relatives living abroad on the deterioration of her condition. Some told me, 'Tell them to give her whatever she wishes, to satisfy her wishes in the last period of life, safe or not.'...While others told me to do what is best and safe for her.

In such cases, finding the right balance to define what was in the best interests for the patient in the management of swallowing difficulties in end-stage dementia was not easy:

"Safety in swallowing is the most important, and also QOL... it is not an easy decision to take and difficult to find the right balance." (Rosa's SLP)

ii. Clinicians' reaction to safeguard their interests in care.

Over the years, the diversity in views between relatives and clinicians regarding the management of swallowing difficulties in dementia has created considerable tension in staff members working in institutions:

> I remember one particular case where the patient was not recommended to take some particular food texture as it put him at risk, but the relative wanted to bring him all types of food. Her opinion was that if her family member in care were to die, he should die happy! …Staff members who were feeding him by mouth were very afraid that he would choke… But, the relative could not understand the situation. (Katarin's SLP)

The study findings showed that family members did generally manage to build a trusting relationship with clinicians (see in Chapter, Sections 4, 7 & 10).

On the other hand, there were certain instances where clinicians, under pressure from relatives, they ended up satisfying what the relatives wanted. Such propensity to satisfy relatives' wishes led to a situation that questioned if the patient's best interests retained centrality in care decision-making:

> She had an advanced form of dementia: she had pressure sores; she was in severe pain; was ultra frail; contractures; skin and bones only; she was febrile … In the face of the forceful insistence of the relatives, in this case, I believe that even with an advance directive, we would have introduced nasogastric tube feeding just the same. (A clinician)

Given the great difficulty to align dissenting relatives, to feed their family members in care, safe to swallow food choices, individual team members reacted to this situation by asking such relatives to fill out a disclaimer form in a move to shift the onus of responsibility of compromised patient safety on these same relatives. Katarin's nutrition nurse explained,

> If there is a relative who continues forcefully insisting to give her whatever she wants, we have a disclaimer form where the relative signs that she will be taking the responsibility. Food in such cases should be brought by the family member herself, she has to feed it to the patient herself, and the left-overs should be taken back by the family member herself. So the relative is taking the risk herself.

Data showed that many clinicians involved in doing hands-on feeding of patients, were in favour in the use of this disclaimer form as a means to detach themselves from the unsafe practices in feeding insisted upon by the relatives and thus be safeguarded. Such a form had been filled out by the respective family members in one of the six cases studied. A clinician interviewed in this case said,

> In this case, we also had their written consent [the disclaimer form] of when they bring food ….I do believe in the consent forms particularly when the relatives bring food for the patient from home so that we the professionals would be safe and safeguarded.

On the other hand, the application of this disclaimer form was observed to be questioned by other clinicians interviewed - because it was neither in the patient's best interests nor did it safeguard the integrity of clinicians and that of the caring institution. One such SLP remarked that,

> When these do happen [the disclaimer form] in most cases, they are going against the medical opinion to provide safer forms of feeding, and you are thus exposing the patient to additional harm. Finally, the responsibility falls on your lap just the same. The institution would suffer a bad name because it is to the institution that the complaint or litigation is addressed to.

One doctor protested, “I was never asked to fill up such a disclaimer form for any of my patients. This disclaimer form poses strong ethical and legal implications on those delivering care to vulnerable patients under their care.”

Some clinicians drew up several arguments to explain why there was a need for them to practice in a guarded, defensive manner. One questioned the ethical relationship between employers and employee, namely the difficulty to find the right balance between developing good standards of care as opposed to the trust of employers in their employees,

> We do have problems with our superiors. If for a simple abrasion, they created uproar and a board of enquiry, followed by another board. Just picture yourself what they would do if there is the suspicion that feeding was denied!

More specific, another clinician remarked on the conflict and fear that was experienced in dealing with family members, while at the same time keeping in mind the patient’s best interests. This doctor said,

> The influence of relatives is significant. Because you do not want to do something that you know, the relatives will create problems for you. … At the same time… I try to put the interests of the patient first.

In addition to the above, relatives’ influence on staff was further complicated by fears of legal reprisal. At the same time, there was a conscious appreciation that such appeasement of relatives’ wishes was potentially threatening the patient’s best interests, as an SLP remarked,

> There is fear of relatives, mainly from being sued. So if you keep the relatives happy, the number of complaints is less, so I would appear more agreeable with the relatives. Yes, in this approach, we are not looking first at the interests of the patient.

The above theme has shown that best interests judgement as applied in this scenario of decision-making for persons lacking mental capacity, did expose the flagrant vulnerability of patients with dementia in care, leading to questionable decisions that in the professionals' judgement did not meet and safeguard dignity concerns and patient's best interests.

This raises the importance of a consensus-building approach as an ethical model, where patient's best interests could perhaps be better sought when all stakeholders come together - with all their values, feelings, interests, expertise, and wishes – with the ultimate aim to focus and come to agreement on what could be reasonably be understood as the patient's best interests.

10. Theme 8: Consensus-Building Approach

This theme considers the evidence in the data on the benefits and difficulties in the provision of shared decision-making in dementia care. This is followed by supporting data why team decision-making should follow a *consensus-building approach*. This theme also explores those situations where limitations to this approach became evident, followed by an appraisal of possible contingency ideas to ensure that the patient with dementia remains safeguarded in the decision-process.

A. A team approach to shared decision-making.

Many stakeholders interviewed were in favour of instituting a team approach, where all concerned were involved in the decision-making process leading to an agreed care plan. Katarin's doctor explained, "We work in a multidisciplinary team where we decide together in the team a plan of action … with the relatives being on board."

A team approach amalgamated the various competencies of the different stakeholders involved leading to shared decision-making: "The decision regarding the commencement of enteral feeding is the decision of the team where every professional has his own area of competence." (Pina's SLP)

A team approach promoted a mutual understanding between clinicians and family members in shared decision-making that benefitted the patient in care. Katarin's nurse pointed out, “The relatives are very involved in the management of this patient…They do feel that what is carried out should be done for the good of the patient.”

From the relatives’ perspective, a positive relatives/clinician relationship of trust and communication helped to promote a satisfactory response to the care provided. Rosa’s son remarked, “I do recall that somebody did in the past talk to me about problems with swallowing difficulties and gave me advice. I have full confidence in the doctors and in the care that is provided… the care that is provided here is like the Hilton!”

i. Challenges in team decision-making.

In the approach to decision-making, various teams were noted to work differently. Gina’s nutrition nurse pointed this out,

> Some wards do multidisciplinary team meetings, and others do not do them. You find some who have the opportunity to take and be involved in the decision, while others do not have this opportunity. Certain consultants leave it in the hands of the relatives; certain relatives leave it in the hands of the consultant.

One problem created by lack of uniformity in team decision-making in end-stage dementia, was that of lack in the continuity in care, leading to difficulty in the setting up of an agreed plan of care. Berta’s consultant remarked,

> The first day she was seen by one doctor, while the next day she was seen by another doctor. As the situation is complex and to show how much this situation is difficult with different opinions, the first doctor decided to treat aggressively, the next day the other doctor said, ‘Why so?’ There were no new changes, the patient was in the same condition, and the line of treatment between the two was diametrically opposite.

The breakdown of adequate communication between doctors was also felt in the lack of case discussion between doctors and their consultant, thus leading to problems in the development of a specialist-led plan of care. Berta’s consultant remarked, “The first thing that should have been done is that the doctor attending the patient should have discussed first with the consultant. That is why we are there!"

On the other hand, the interaction between relatives and clinicians in team decision-making was at times discordant and was a reflection of different values of what constitutes the best care strategy (dying with dignity as opposed to prolonging life) to follow in the management of swallowing difficulties in end-stage dementia (see also in Chapter, Sections 3, 5 & 9).

One such example was the discord unveiled in Berta's case study, where Berta's son was totally in favour of tube feeding and expressed his concern when clinicians decided to withdraw tube feeding, "All they offered was that they were going to keep my mum comfortable … they wanted to remove the tube." This relative's view was discordant with the views expressed by the nutrition nurse involved in the same case study, who argued that, "This patient was not at all in good condition. We who saw the state of the patient saw that she would not gain [from tube feeding] in this state."

It is necessary to point out that the discord between relatives and clinicians was not always a matter of clinicians constantly wanting palliation and relatives aiming to prolong life. The dispute observed in Gina's case indicated a reversal of views and values. Gina's husband showed his dissent with the medical opinion when we pushed for comfort EOL care instead of tube feeding,

> They told us they were going to insert a tube. I asked him, 'Why?' The doctor told me that, for example, instead of dying in one month, she would die in two months. For us this would be unnecessary additional torture on her!

In many situations, the root of discord between relatives and clinicians was observed to relate to a lack of communication between stakeholders in decision-making. Lorenza's doctor remarked, "At times we take a decision and then later on the relatives come and tell us, 'Aren't we going to continue feeding her?' This happens mostly in families who are not involved from the start."

In other situations, the relatives/clinician interaction was doomed from the start when decisional stakeholders were not at all ready to agree with care decisions with the other stakeholders. In a generic comment on relatives discord, Pina's nutrition nurse remarked, "Relatives would want to hijack the decision, nearly to the point that they want to decide for everybody."

There was also discord between attending clinicians on what constitutes optimal care for the patient. A clinician said after the patient was started on tube feeding, "We are supposed to be there to help improve QOL and extend life, but I must tell… there is no QOL here, this to me is not life."

B. Consensus-building approach.

i. Consensus-building approach holds the key to converge decisional stakeholders to an agreed plan of care.

Many stakeholders were in favour that decision-making in the management of swallowing difficulties in end-stage dementia should be based on a process that seeks agreement between all parties through a consensus-building approach. Katarin's SLP remarked, "I believe that taking a joint decision, where all are in agreement, is the best way, the middle ground."

Clinicians and relatives remarked that to achieve consensus, the views of all stakeholders need to be given value and be contributory to the decision process. Rosa's SLP stated,

> You do not take the decision on your own; it has to be a team decision because you do not have all the information. You can only help come to decide by giving your perspective of it and coming to a common ground regarding feeding strategy.

However, enabling stakeholders to reach consensus in the management of swallowing difficulties in end-stage dementia involved certain expertise in the process, where decision-making in each case is taken on its own merits: “Keep the team dynamics in line, and be able to negotiate very wisely between all stakeholders to come to a commonly agreed decision that reaches consensus... Every case has its ins and outs. Moreover, this is a question of experience and wisdom” (Rosa’s doctor)

At the same time, clinicians pointed out that a consensus-building approach had to be focused on safeguarding the person’s interests and dignity in EOL care. Lorenza’s SLP remarked that it is,

> Better if all team members and family members were to be present … all aiming to achieve in agreement that the patient is comfortable, nourished as far as possible with all the limitations of the case, take in consideration safety, and in so doing we safeguard the dignity of the person in care.

Furthermore, various responses highlighted the need that relatives had to be involved in the decision-making process. Berta’ nutrition nurse remarked, “If the members of staff appreciate the problem but the relatives are not on board, you will have considerable conflict. So first you must bring all involved on board, so that a decision is taken in agreement.”

The inclusion of relatives in decision-making to reach consensus demanded that they are informed of the various problems related to care, in a way to guide them to contribute to the process based on an informed decision. Rosa’s SLP remarked, “There needs to be a lot more education to the relatives so that they appreciate and understand it and then they realise that they have a role to play in this.”

Moreover, taking decisions through a consensus-building approach ensured that the relatives could bring to the table the patient’s past wishes and values, which information could serve as guidance to develop values-based decision-making. Lorenza’s daughter explained the spirituality that characterised her mother’s life, “She comes from a family of strong Christian values. She was our cornerstone upon which our Christian values were ingrained in us."

Such appreciation of the patient's and relatives' values helped the clinician involved to be better guided in the decision process. Lorenza's daughter added regarding the spirituality that guided the relatives' reasoning for care,

> I told the doctor that we do not want her to suffer any longer; we leave it in the hands of our Lord on what happens from here onwards, she has lived her life, a normal life, she is 83 years old, and she deserves to die in peace.

The spirituality of older people with dementia influenced some clinicians to factor in these religious values in the general consideration to decide for or against life prolongation in swallowing difficulty management in dementia. For instance, Gina's doctor remarked, "I assume that many of these elderly, many of them were practising Catholics, they have the faith not to let themselves die and do respect life."

A consensus-building approach required effective communication and the virtue of patience to enable all stakeholders to inter-relate and come to a collective agreement:

> A number of family members do often resist, asking many questions. The only way how to deal with such problems is with patience and communication, and that is why team meetings should involve all team members and relatives with an ideal to reach consensus. (Katarin's doctor)

One additional benefit of instituting a consensus-building approach to decision-making was that it helped to avoid rushed decisions. In fact, to reach agreement, the decision-making process involved giving the relatives sufficient time to digest the situation and understand better what was happening. Rosa's SLP said,

> It all depends on the approach, and you have to be extremely patient because they are usually quite traumatised and they cannot take in much information. So you

> have to repeat it again and again. I think it is quite natural that they get anxious and stressed, as they cannot take in everything at one go.

Furthermore, a consensus-based decision, although time-consuming, allowed for all stakeholders, time to analyse the situation and consider treatment options as the disease progresses through time. Berta’s nurse remarked, “One of the problems faced is that you need time to digest and get to know them as you face changes in their condition.”

ii. Factors that helped to achieve better consensus in decision-making.

Many respondents in the interviews mentioned several factors that were of help to achieve success in decision-making through a consensus-building approach.

In the quest to achieve consensus between all parties, many clinicians felt that agreement should be first achieved within the clinical team itself before widening the discussion to involve the relatives. Gina’s doctor argued that, “If first, you develop consensus between us the team members on what is the best-agreed way to go forward, then the relatives would be more amenable to accept our team decision.”

Moreover, it was observed that better consensus was reached if the care plan was reasoned out on evidence-based care guidelines, as a means to maximise patient benefit. Rosa’s doctor remarked, “If you give the right picture which is realistic, evidence-based, and based on experience, usually it is quite easy for those involved, to agree.”

iii. Limitations of consensus-building approach and ways to overcome them.

The cardinal argument of a consensus-building approach rests on the assumption that all parties are ready to play by the rules of consensus-building, where everyone is committed to a compromise that all stakeholders could live with. Katarin’s SLP explained the problems that could arise when agreement cannot be reached due to a dissenting party,

> The problem is when you have somebody who insists on holding his opposing decision, and in such cases, the rest will suffer. In many situations, it is one person

> who causes this, who defies team decision-making; this will be enough to break consensus.

Similarly, Berta's nutrition nurse observed that, "People differ and their approach varies, some accept and give an opinion, while others give a decision but do not accept an opinion!"

In the face of such problems to achieve consensus, one important factor that helped to prevent conflict was to invest early in dementia in adequate communication between all stakeholders. The nutrition nurse remarked, "We need meetings, not only when the problem occurs but also a proactive approach where team meetings discuss possible problems that might arise in the future."

Further to this, reaching consensus between stakeholders was better facilitated if the focus rested on reaching an agreement that safeguards the patient's best interests. Rosa's doctor pointed out, "Wherever the relatives might not agree completely you try to arrive at a consensus always keeping the best interests of the patient as your goal… [where] my focus would be to meet the patient's wishes, values, and desires."

It was also suggested that wherever the situation to reach consensus was blocked because of lack of agreement between parties, the intervention of an ethics committee could be an asset to resolve the stalemate and offer solutions that could safeguard the patient's interests and dignity in care. Gina's nutrition nurse remarked,

> I believe there should be created a type of ethics committee that in such complex decision-making situations, this ethics committee is called in to be involved. Moreover, whether it is a consultant, or doctor, or nurse or SLP or nutritionist or whatever, even the relatives, then they would have to abide by their recommendations.

In conclusion, a consensus-building approach was a process that unified relevant ethical values and principles that safeguard patient dignity and interests. At the same time, it motivated all stakeholders to agree about a shared management plan to address swallowing difficulties in end-stage dementia.

11. The Conclusion to the Chapter

The findings showed that the six case studies applied a wide variation of ethical models and values in decision-making to manage swallowing difficulties in end-stage dementia. At the same time, it was striking that in none of the case studies was there evidenced the stakeholders' application of utilitarianism.

Both clinicians and family members involved in decision-making in end-stage dementia were particularly conscious of the patient's lack of decisional capacity in decision-making. At the same time, in most instances, the past wishes were not sought out and utilised in the decision-making process.

In a situation of care where cultural issues did press clinicians to hide serious illness, coupled with the fact that Maltese law remains silent regards advance directives and EOL guidelines in dementia, did all strongly influence clinicians to avoid disclosure to patients of the diagnosis in early dementia. These factors rendered cognitively impaired persons more vulnerable to threats to their autonomy, leading to a situation where the patient's dignity and interests were challenged in end-stage dementia care, by values, ideas of practice and interests that were not their own.

The central clinical and ethical dilemma arising from the study related to the choice between two distinct care strategies in the management of swallowing difficulties in end-stage dementia, namely:

1. Giving value to *prolonging life* through the provision of adequate safe oral nutrition, which often led to consideration for starting tube feeding.
2. The promotion of *dying with dignity* by giving value to a QOL approach, involving comfort mouth feeding and avoiding tube feeding in a palliative approach to EOL care.

Many stakeholders followed a best interests approach in decision-making, where virtue theory helped to define optimal care to safeguard the personhood of the patient. In this approach, it was observed that various ethical models played a significant part in the moral reasoning of the situation in care.

The principles of beneficence and non-maleficence were widely observed to be involved in decision-making, particularly about situations of care where nutrition, safety, and avoiding burdensome futile care in late-stage care were given consideration.

On the other hand, the debate between sanctity-of-life and quality-of-life was frequently observed to hold importance in a dispute of values between stakeholders. In one case study, vitalism was given prime attention as a value, leading to conflict on the true meaning of human existence in late-stage care.

In consideration of a deontological approach to decision-making, it was observed that a number of clinicians sought out a rigid duty-based approach that followed the rules and duties of their particular profession. These age-old practices were further compounded by observed instances of medical paternalism, leading to fragmentation and compromised team decision-making.

On the other hand, many clinicians and relatives involved in the decision-process gave value to a shared decision-making process, leading to agreement in care that safeguarded the patient’s best interests. Many stakeholders expressed a preference for team decision-making through a consensus-building approach, as it is inclusive of all concerned in an honest, collaborative decisional environment of compromise and agreement that safeguards the dignity and best interests of the person in care.

The results of this study showed significant clinical, social, and ethical complexity that is characteristically found in end-stage dementia care, leading to significant challenges to human dignity and multiple conflicts in the relationship between clinicians and family members involved in decision-making.

The next chapter will discuss the findings in corroboration with the literature review. At the same time, the discussion will expand the arguments related to the ethical models of decision-making in such a way to help define solutions to the moral dilemmas that were identified in this situation of care.

Chapter 6: Discussion

1. Introduction

This chapter discusses the research findings as they relate to the research question and relevant literature. Any new contributions to knowledge are explored critically as they relate to ethical models of decision-making in end-stage dementia in Maltese institutions.

The main issues identified are apparent in the world literature but are newly represented here in the context of Malta. The issues are underpinned by a variety of ethical considerations, such as the principles of medical ethics, professional and general virtues, sociological trends and religious beliefs. So in this chapter, I shall:

1. Discuss the issues that are causing tension and relate these both to the world literature while bringing out the Maltese context.
2. Discuss the underpinning ethical [and/or legal] considerations;
3. Deliberate through moral reasoning, which ethical model of decision-making could best be applied in clinical practice to manage swallowing difficulties in end-stage dementia.

2. Factors Influencing Decision-Making in End-Stage Dementia

This section discusses clinical issues, cultural factors, and care attitudes, which, in their complexity, render the identification of appropriate care in end-stage dementia a challenging process.

A. Multi-factorial challenges affecting decision-making in swallowing difficulties.

Many clinicians and relatives commented on the fact that in end-stage dementia, the person in care was in a very poor state of health, leading to a complex situation of care. Clinicians described the clinical features present in end-stage dementia, namely: severe cognitive decline, immobility, contractures, pressure sores, swallowing and feeding difficulties, recurrent chest infections and severe loss of weight. Gillick (2010) too reported that poor medical, functional and cognitive problems are characteristic features of the condition.

The severe frailty in dementia created difficulty for clinicians to decide what treatment strategy to follow in the management of swallowing difficulties. For instance, Katarin's nurse recalled the team's struggle to define what a virtuous decision would be by stating, "What are we going to do about it?" This widely reported indecision concerning what treatment strategy to follow in swallowing difficulties (RCP, 2010) was exacerbated in the Maltese situation where EOL management was not supported by appropriate care guidance regulating end-stage dementia care (*Consensus Document Endcare,* 2018) (see also in Chapter, Section 3).

Likewise, family members were disconcerted by the situation: "She is finished… She does not move, she does not speak, all the time staring blankly in front of her, she cannot swallow!" said Gina's husband. As the analysis showed, relatives were baffled by the swallowing difficulties and its management, both in terms of beneficence, QOL, and virtue in care. These findings confirm Gillick's (2010) observations that decision-makers experience severe difficulty to manage the complex care situation in the management of swallowing problems in the EOL, a problem that was closely felt by family members (Hertogh, 2006).

At the same time, family members found great difficulty to decide care given the emotional challenges faced in EOL decision-making. For instance, Berta's nurse remarked, "It is not easy to mention palliative care for them [the relatives] to let go." Such difficulty in defining what best meets the needs of the patient was reported by Candy et al. (2009), particularly where the role of CANH in end-stage dementia remains of questionable significance (*RCP*, 2010). The document *RCP* added that such difficulty is particularly evident where the patient's past expressed wishes are unknown and thus cannot be utilised as a guideline for end-stage dementia care.

B. Better knowledge, guidelines and values-based decisions.

Many clinicians mentioned the need for appropriate training: "[We need] better education regarding palliative care" said Katarin's nurse. The necessity for further training of clinicians in geriatric care in Malta was mentioned by Formosa (2016). Such training was seen by clinicians in the study as a way of promoting evidence-based practices, which ultimately helps promote agreement between stakeholders in decision-making (Rosa's SLP). This was reflected in the literature as the quest for values-based practice is best done where it is aligned with evidence-based practice (Hughes & Williamson, 2019). Reyna (2008) added that evidence-based care helps to promote quality patient care and also helps the convergence of ideas regarding management.

The study findings showed that family members were poorly informed about problems faced in dementia, thus leading to limited guidance in decision-making: "We do not understand how she came to be in this condition… For us food is life! All they offered was to keep her comfortable" (Berta's son). Innes et al. (2011) too reported that informal carers in Malta were often at a loss to appreciate the intricacies related to dementia and thus suffered from an additional burden in decision-making. Palecek et al. (2010) mentioned one such problem in swallowing difficulty management resulting from diminished communication between clinicians and the family. Palecek et al. explained that when clinicians decide for palliation and thus removal or foregoing tube feeding, many family members should be made aware that such a decision is not a "do-not-feed' order (p. 580), but instead measures will be taken in favour of comfort hand feeding.

Family members themselves requested better information regarding the management of end-stage dementia. Relatives felt that such information was fundamental for them to cope and contribute effectively in the decision-making process: "It would be better if professionals here do give more information of what is happening, the reasons why some things are being done, the future" (Lorenza's daughter). The clinicians sensed this problem: "The people out there think that dementia is solely loss of memory" (Pina's SLP).

These observations highlighted the problem faced by relatives that they are often left ignorant of the medical, cognitive and palliative reality faced in end-stage dementia, including its limited prognosis and care options. The world literature hinted that such situations of lack of family training in EOL care is often related to the lack of structure in EOL management in dementia (Abbey et al., 2007). *Consensus Document Endcare* (2018) remarked that the lack of EOL care guidelines in dementia in Malta effectively leads patients and their relatives to be poorly prepared regarding the management of feeding difficulties in end-stage dementia care.

At the same time, the study findings evidenced the concern that the lack of practice procedures to guide EOL management in dementia made it difficult also for clinicians to take decisions concerning the withholding and withdrawal of futile care. In terms of non-maleficence, Katarin's doctor said, "We need EOL guidelines." Moreover, from a virtue theory perspective, Gina's nutrition nurse called for guidance in the delivery of proportionate care: "The dilemma is where do you stop and where do you proceed, where do you withhold the tube and where do you insert it?" Deguara (2011) too had found that the deficiency in regulatory guidelines for EOL care in Malta created a medico-legal vacuum that strongly weakened decisions to forego futile care.

Also, it was observed that in some instances, the personal values in clinicians took hold over the decisions taken. For instance, in a values-based decision, Gina's doctor stated, "What I do for others, I want for myself." This approach was reported by Abela (2015), who related it to situations that were unregulated by proper EOL care guidelines. This approach placed the person with dementia in a heightened vulnerability state, as there is no guarantee that the physician's beliefs in decision-making reflected the patient's values and wishes for the EOL (Gastmans, 2016).

C. Survival time and co-morbidities as determinants of end-of-life care in dementia.

The difficulty to determine an accurate prognosis in end-stage dementia was observed to be a feature of the complexity in decision-making. Such lack of prognostic accuracy particularly worried clinicians as the determination of survival time was one of the cardinal features that defined a disease process as being a terminal condition and thus invoking palliative management: “You might think she is coming to an end and then she is sort of like restored again.” (Rosa’s SLP) This concern was reflected in the literature as the difficulty experienced in dementia to define an accurate estimation of the survival time is a complicating factor that renders EOL care decision-making a challenging process (*NICE,* 2010, June).

Estimation of survival time in two of the six case studies was complicated further by the presence of significant active co-morbidities: stage five Parkinson’s disease in Gina’s case study; and newly diagnosed multiple myeloma in Pina’s case. In both, there was notable belief in attending clinicians that such co-morbidities should be treated aggressively with disregard to the underlying picture of end-stage dementia. Thus Pina’s doctor said, “As this associated medical problem [multiple myeloma] was potentially reversible and the patient was not eating or drinking at all, we decided to insert a nasogastric tube.” Sampson et al. (2009) too reported that co-morbidities in dementia bear a strong influence on the late life management strategy to be followed by the attending physician, leading to a move away from palliation towards aggressive/curative approaches.

One of the reasons that contributed to an aggressive approach to care in end-stage dementia plus co-morbidities, was that such a move aimed to overcome the despair that was frequently associated to end-stage dementia care: “When you are faced by disaster you try to grasp to anything that could offer hope!” (Pina’s daughter) Dugdale (2010) too found that in highly emotional situations of decision-making, desperate measures were often taken by those involved in a semblance to keep up hope.

On the other hand, such measures for aggressive/curative management in these two patients in study did not seem to leave significant improvement in survival time. In fact, all the patients involved in the six case studies passed away within seven months of deciding to manage swallowing difficulties. Furthermore, five of these six persons (including the two patients where dementia was associated with co-morbidities) passed away within three months of the decision taken. These findings concur with Aminoff and Adunsky's (2006) report that most persons in end-stage dementia in institutional care would eventually die off within six months. Furthermore, the study findings showed that the utilisation of the FAST score 7c + co-morbidities ("Hospice Eligibility Criteria", 2008; Reisberg, 1988) in Maltese patients with dementia having swallowing difficulties seemed to be indicative of an association with a curtailed survival time. These results echoed the findings of Hanrahan et al. (1999) that of the persons with dementia who had reached stage 7c on the FAST score, 71% had passed away within 6 months; with 6 months survival being indicative of the need for a palliative approach to care (Mitchell et al., 2010).

In the present study, it was evident that whether or not associated with significant co-morbidities, end-stage dementia left a decisive effect on the clinical picture leading to a shortened survival time. This statement is based on the survival data of only two case studies where dementia was associated with co-morbidities, in a study total of six. Therefore this finding can only be extrapolated to theory, while extrapolation to the universe has to be done with extreme caution (Gomm et al., 2011).

The findings also highlighted the limitation of effective treatment options in end-stage dementia: "The patient's condition was very poor…she would not gain from tube feeding, what aggressive input we do, is futile" (Gina's nurse, in appreciation of QOL). Indeed, tube feeding in end-stage dementia was considered as burdensome and inappropriate care (Bowker et al., 2006).

D. Socio-cultural factors.

The study findings indicated that socio-cultural factors in their own right rendered decision-making in dementia more complex.

One factor that influenced decision-making in dementia was the quest for prolongation and respect for life. Such respect for life held a strong relationship to the spirituality ingrained in Christian values in the Maltese people: Gina's doctor remarked in sanctity-of-life, "I assume that many of these elderly, many of them were practising Catholics, they have the faith not to let themselves die and do respect life." This phenomenon in decision-making, where measures to prolong life are given primacy based on the beliefs of persons in care, has already been reporteed in Maltese literature (Abela, 2015).

The study findings also highlighted Maltese cultural trends regarding fondness for food. The propensity of relatives for aggressive life-prolonging measures did reflect in measures to push for proper nutrition: Berta's son said in terms of beneficence, "Food is life!" Maltese studies reported that Maltese people like to eat, at times, excessively. The pilot study of the European Health Examination Survey (2010) indicated that Maltese women had the third highest rate of obesity in EU member states (*Food Nutrition Policy*, 2014).

The present study showed that measures taken by the Maltese for aggressive life-prolonging nutrition were also extended to the late stages of life as in end-stage dementia. This pressure to feed was one point of discord between clinicians and relatives in the management of swallowing difficulties:

> There is a mentality in general, amongst relatives that the more a patient eats, the healthier you would be … Yet we know that with advancing dementia, automatically the patient will diminish in the quantity of food eaten (Pina's SLP).

Concerning this Maltese phenomenon, the world literature indicated that the pressure for aggressive nutritional measures was strongly challenged in end-stage dementia care (“Stages Alzheimer-type”, 2011). At the same time, Gordon (2002) pointed out that in order that family members understand the limitations and futility of pushing aggressive nutrition in end-stage dementia, they need to be exposed to a programme of education to help them understand the limitations in end-stage dementia care (see in Chapter, Section 2.B). In so doing, the relatives could thus better understand that weight loss and decreased intake are neither a result of mal-practice nor an element upon which to bear guilt.

It was also observed that for many family members, swallowing difficulties and resulting mal-nutrition gave rise to a deep fear that the patient could end up suffering from hunger and die from starvation. For instance, Pina’s daughter said in terms of beneficence and non-maleficence, “We [the siblings] all agreed about it [tube feeding] … if a person does not eat, you know what happens!” This fear of hunger and starvation in Maltese family members and the associated pressure to start tube feeding in EOL care has already been documented in the literature (*Consensus Document Endcare,* 2018). On the other hand, tube feeding in end-stage dementia is deemed to be a clinical burden that is also futile (*RCP*, 2010). Thus it is a deontological duty on clinicians to pass this information with tact and empathy to family members (Beauchamp & Childress, 2013), leading to appropriate negotiation to help define agreement between stakeholders on a proper EOL care strategy that respects the best interests of the patient in care (Hughes & Baldwin, 2006).

E. Death and dying.

Various stakeholders in the study found it difficult to accept and discuss issues that relate to death and dying. This phenomenon was elicited in the family members’ response regarding their aspirations for their own EOL in similar circumstances to their elders in the study: “Oh my God! What a difficult question, I find great difficulty to answer” (Katarin’s sister-in-law). This difficulty to give attention, earlier in life, to death and dying (*Department* *of Health* [UK], 2008, July) is a situation that was already reported in Maltese literature in relation to dementia care (*Empowering Change,* 2015).

One consideration that was found to be associated with the difficulty to discuss care in the dying phase of life was a fear of death: “Everybody is afraid of death” (Berta’s nurse). Mallia (2017, January 21) suggested that this fear was related to an innate fear of the unknown.

The fear of death and dying appeared to be also linked in the data to the clinicians’ tendency to favour a disproportionate use of aggressive medical intervention in the EOL. The *Consensus Document Endcare* (2018) reported that there exists a drive in some Maltese health professionals to medicalise the natural process of dying through a tendency to utilise invasive procedures that are not only inappropriate and burdensome but also lead to increased morbidity in patient care. This tendency was challenged in the present study by the relatives in at least one case: “They were going to insert a tube. He [the doctor] told me that for example instead of dying in one month she would die in two months. For us, this would be additional torture on her” (Gina’s husband).

One observed manifestation to medicalise the EOL was the common practice to manage hydration issues in swallowing difficulties through the administration of subcutaneous fluids: “In many terminal cases, we give them a drip to keep adequate hydration, when they die they die!” (Berta’s doctor). The use of drip hydration as a standard procedure in EOL care was documented in the *Consensus Document Endcare* (2018), which practice Hertogh (2006) remarked only leads to prolongation of the burden and suffering in the EOL. Still, one must appreciate that as yet there does not exist international consensus on the futility of drip hydration in end-stage dementia care (van der Steen et al., 2014).

On the other hand, some participants in the present study resisted this tendency for aggressive care in the EOL. For instance, Rosa’s SLP stated in terms of beneficence and sanctity-of-life, “Part of my role is to walk hand in hand with nature…I am just trying to make sure that the person has a more comfortable journey" This approach of acceptance of death and dying was documented in the literature, leading to the recommendation in favour of a palliative approach in end-stage dementia care (Emanuel & Scandrett, 2010).

One factor why lay persons tended to stay away from tackling arguments regarding the EOL appeared to be also related to the high level of trust that older patients and relatives have in their attending physician. Gina's doctor remarked regarding the virtue of trust of patients in their physicians, "If the doctor tells you to stand upside down, especially this elderly generation, they do it." The absolute trust in clinicians was found to lead patients and relatives to leave the responsibility of clinical decision-making solely in the hands of their physician (Kuraoka & Nakayama, 2014).

In conclusion to this section, it was observed that the research findings mirrored the literature review with regards to the difficulty in decision-making to manage swallowing difficulties in end-stage dementia. Most notable of which was the considerable variation in decision-making between different case studies: in some cases, there was a preference for measures to prolong life while in other cases primacy was given to dying with dignity. This variance in care choices in the management of swallowing difficulties in end-stage dementia has not been debated in Malta. While these two clinical strategies might seem contradictory, they do underpin the strong values inherent in the Maltese people and the respect aimed to support vulnerable persons in care.

The next section will discuss the study findings of how legal lacunae and medical practices affected patients with dementia, leading to aggravation in their vulnerability. Additional attention is given to how these factors challenged patient rights for the respect of past wishes, leading to a potential threat to human dignity in dementia care.

3. Safeguarding Human Dignity in the Decision-Making Process

This section discusses the research findings as they related to the challenges to human dignity in the face of vulnerability concerns in end-stage dementia care. The arguments of rights, advance directives, dignity concerns in institutions, and advance care planning are considered in separate sub-sections. The section rounds up with examples of good practices that could be of help to improve the respect for human dignity in EOL institutional care.

A. The rights of persons with dementia for proper care.

Many clinicians and relatives acknowledged the approach in deontology to safeguard the rights of persons with dementia for proper care: “It is very important that the clients have the right care at every stage of dementia.” (Rosa’s SLP) This replicated the recommendations in *Nuffield Council Bioethics* (2009) that persons with dementia retain the right for provision of appropriate care that meet their needs as dementia progresses through time.

The research findings also showed that in order for persons with dementia to retain their rights for involvement in EOL decision-making, they need to be allowed to know their diagnosis earlier on in dementia. For instance, Gina’s nurse stated, “This is your body, and you should decide for it, but you need to know beforehand, before losing mental capacity.” This approach mirrored Hughes and Baldwin (2006) who remarked that one of the human rights that needs to be safeguarded in dementia is that patients are allowed to retain a presence in EOL decision-making, through involvement earlier on after diagnosis, in the setting up of current and future care. This approach thus encourages a process where the patient expresses their treatment preferences based on informed consent (Welie, 2010). To do so, the patient’s right for diagnosis needs to be executed (*European Charter Patients*, 2011). Such desirable disclosure of diagnosis goes in line with the recommendations of the Maltese *Mental Health Act* (2012), which safeguards the right of persons with mental disorders for involvement in their diagnosis and care decision-making.

B. Measures in early dementia to safeguard human dignity in end-of-life care.

The themes indicated a prevalent deontological duty by clinicians and family members to respect the human dignity of persons with dementia: “You see the patient as a person. To ensure my safety, I would go for an NG tube, but no …., this is not the right method to work with vulnerable persons, there is their dignity" (Lorenza's SLP). Respect for human dignity is indeed a cornerstone in the delivery of health care (*Nuffield Council Bioethics*, 2009). The need to safeguard dignity in care is particularly relevant in dementia (Kitwood, 1997), where it is fundamental to safeguard the patient's respect as a person (Franklin et al., 2006), through a patient-centred approach to care (Higgs & Gilleard, 2016).

At the same time, it was observed that persons with dementia suffer from vulnerability concerns in EOL decision-making that result from the loss of decisional capacity: "She is finished ... she does not speak … she cannot decide for herself" (Gina's husband). The vulnerability associated to the loss of EOL decision-making capacity in dementia is recognised in the literature (Gastmans, 2016), as loss of decisional capacity renders a crippling insult to their agency, identity and personhood (Welie, 2010).

In the face of this vulnerability, many clinicians and family members pointed out the need that care delivery should safeguard and protect the patient's interests and dignity. For instance: "The aim should be that …we safeguard the dignity of the person in care" (Katarin's SLP). This concern mirrored the views expressed in Gastmans, (2016) as in so doing the personhood of the patient in care is protected.

In order to safeguard dignity in the EOL, some clinicians indicated the need for disclosure of an early diagnosis to patients and their consequent intervention in the planning of care: "Planning [for the EOL] should start … earlier with the diagnosis of dementia. So that the person with dementia herself would be given the possibility to take certain decisions herself" (Pina's SLP). Such findings concur with Panke and Volicer (2002) as patient participation in discussions regarding future treatment options for their EOL ensures that their wishes and values are respected in the late stages of dementia care.

However, it is relevant to mention that advance care planning remains rarely utilised in Maltese clinical practice as a means to respect patient autonomy in decision-making (Caruana-Pulpan & Scerri, 2014).

Furthermore, the present study showed that, despite a general agreement in clinicians to safeguard patient dignity through their involvement in their diagnosis and planning of care, it was quite rare to see clinicians disclose a diagnosis of dementia to the concerned patients. For example, Rosa’s nurse in terms of non-maleficence voiced such concern, “There are doctors who prefer to tell the person even a bad diagnosis, which makes them very sad. It is better to give the message to the relatives.” This phenomenon in Maltese practice was reported by Caruana-Pulpan and Scerri (2014), who correlated this protectiveness to a cultural tendency to hide a grave diagnosis from patients, as in dementia. Of interest are the results of the study by Azzopardi et al. (2017) who found that Maltese cancer patients preferred to be informed about their diagnosis. These study results contrast with the views of relatives who were reported to put pressure on clinicians to hide and spare the patients from devastating news (*Empowering Change,* 2015), even where they have no legal right to do so (Tuckett, 2006). Ultimately, the lack of communication of a dementia diagnosis leads to disrespect and denial of the patient’s autonomy in health decision-making (Kirsch, 2003), constituting paternalistic deception that severely hampers the patient’s right for involvement in the planning of current and future care decisions (Soler, 2005).

As a consequence of the denial of patients of the veracity of their diagnosis early in dementia and the resultant lack of their participation in advance care planning, the data showed a wide prevalence of lack of knowledge among clinicians regarding the patients’ preferences for care in their EOL. Rosa’s SLP was categorical on this, “I have no idea what were the patient’s past wishes, the relatives have never told me.” This observation of lack of awareness of the patient’s wishes, given lack of earlier involvement in the planning of care, was reported in the literature (Scheirton, 2010; Givens, Kiely, Carey, & Mitchell, 2009). One consequence is that such patients are denied their autonomy and are at increased vulnerability to their dignity in decision-making (Gastmans, 2016).

The data showed that one of the possible reasons for the lack of advance care planning with patients and family members was a lacuna in the training of clinicians on how to appropriately communicate with patients: “Health professionals are not confident to communicate with the relatives… we do much training on various things but not on communication skills.” Berta’s nutrition nurse remarked. Poor communication undermines effective interaction between family members and clinicians (“American Heart Association”, 2010) and leads to poor group decision quality (Kolbe & Ross, 2009).

Clinicians also found difficulty with early disclosure of a diagnosis of dementia and subsequent planning because of the lack of guidelines on the relevant procedures. Thus the nutrition nurse described this need to guide practitioners who are often inexperienced in the process: “We need a policy one step after the other …Like a clinical paradigm to guide the process.” Although the *National Dementia Strategy* for Malta (*Empowering Change*, 2015) highlighted in detail the problem areas for intervention to safeguard the interests of patients with dementia and their relatives, this document stopped short of indicating a practical process to guide clinicians how to practice and interact, with patients and relatives, in the various stages of dementia. Thus clinicians remain hesitant in how to pursue advance care planning and lack practice guidelines in the care procedures to follow in end-stage dementia care.

C. Legally unrecognised advance directives: a major handicap in dementia care.

Through the Guardianship Act (2012), patients with dementia retain the right for representation when their mental capacity is lost by the appointment of a guardian. However, the research findings identified a trend that has not been debated before in Malta, as to why many family members shun away from taking up the role of a guardian. None of the six cases under study had a legally appointed guardian. Some clinicians chose to explain this phenomenon. For instance, Berta’s doctor said, “In need of an immediate family response …the guardianship process takes too long.” Also, Katarin’s nutrition nurse remarked, "Guardianship has not gained the necessary application in practice…because of dissent between siblings." The Mental Health Commissioner (J. Cachia, personal communication, January 8, 2019), acknowledged these difficulties and pointed out that resolution for these difficulties could find a solution once the regulatory system would be in a position to appoint public guardians to intervene promptly in situations of urgency and severe family conflict.

Furthermore, the fact that Maltese law does not acknowledge the legality of advance directives rendered many clinicians in severe difficulty to practice EOL decision-making, in an approach that favours discussion of the patients' past wishes:

> Regarding the past wishes of patient*?* … They are not legally binding…So we as professionals do not feel comfortable to discuss a difficult argument in the absence of a legal framework that could be used as a guide. (Katarin's SLP)

The lack of a legal framework to regulate the patient's past wishes in EOL care puts clinicians in difficulty in how to act in such situations (Cassar, 2010). Consequently, clinicians tend to steer away from bringing up such morally charged arguments in the planning of care in dementia (*Consensus Document Endcare*, 2018).

One of the observed consequences of lack of legality to regulate advance directives was that, even where the past wishes were known, the patient's past expressed wishes ended up being disregarded: "I know of cases, where there were patients who had expressed their past wishes re management of swallowing difficulties and …what was decided went in the opposite direction of what the patient would have wanted" (Pina's SLP). Gastmans (2016) remarked that such disregard to the patients' past wishes increased the vulnerability in end-stage dementia care as it constituted disrespect to the patient's values and a denial of the EOL dignity they deserve.

D. Depersonalisation in long-term care.

Some relatives in study commented that care practices in institutions often left an adverse effect on the dignity of the person, particularly in dementia. On this, Lorenza's daughter gave a vivid account of her mother's lived experience and the problems created by the rigid approach to care in institutions,

> In the past my mother was a vain person, she liked to dress beautifully.... after some two years after her diagnosis …. She was being worn baggy dull clothes, her liveliness had gone, and people here are all dressed practically the same, as if they were children in an institution, the loss of that personal touch did put her in a sad state, and I believe she lost her identity.

Hall et al. (2009) suggested that safeguarding of human dignity in institutional care is a fundamental concept about which caring staff can and should do more. Hall added that attending staff can help support patient dignity by maintaining in care a semblance of the person and her identity. Safeguarding personhood could encourage a sense of pride in residents by maintaining a living remembrance of the person they once were.

E. Meeting current needs in care.

A number of clinicians remarked that the dignity of the person in end-stage dementia could be significantly safeguarded if stakeholders in decision-making focus on what are their current needs in care. For example, Pina's doctor said, "When you decide earlier on in life against aggressive treatment for the EOL, you are still healthy, you have in your mind your current style of life. It could be that when you become more disabled, your preferences, needs and views change." This unlocked one major limitation of advance directives in dementia as giving importance to current situation does consider the actual true needs (Wellie,2010), rather than basing everything on their past likes and wishes. In fact, giving importance to the patient's current needs helps to respect the person with dementia as a human being in care (Hughes, 2001). Such focus on current needs can be done through continuous observation of the patient's experience of her clinical condition as she responds to treatment and care (*RCP,* 2010).

In conclusion, the study findings showed that safeguarding the dignity of the person in institutional care was high on the agenda of care of both clinicians and family members. However, more can be done, at legal, clinical, and regulatory levels, to help ensure that such vulnerable patients with dementia remain effectively considered as human beings with their own identity, preferences and values (Franklin et al., 2006).

The next chapter will discuss the often turbulent relationship between clinicians and family members in their respective roles as decision-making stakeholders in end-stage dementia.

4. Family Members’ Involvement in the Decision-Making Process

In this section, consideration is given to the role and difficulties experienced by family members in the decision-making process in end-stage dementia. Further reflection is given to the interaction of family members with clinicians in the decision process, including their views regarding the application of the ethical model of substituted judgement.

A. The important role of the relatives in care.

The research findings showed that the primary intention of family members was to let the patients themselves decide issues regarding their health. However, as a result of cognitive decline, such decisions were taken by family members as surrogates in decision-making. “When she could still talk …the decision would have been hers” Gina’s husband. Torke et al. (2008) documented this pathway of decision-making where, once decision-making capacity is lost, clinicians usually turn to involved family members as surrogates to give testimony of the patient’s values and wishes in care.

The study findings showed that the relatives’ intervention in the care of their kin was strong and consistent: “I have been attending here for three years always feeding her myself” (Rosa’s son). These findings contrast with what Borg Xuereb (2015) had found, namely that relatives’ involvement at SVP was rather weak. Maybe the participants in this study were more involved because such involvement was one of the conditions required for inclusion in the study (see Chapter 4, Section 8). However, the findings showed that wherever family members were involved, their input in the life and care of their elders with swallowing difficulties in end-stage dementia at SVP seemed to be significant, constant and valued by clinicians and family members themselves. However as Farrugia, (2008) remarked, there is room for improvement in the interaction between clinicians and the family at SVP. Thus Katarin's doctor said, "When the patient is in end-stage dementia …you need to talk more with their children to decide care."

Furthermore, family members repeatedly expressed their desire to be involved in the decision-making process of their elders with dementia. For instance, Rosa's son stated, "I feel it is of priority to involve the relatives when they decide to revise her management of swallowing difficulties." Epp (2003) too reported that family members do prefer to be involved in the care of their elders.

Family members' intervention in EOL decision-making in dementia was often found to be the best source of information about the patient's wishes and values. Thus Rosa's son bore witness of his mother's dislike and decision against tube feeding, "I was sure 100% she would pull the feeding tube out." Likewise, in an appraisal of the patient's values, the family was reported to be the prime source of such information. For example, Pina's daughter argued in favour of tube feeding based on knowledge of her mother's values: "My mother loves life so much that she would definitely tell me yes!" Agius (2010) too reported that relatives' intervention often bore witness to the patient's preferences, interests and values as appreciated in the past.

B. Substituted judgement and values-based decision-making.

Substituted judgement was evidenced in two of the six case studies. The first was Katarin's sister-in-law who provided food choices to her kin in swallowing difficulties based on her past preferences: "I used to bring her solid food she likes." On the other hand, Lorenza's daughter, being knowledgeable of her mother's way of thinking to avoid aggressive management in the EOL, had actually found it helpful to decide for non-aggressive treatment, as it was in line with her mother's wishes: "Yes it helped me personally to decide with more conviction, as that was her wish." This framework of reasoning in substituted judgement, where decisions are taken on the basis of what the patient would have wanted for themselves (Gordon & Baker, 2011), does end up giving family members better satisfaction in decisions taken as through this process, the surrogate acts to safeguard the patient's autonomy and dignity (Beauchamp & Childress, 2013).

However, substituted judgement created a conflict of principles and values, including different interpretations of non-maleficence, beneficence, QOL and patient's best interests (see also in Chapter, Section 9.B). Thus while Katarin' kin insisted on solid food to please the likes of her sister-in-law, her SLP argued in a deontological approach for proper care against such risky food choices to satisfy patient's wishes as, "She will be at increased risk of coughing, and she could also choke." Such variance in ideas for care was one example of values-dispute between family members and clinicians, where values do closely relate to interpretations of an individual's morals, beliefs, rights, virtues, a personal appreciation of what constitutes best interests, quality-of-life, safety of the intervention, principles, and decision-making (Woolbridge & Fulford, 2005). Hughes and Williamson (2019) argued that such disputed values need to be acknowledged through values-based practice, which helps define a framework to support decision-making through communication, negotiation and consensus-building. Such an approach leads to a balanced decision, based on evidenced-based practice that respects shared values while maintaining the centrality of the patient's interests in decision-making.

Based on the knowledge gained, substituted judgement could be a helpful model in decision-making as it helps to allay decisional anxiety in family members. At the same time, clinicians need to be trained to utilise their influence in decision-making to guide family members to decide for the patient, based on the patient’s values and wishes (Chun-yan & Tao, 2004).

C. Difficulties faced by family members in decision-making.

The study findings indicated that many family members were emotionally distressed and concerned with the poor health situation of their relatives with dementia. One such response came from Pina’s daughter who seemed traumatised in her difficulty to accept the marked deterioration of her mother’s health and the anticipated fear of her impending death, “If she passes away, what could I tell her, I would not be able to tell her I love her!” Such a touching response to care was reflected in the literature, as many relatives’ responses to push for aggressive feeding in end-stage dementia has to be inferred in a reflection of the emotional bond that exists between Maltese family members and their elders (Satariano et al., 2010).

The emotional turmoil experienced by family members made it also difficult for them to shoulder the decisional burden regarding EOL care. Thus Gina’s husband transferred the responsibility to the clinicians: “Whenever they asked me, I always answered, whatever is best for her, do it!” Scheirton (2010) pointed out that such hesitation in taking responsibility is often symptomatic of the considerable difficulty experienced by family members to decide about the care for their elders with dementia.

The emotionally charged approach by family members to EOL decision-making was noted to leave a major detrimental effect on the wellbeing of relatives, some of whom were found to be already in a state of grief. “I cry at times, and then I come here, my life is here. We used to go out together when she was still healthy, but now what life do I have?” said Gina’s husband. Stress experienced by relatives of patients with dementia in care is a common finding (Gastmans, 2016). At the same time, one must appreciate that in end-stage dementia it is quite common to observe that family members do suffer from anticipatory grief even before their elders pass away with dementia and associated co-morbidities (Pace et al., 2011).

The study findings indicated concern in clinicians to act in support of family members in the decision-making process. One such method proposed was to involve family members earlier on in the decision process through advance care planning. For instance, Pina's SLP remarked, "Through advance care planning, once you know the possible trajectory of the disease, you can plan ahead with the relatives how to meet this challenge." Volicer et al. (2002) remarked that family members would benefit from inclusion in advance care planning in early dementia, as through such involvement, the patient's wishes and values for their EOL would be made known to clinicians and family members alike.

Many clinicians did acknowledge the need to appreciate the relatives' values in the decision-making process. This view was highlighted by Lorenza's doctor: "The relatives have much weight in the decision process as at the end of the day the relatives' values, and thus those of the patient, need to be considered." *Nuffield Council Bioethics* (2009) remarked that wherever the values of the family are included in the decision process, this leads to a better outcome in a holistic approach to safeguard the dignity and interests of the person in care.

The study findings also showed that family members themselves asked for better support from clinicians in decision-making: "It would be better if professionals here do give more information of what is happening, the reasons why some things are being done…This support we did not receive it." (Lorenza's daughter) In fact, the literature supports the need for such assistance as the relatives need better guidance to decide appropriately for the patient in care (Scheirton, 2010). In so doing clinicians in the study pointed out how family members can be guided to focus on the current situation of their elders in care (see in Chapter, Section 3.E). On this argument, Watson et al. (2010) remarked that family members need to be helped to focus on the present and in so doing sideline ideas for care based on the [better] cognitive and functional abilities of the past.

One of the observed consequences of lack of appropriate guidance and support to family members was the struggle in surrogates to accept the current situation of poor health and poor prognosis: “Of course it made us worried! At one point she was ok, and soon afterwards you are going to tell me that you have stopped everything for her so that she will die off slowly.” Berta’s phenomenon of lack of acceptance of the current situation in end-stage dementia was reported in the literature and is often reflective of a diminution of the virtue of trust of surrogates in clinicians in care (Givens et al., 2009).

In conclusion to this section, the research findings showed that the relationship between clinicians and family members was often found to be challenging and reflective of limited communication, poor support, and disputed-values. Family members were often observed to be markedly distressed, and this reflected both in their decision-making and the relationship of trust that is desired with clinicians in care. To this end, family members need to be adequately supported to enable their active participation in the decision-process to safeguard the dignity and interests of the person in care.

The discord between clinicians and family members in defining proper management in swallowing difficulties did often reflect in a difference in interpretation of what constitutes proper care in terms of beneficence and non-maleficence. The next section to be discussed is the principlism theory; in this section, the various principles are deliberated as they affected the decision-making process in end-stage dementia.

5. Principlism

The principles of beneficence, non-maleficence, autonomy and justice were observed to play a significant part in their application to help resolve conflicting values in decision-making. The main focus concerned the decision taken between two care strategies, namely: to give value to *prolonging life* through various methods of feeding and safety; while the other care strategy concerned measures to promote *dying with dignity* through a QOL approach to the EOL. Reflection on the role of vitalism, sanctity-of-life and QOL in this decisional dilemma will be considered in this Chapter, in Section 6.

A. Beneficence.

i. Safety in swallowing, proper nutrition and quality-of-life.

The principle of beneficence held a strong presence in the decision-making process to manage swallowing difficulties in end-stage dementia. It was interesting to identify that defining patient benefit between the two care strategies of prolonging life as opposed to dying with dignity rested heavily on interplay between three clinical procedures/attitudes [*good nutrition, safety in swallowing* and *avoidance of burdensome futile care*]. It was interesting to observe that all three clinical procedures/attitudes aimed to promote benevolent care for the patient. Katarin's SLP stated the three in one sentence: "The aim should be that the patient is comfortable, nourished as far as possible, taking in consideration safety."

However, synchronising together the three clinical procedures/attitudes to a common care strategy in terms of beneficence in the management of swallowing difficulties in end-stage dementia was far from easy. Hereunder are three situations that elicited such conflict.

- Rosa's SLP mentioned the difficulty to find the right balance between safety in swallowing and avoidance of burdensome futile care in a QOL approach, as the centrality of this balance changed as the patient came closer to the EOL:

> Safety in swallowing is the most important, and also quality-of-life ... Sometimes you might tilt the balance based on the prognosis of the patient…. If you are seeing someone who is coming to an EOL period, you are going to give a more significant weighting to the quality of time left. Moreover, even if there is potential for aspiration in this approach, you try to minimise that as much as possible.

-The second potential source of conflict between these variables in care was observed in circumstances where safety in swallowing jeopardised proper oral nutrition, Gina's SLP stated, “Given the difficulty to initiate swallowing, she would not be taking the required nutrients for the day, because her feeding had to be so slow … [we could not push nutrition as] she was prone to repeat chest infections.” This brought a strong reaction from Gina’s nurse who in a deontological approach for proper feeding, argued for tube feeding by saying, “Time was passing, the patient was not getting any better; she developed some bed sores; she was losing weight, ….We could not leave her in this condition!”

-Thirdly, in the presence of swallowing difficulties, the drive for proper nutrition through tube-feeding did not go hand in hand with a diminution of burden approach. In fact, in opposition to a decision for insertion of a nasogastric tube, Gina’s husband remarked, “They told us they were going to insert a tube…For us this would be additional torture on her.”

To my knowledge, the interplay and influence of these three clinical procedures/attitudes of, proper nutrition, safety in swallowing and avoidance of burdensome futile care, is a new finding in the Maltese literature. “EOL care people” (2008) pointed out that the deliberation of risk and benefit in terms of beneficence is based on multiple factors that relate to how decision-makers interpret prognosis, patient wishes and a medical interpretation of values and QOL. Hughes and Williamson (2019) pointed out that such situations do often involve severe values-conflict, as in opposition to supporters of comfort feeding in the EOL, other stakeholders do favour the commencement of tube feeding, as in their views, denying the patient such proper nutrition amounts to passive euthanasia. Such conflicting values in decision-making have to be considered in the clinical picture where decisions for or against tube feeding in end-stage dementia still defy consensus between experts in the field (Sampson et al., 2009; van der Steen et al., 2014) thus rendering management of such situations ever more difficult.

In the provision of measures to prolong life, it was observed that many responses aimed in deontology and in terms of beneficence to promote the provision of proper *oral nutrition*, while at the same time measures were taken in terms of non-maleficence to diminish the risk of problem swallowing. One feels the pride in the statement made by Rosa's SLP: "This patient would not be here if it weren't for the care that the nursing and care staff are giving her, she has quite severe dysphagia you know!" This echoed the statement in *RCP* (2010) that one of the prime aims of beneficence in care is to preserve life and restore health, with proper feeding being one intervention to ensure this. Walshe and Regan (2017) stated that patients prefer to eat normally by mouth, as this is a good indication of health and QOL. At the same time, Beauchamps and Childress (2013) pointed out that in order to prevent harm and promote good care, management of swallowing difficulties relates closely to the issue of safety (Linzer, 2002).

On the other hand, certain interview responses indicated an approach in accordance with beneficence, where decisions to prolong life in the face of swallowing difficulties favoured the commencement of *tube feeding*, a measure that was done to promote proper nutrition, promote health and as adequate access for drug administration. For instance, Pina's doctors said, "If we decide to insert a nasogastric tube for nutrition purposes and administration of medications; we would then be doing this for the primary aim to improve the patient's situation." This approach followed Gordon's (2002) argument that in certain circumstances, the promotion of proper nutrition in swallowing difficulties may give allowance for the commencement of tube feeding.

One over-arching issue in terms of beneficence that was observed to hold meaning in end-stage dementia was the respect of human dignity: "The right method to work with vulnerable persons is to respect their dignity" (Lorenza's SLP). Such an approach ensures that benevolent care is based on a moral interpretation of what is right for the patient at that particular time to help respect their human dignity ("EOL care people", 2008).

To this end, wherever decisions favoured an approach to safeguard dying with dignity, care interventions in terms of beneficence gave primacy to the appreciation that the EOL was close and thus led to treatment adjustment to promote *palliation*. For instance, Berta's doctor remarked, “In my opinion, in such situations in dementia…what is important is to keep them comfortable, no pain; with a tube she would not be comfortable.” This palliative approach in treatment strategy gives value to respect to the patient’s dignity in the EOL through the diminution of suffering and promoting comfort in feeding (“EOL care people”, 2008).

B. Non-maleficence.

Beauchamp and Childress (2013) wrote that the prime obligation of care in terms of non-maleficence is not to inflict harm. Some such examples of how this principle was applied in the case studies concerning safety in swallowing have already been discussed (see in Chapter, Section 5.A).

One application of this principle did relate to particular interventions that aimed to avoid threats to human dignity in the best interests of vulnerable persons in care. Many stakeholders were in terms of non-maleficence against forced feeding, as actually such action would not only affect the patient’s dignity but would also increase the possibility of choking and aspiration. For instance, Pina’s SLP said, “If you are going to force feed, such food is going nowhere, and thus, this food will lead to aspiration and chest infection.” On this approach, Pasman et al. (2003) argued that although oral feeding and hydration are regarded as basic care, one should not force feed patients with dementia.

Another observed decision related to the principle of non-maleficence was the idea in some clinicians to avoid aggressive care in end-stage dementia (see also in Chapter, Section 2). For instance, Rosa’s doctor stated, “You have to avoid using treatments which are futile, burdensome and which do not contribute to the patient’s wellbeing.” Indeed, Kirsch (2003) remarked that clinicians should help to safeguard the patient’s dignity by avoiding undue pain and suffering. A question which the clinician should always ask is the query if tube feeding could be of harm to the patient (Harstell & Williams, 2010).

In line with the above, the avoidance of futile treatment in accordance with non-maleficence was a line of reasoning that found agreement in stakeholders. However, it was observed that clinicians experienced difficulty in withdrawing care interventions, as is tube feeding, even if such care was deemed to be futile. One such account was that given by Lorenza's nurse in a testimonial of another patient not in the study, "Now no, it is too late! It is quite difficult [to remove the tube]."

The difficulty to withdraw futile tube feeding was also observed in family members. In a values-based account, Berta's son adversely reacted to the withdrawal of tube feeding, arguing that, "For us food is life!" This approach is widely documented in the literature, as withholding and withdrawal of unnecessary treatment are firmly ingrained in the principle of non-maleficence (Beauchamp & Childress, 2013). However, in practice, it is quite difficult to accomplish because of a conflict of values (Bregje et al., 2001).

Apart from an emotional reaction by family members, the challenging experience to withhold/withdraw futile care in Malta was found to be related also to other factors already mentioned earlier in this chapter (see Sections 2.B, 2.D, & 3), namely:

- The lack of Maltese legislation to regularise situations of care regarding withholding and withdrawal of extraordinary treatment. This hampered clinicians to appropriately manage EOL care, of which both Deguara (2010) and Cassar (2013) remarked that foregoing CANH is a relevant example.
- Decisions regarding withholding and withdrawal of treatment are often strongly influenced, in respect of autonomy, by the patient's expressed wishes for inspiration of what to do (Chun-yan & Tao, 2004). This method of decision-making in Maltese medical practice finds a shortfall in the absence of legal backing for advance directives.
- Furthermore, the fact that stakeholders rarely considered planning for the EOL did leave those involved in an eventual EOL without the guidance of the patient's preferences in care (Gastmans, 2016). This phenomenon was epitomised in Berta's son's response when he seemed perplexed to declare personal preferences for his EOL: "About my end of life, I cannot say, I do not know."

A possible means of support, in terms of non-maleficence, that was suggested by a clinician to help decisions related to withholding and withdrawal of futile treatment in institutions was the idea to set up protocols of guidance in care (see in Chapter, Section 2.B) and addressing support in difficult situations through the setting up of an ethics committee. On these issues, the nutrition nurse said, “We need to have guidelines, a structured process to aid how to go about the management of swallowing difficulties in dementia….I believe there should be created a type of ethics committee.” The benefit of regulating EOL care through the support of care guidelines and the mobilisation of ethical support in long-term care is already mentioned in the literature (Schwartz & O’Sullivan Mailliet, 2013). In terms of non-maleficence, such EOL guidelines could be of great help to diminish the risk of negligence (Beauchamp & Childress, 2013). However, here again, Maltese medical practice is severely handicapped given lack of EOL care guidelines (*Consensus Document Endcare*, 2018). In addition, whilst the Maltese Medical Council retains the lawful right to set up “committees for the purpose of enforcing professional and ethical standards applicable to the health care professions” (*Health Care Professions Act*, 2003, p. 8), yet the *Maltese Health Act* (2013) is silent regarding ethics committee to help regulate bedside clinical situations of care, this renders the appointment of ethics committees at a disadvantage as they lack legal backing to operate.

C. Autonomy and authenticity.

The ability for human beings to decide for themselves is an important bioethical principle in EOL care (ten Have, 2010). However, the research findings indicated awareness that the patients involved in the case studies could not do so given cognitive decline associated with dementia: “It is the fault of dementia… For her, this is difficult, as she lacks the insight into what is right or wrong” said Katarin’s nurse. The loss of decisional capacity in end-stage dementia, hands in a severe blow to the person to maintain autonomous control on decisions regarding their health (Welie, 2010). This decisional difficulty is particularly relevant in the management of swallowing difficulties as ideally decisions for or against tube feeding does require informed consent (Druml et al., 2016).

In most case studies, clinicians reported that the patient's past values and wishes were unknown (see in Chapter, Section 3.B). However, there were other instances where family members gave detailed accounts of the patient's preferences, values and life history. For instance, Lorenza's daughter's account was very eloquent,

> She did express the wish to die, especially when she was admitted here, she liked to dress beautifully, she was a very elegant and stylish person, she was very colourful in her dresses… So there were moments when she came here, and she saw herself, after some two years after her diagnosis her liveliness had gone.

Such accounts from the relatives helped to provide all stakeholders with the necessary narrative to implement a more profound reflection in decision-making. This approach to address this situation of lack of autonomy in dementia, could lead to decision-making in *authenticity* (ten Have, 2010), where moral appreciation is done of the fragility and dependence of the person in care (ten Have, 2010), whilst giving importance to the patient's values, life history (Gefenas, 2010), biography and personality (Janssens et al., 1999). This approach in authenticity shows a relationship to the *actual autonomy* promoted by Agich (2003), and that of a "*situated-embodied agent*" (Hughes, 2001, p. 86), where attention is given to the current situation in care, in appreciation of the person's self, identity and biography.

D. Justice.

The research findings indicated problems in connection with justice as they affected the management of swallowing difficulties in end-stage dementia.

Some clinicians showed concern that the provision of feeding time in the face of swallowing difficulties was often found to be inadequate. To this situation, Rosa's SLP reacted in her comment regarding the equitable allocation of resources, "I cannot understand why people do not realise that a patient with problem swallowing, needs more time to feed … What is the point of spending millions on an MRI scanner if then you cannot feed the person properly." This problem of due justice has been already documented in the Maltese literature, where limited feeding time (Brincat, 2008), showed a relationship to poor staffing levels in institutions (Scerri, A. 2015). Such concern underlines a morality at health care policy level where matters regarding provision of appropriate staffing levels (Summers, 2009) find consideration. At the same time, it is widely accepted that swallowing difficulties in dementia, is best managed through careful hand feeding, (*RCP,* 2010) that demands more prolonged feeding time to be effective (Walshe & Regan, 2017).

A second challenge to the principle of justice was that tube-fed persons living in institutions for older people tended to wait too long for an appointment for a PEG insertion. A clinician called out for fairness on this issue: "What I would want is that if she were given priority of urgency to insert a PEG, this would have helped the patient to suffer less, as we all know what the problems of nasogastric tube-feeding are… I know of patients at SVP who have waited for more than a year for a PEG tube to be inserted." It is true that several persons on long-term feeding via a nasogastric tube could be managed more appropriately by insertion of a RIG tube (Chircop, K., November 18, 2017), where the waiting time for insertion is much shorter. However, wherever RIG insertion was technically not possible, the only option left was to wait for a lengthy period for PEG insertion, during which such patients would have to endure the QOL burden of a nasogastric tube that: "Seriously affects the lifestyle of the person in care. It is aesthetically ugly, you have changed the patient's body image, and it causes discomfort and embarrassment." (Katarin's nutrition nurse)

Looking at the number of patients with dementia at SVP being fed via tube feeding at the time of this study, I observed that of the 18 patients with advanced/end-stage dementia being tube fed, half of them were still being fed via a nasogastric tube [NG= 9; PEG = 6; LPG = 3; RIG = 0]. This finding has to be aligned with the recommendations arising from the literature that state that, given the relative discomfort, nasogastric tubes should only be utilised as a short-term method of feeding (Howland, 2009), while for longer periods, PEG tubes are preferred (Byrd, 2004).

In conclusion to this section, it was evident that the four principles of beneficence, non-maleficence, autonomy, and justice played a significant part in the decision-making process in the management of swallowing difficulties in end-stage dementia. In many situations, these principles influenced the decisions to decide between approaches to prolong life as opposed to measures to promote dying with dignity. It was also clear that the various clinical, legal and cultural issues seriously hindered the safeguarding of autonomy in decision-making in end-stage dementia care.

In the next chapter, attention is given to vitalism, sanctity-of-life and QOL, particularly in their role in the decision-making process to evaluate between life-prolonging measures and dying with dignity.

6. An appraisal of how Vitalism, Sanctity-of-Life and Quality-of-Life influence Decision-Making in End-Stage Dementia

This section focuses on vitalism, sanctity-of-life and QOL, as they impinge on decision-making to manage swallowing difficulties in end-stage dementia. Particular attention is given to the views expressed by interview respondents concerning resolution of the clinical decisional dilemma between measures taken to prolong life versus a palliative approach that favours dying with dignity. At the end of the section, a reflection is done on how clinicians in the study were influenced in decision-making by the overbearing shadow of euthanasia, which is not legally practised in Malta.

A. The connection of vitalism to prolonging life through tube feeding.

Some clinicians and family members in the study gave primacy to the absolute respect for life and consequently carried out measures that favoured the prolongation of life in end-stage dementia care. Such approach was done from the viewpoint of the religious beliefs of the Maltese people for respect for life. For instance, a clinician said in vitalism and respect for life,

> If I were to be in this situation of end-stage dementia, I would say I want to remain alive… I assume that many of these elderly, many of them were practising Catholics, they have the faith not to let themselves die and do respect life.

Likewise, Berta's son remarked in terms of beneficence and vitalism, "Feeding was very important, for us food is life!!" Hollinger (2003) pointed out that keeping a person alive at all costs equates to vitalism, where life is of supreme value and cannot be curtailed (Keown, 2015).

The above interview response given by this clinician in study did direct a vitalistic approach for tube feeding, based on a personal interpretation of Catholic teachings. However, Pope John Paul II in his encyclical letter *Evangelium Vitae* (1995, March 25) wrote that when death is imminent and inevitable, care providers should respect the human condition in dying. To this end, such care should make allowance to forego extraordinary and disproportionate treatment. In other words, in such situations, the withdrawal or withholding of futile treatment as is tube feeding should thus not be considered as euthanasia.

The crux of the difficulty is to give an interpretation, whether or not the patient was imminently dying? An answer to this question opens up two possible care strategy scenarios.

Based on an interpretation that the patient was not dying, this clinician's action to promote tube feeding could be considered as correct. Such a decision for tube feeding is evidently also dependent on having, a realistic clinical indication, issues of comfort, observation of the patient's reaction to a trial of tube feeding (*RCP*, 2010), and the need for an in-depth moral interpretation of the medical intervention within the patient's values and QOL ("EOL Care People", 2008).

On the other hand, if the patient were to be considered as dying, the proposal for tube feeding would amount to an erroneous interpretation of Catholic teaching. Maltese studies have already considered this difficulty. In fact, in the absence of EOL guidelines, Abela (2015) reported that GP's tended to take EOL decisions based on their personal religious / philosophy of life beliefs. Such spiritual guidance in decision-making has to be considered in the context that many stakeholders "may not be aware of what their religion, for example, allows or not." (*Consensus Document EndCare,* 2018, p. 20). Van der Steen et al. (2014) pointed that prognostication in dementia renders decision-making more complex as the inaccuracy of determining survival time in this condition is one of the major difficulties faced by clinicians to determine appropriate EOL care. Van der Steen made reference to certain prognostic tools that could be used, one of the tools that could be considered is the utilisation of the stage 7c on the FAST score + co-morbidities ("Hospice Eligibility Criteria, 2008) which was utilised in this study with moderate accuracy to determine six-months survival time in patients in end-stage dementia.

The problem with these prognostic tools in end-stage dementia is not only their inaccuracy to determine survival time (van der Steen et al., 2014), but also their inherent difficulty in determining the impending closeness to death (Gordon, 2002), when passing away is a matter of hours to days away. Although patients in end-stage dementia have been known to have revived from situations of life-threatening clinical situations (*NICE,* 2010, June), Pace et al. (2011) remarked that the dying process carries some characteristic signs which are also experienced in terminal persons with dementia. It is in such conditions that clinicians need to be alert to identify signs of a terminal state of life, such as semi-consciousness, laboured breathing, and loss of control of skin circulation (Pace et al.). Ultimately, Schwartz and O'Sullivan Maillet (2013) pointed out that most clinicians agree that when a patient is close to dying, CANH should be stopped to minimise treatment burden that does only help increase discomfort in the terminal phase of life.

Reasoning out ideas in favour of prolonging life, the severity of swallowing difficulties led to a commonly held conclusion that food by mouth was often seen to be too limited to sustain life: “In view of difficulty to initiate the swallow, even if I spent all day with her, she wouldn’t be taking the required nutrients for the day.” (Gina’s SLP) The *RCP* (2010) too commented that careful hand feeding is often seen to lead to sub-optimal nutrition, leading to consideration to start tube feeding as a solution to improve survival.

It was observed in some case studies, that the fear of death from starvation and the quest to prolong life led to decisions to commence tube-feeding. For instance, Pina’s nurse remarked that the relatives in terms of beneficence and vitalism wanted, “Tube feeding as they said that they did not want their mother to die of hunger.” Likewise, Pina’s doctor argued in accordance with beneficence, “The most important factor for me was that the nasogastric tube was inserted for nutrition purposes.” On this account, it is documented in the literature that many clinicians, while appreciating that dementia is a terminal condition, they do still revert to pushing nutrition, with tube feeding being a good method to do so in order to safeguard feeding and prolong life (Dunlop, 2006).

The study findings also showed that wherever a decision was taken by clinicians (excluding Berta’s case in view of undue pressure from the family) to start tube feeding; this was done with the idea to aim for a curative approach of associated co-morbidities to dementia (see also in Chapter, Section 2). This approach in terms of beneficence and vitalism reflects what is written in the literature, where curative and aggressive approaches do refer to invasiveness that aims to prolong life (Gopalraj et al., 2012). One such example is the implementation of CANH in advance dementia (*GMC*, 2012), particularly where dementia is associated with co-morbidities (Birch & Stokoe, 2010, p. 34).

Furthermore, some clinicians in the study argued that tube feeding was not considered to be a futile measure in end-stage dementia. These same clinicians argued that this frame of thinking is quite common in the Maltese population as the Maltese do show high respect for life. For instance, Gina’s doctor said, “We the Maltese have the tendency that if the patient is not terminally ill, we do go for tube feeding, as we do not consider it as an extraordinary measure.” There is no reference to this in Maltese literature, but Cantor (2003) suggests that if tube feeding helps to sustain life it cannot be considered as a futile treatment, and thus can be considered as a humane act in advance dementia (Buff, 2006).

In line with the above assumption that the Maltese do favour life-prolonging measures in the EOL based on their spirituality, some clinicians in the study indicated that such measures safeguarded the absolute value of life, it being of divine origin. On this issue, Berta’s SLP remarked in apparent reference to divine intervention, “Who am it to decide to stop!” Keyserlingk (1979) too remarked that pushing for vitalism to sustain life rests on the notion that man cannot play God.

B. A sanctity-of-life approach in care that reflects the various stages of prognosis.

The principle of sanctity-of-life holds a moral conviction that at the EOL, human dignity and worth of the person need to be respected in recognition of the natural cycle of life (McCormick, 2008). Sanctity-of-life was observed to strongly underpin the clinical practice of many clinicians in the study, as the notion of safeguarding patient dignity was a constant concern in professional practice in end-stage dementia. For instance, Lorenza’s SLP remarked, “You see the patient as a person. … A nasogastric tube? No, many patients do not tolerate it … there is their dignity.” This approach was highlighted by Jewell (2005) in the sense that sanctity-of-life holds ethical primacy in professional practice, where dignity and worth of the dying person hold a central position in the decision-process (McCormick).

In clarifying the worth of life, family members often preferred to leave the finality of life in the hands of God. For instance, Lorenza’s daughter after consulting her siblings said, “We said that we do not want her to suffer any longer, we leave it in the hands of our Lord on what happens from here onwards.” The application of the principle of sanctity-of-life in defining the finality of life, where death with dignity should stand in the hands of the Almighty, is reflected in the literature where Keyserlingk (1979) pointed out that religious beliefs do often guide decision-makers on the EOL to leave the worth of life and the time of death in divine hands.

It was apparent from the research findings that decision-making based on the principle of sanctity-of-life, depending on the perceived prognosis at that particular point in time. In those instances where clinicians and family members appreciated that life expectancy was not curtailed, they opted for management, which aimed to prolong life in respect of human dignity and worth of life. For instance, Pina’s daughter justified the decision for tube-feeding by saying, “There was a chance she might improve. We all wanted her to live longer…we did not want to prolong her life with the loss of dignity.” This approach in sanctity-of-life is documented in the literature, as measures taken to prolong life, when the EOL is not looming close, is permitted in appreciation that life is worthy of protection (Keyserlingk, 1979)

On the other hand, where sanctity-of-life was valued in a situation of proximity to the EOL, in such instances, QOL concerns were given prominence in the deliberation leading to the decision. On this, Lorenza’s daughter said with conviction, “The illness is progressing so fast! … We, the relatives all agreed to let her go with the minimal intervention possible; we do not want her to suffer any longer.” In such instances, sanctity-of-life gives attention to a QOL perspective in acceptance to preserve human dignity in EOL care (McCormck, 2008). Such an approach aims to minimise burdensome interventions that are disproportionate and extraordinary (Druml et al., 2016). To this end, one appreciates that based on sanctity-of-life reasoning, in end-stage dementia when the patient is close to dying, tube feeding can be withheld or withdrawn as in such instances tube feeding is deemed futile (Walter, 2003).

C. Quality-of-life.

It was observed that a number of clinicians favoured a QOL approach in end-stage dementia care. On this Pina’s SLP was categorical, “Geriatrics is about QOL.” Many such clinicians amplified this approach as in their reasoning, tube feeding in end-stage dementia amounts to futile treatment as the EOL was close. Berta's doctor pointed out, "She was in a terminal state…. yes we agreed that we should aim for comfort care, tube feeding will not help." This view echoes similar recommendations in the literature (Amella et al., 2005; Singer & Kuhse, 1988) with a conviction in QOL ideals that tube feeding close to the EOL is a futile disproportionate measure in the dying process that can create suffering.

It is interesting to point out that Maltese literature has until now indicated that family members are the prime motors that push for invasive tube feeding in EOL decision-making (*Consensus Document EndCare,* 2018). However, in at least one of the six case studies, it was the relatives that pushed for a QOL approach, while clinicians favoured tube feeding. Thus Gina's husband questioned if life was worth living by saying, "What is the QOL here? … Why live a longer life that has nothing more to offer than more suffering?" The fact that family members themselves have been observed to push for a QOL approach could be symptomatic that cultural and religious values in the Maltese people are slowly changing with time (Haber, 2015). At the same time these ideas that project forward a QOL approach in the EOL, might indicate emerging ideas in Maltese society that question the value of life in situations of EOL suffering (Walter, 2003), leading to arguments that could promote practices in favour of euthanasia as a means to relieve suffering (Onwuteaka-Philipsen, Muller, & van der Wal, 1997).

i. A reflection on euthanasia.

In doing a reflection on euthanasia there is the need to give consideration to beliefs, values, personal wishes, medical practice and the legality that governs such practice ("Cultural Evolution", 2013; "Personal Values Beliefs", 2009; Ellul, 2014; Furlong, 2010; Onwuteaka-Philipsen et al., 1997).

The following arguments are made in the context that there exists a published opinion of the Maltese Bioethics Committee on ordinary/extraordinary care in EOL nutrition and hydration (Asciak, 2010). However, there is as yet the absence of legality governing medical practice in EOL care (*Consensus Document EndCare,* 2018), while in Malta, the practice of euthanasia remains illegal (Frendo, 2017).

Some clinicians expressed belief in divine control on the EOL by giving worth to life, and in so doing expressed views against euthanasia. For instance, Rosa's nurse in debating for and against advance directives stated, "I hope it is not used to introduce euthanasia. The biggest insult to humanity is when a person terminates his life." This approach to EOL decision-making based on personal beliefs was pointed out by Abela (2015), who remarked that many Maltese GP's, do take EOL decisions according to their personal religious / philosophy of life beliefs. Keyserlingk (1979) argued that in giving value to an approach to the EOL through sanctity-of-life, this approach holds in high esteem that human life is sacred, so termination of life without appropriate justification is not permitted.

Furthermore, the responses of some clinicians in the study showed that although euthanasia is not legal in Malta, the overbearing shadow of euthanasia appeared to influence clinical decision-making, particularly in the difficulty to distinguish between withholding and withdrawing of care and euthanasia itself:

> What would be the right response, if the daughter asks me, 'See, I cannot see my mother suffering any longer'? What are our borders in order not to fall in the trap of euthanasia? What are our legal borders? I do not wish to be put in a position to be accused that I am administering euthanasia. (Katarin's consultant)

Thus the absence of regulatory guidelines for the EOL (see in Chapter, Sections 2.B & 3.C), does appear to leave an adverse effect in the serenity of how physicians manage complex care situations in the EOL. Katarin's consultant added, "What is the norm of EOL care that stands away from extremes of care to ensure benefit for the patient? Do we have a legal framework to cover our backs?" This also increased the vulnerability of the person with dementia in care (Gastmans, 2016), as decisions taken in the EOL could lead to over- or under-treatment, and thus creating a situation where respect of the patient's dignity and interests in their dying phase of life are seriously challenged (Owen, 2006).

It is necessary to point out that of all the responses given by clinicians and family members, who favoured a QOL approach, none expressed a view in favour of intentional killing as a possible strategy to follow in end-stage dementia. Notwithstanding, stakeholders favoured the idea to allow near terminal patients to be left to die peacefully, letting nature take its course. For instance, Lorenza's daughter mentioned her personal inclination for what type of EOL care she would prefer for herself in a hypothetical future in similar circumstances as the patient, "I would decide to let nature take its course, it is not that I would want to kill myself but the time has passed for drips, tubes." Likewise, Gina's husband, who was a fervent advocate for a QOL approach stated that, "If it depended solely on me for myself, I would tell them, leave me to die in peace. Moreover, in such a situation if I die today, it is better than if it is left for tomorrow." These statements do appear to indicate a distinction between *killing* and *let die* (Beauchamp & Childress, 2013), but do open complicated ethical and philosophical arguments in defining a dividing line between palliative/terminal support to the dying versus passive euthanasia where persons are allowed to die as treatment is foregone (Hughes & Dove, 2006). One such example of passive euthanasia in dementia to contend with is when food or fluid is stopped (Hughes, 2006, p. 51). It needs to be appreciated that *RCP* (2010) recommended that euthanasia should expressly refer to the "active and intended termination of life" (p. 45), as is applied in the Netherlands.

I believe that Maltese Society, after appropriate public debate and subsequent legislation should help clarify a better definition of what amounts to appropriate withdrawal or withholding of futile treatment that is disproportionate and burdensome in the EOL (Cassar, 2013; Deguara, 2011). This should be distinguished from care practices where passive euthanasia is instituted on the basis of QOL arguments, where persons in end-stage dementia are labelled as being of no value (Finnes, 1994), leading to intentional withdrawal and withholding of treatment, as is food and drink aimed to hasten death (“Active Passive Euthanasia”, 2014).

In this section, the differences between sanctity-of-life and QOL have been debated from a perspective where the clinical decision hangs between measures taken to prolong life versus a palliative approach that favours dying with dignity. In the next section, virtue theory is debated as a decisional framework to define an ethical approach that safeguards the dignity and interests of the person in care.

7. Virtue Theory as an Ethical Framework to promote Optimal Care

In this section, attention is given to virtue theory as a fundamental process in normative ethics (Hursthouse & Pettigrove, 2018) in its use as a framework to define optimal care in end-stage dementia.

One of the difficulties faced by clinicians in the study was the problem how to balance care between an aggressive life-prolonging strategy versus a dying with dignity approach in appreciation of the EOL: “It is not an easy decision to take and difficult to find the right balance” (Rosa’s SLP). The difficulty to define a virtue theory approach to re-orientate care away from curative approach towards palliation was highlighted in the literature (Sampson et al., 2009) as one of the major concerns in end-stage dementia decision-making.

The problem to define the right balance in care in end-stage dementia often escalated wherever there was a values-dispute between family members and clinicians (see in Chapter, Section 4.B). In such situations, the conversion from aggressive care to comfort care is often experienced as a clinical decisional nightmare that brings out strongly ingrained ethical dilemmas that need to be confronted and decided upon (Arenella, 2005). Such a clinical situation has to make various considerations in terms of beneficence, non-maleficence, autonomy, sanctity-of-life, QOL, best interests, and the meaning of virtue in care.

Clinicians were well aware of the need to define a virtuous decision that leads to the provision of good care. To this end, Rosa’s nurse remarked in terms of beneficence and virtuous approach to care, “I always ask the question ‘Will the patient benefit?’” The quest to define a virtuous decision in the management of swallowing difficulties was given prominence in the literature (*RCP*, 2010), as it most often relates to the question of whether or not the patient would benefit from tube feeding (Sampson et al., 2009) (see in Chapter, Sections 2.C, 3.A & 5.A).

The quest to seek a balance in care involved the need to set up a realistic appreciation of the situation and the courage and wisdom to define when to stop unnecessary treatment by withholding or withdrawal of burdensome inappropriate care interventions. Attention to virtue theory in terms of non-maleficence was noted in the response given by Berta’s nurse who said, “She would not gain [from tube feeding] in this state, in other words, what aggressive input we do, is futile.” This finding mirrors the observation made by Zsambok (1997), who reported that better decision-making rests on a realistic appraisal of the situation. A reality focused approach does help denote a balance, or golden mean that avoids patients from being exposed to over-treatment and under-treatment (Hertogh, 2010).

One of the cardinal virtues that were observed to be given importance in decision-making in dementia was that of prudent practice: “If you decide to insert a nasogastric tube for nutrition purposes, in such instances, the patient is being subjected to this invasive intervention only if she has the chance to improve.” (Pina’s consultant) Such an approach for cautious intervention was in some cases tied with a virtuous approach based on wisdom and experience in dealing with swallowing difficulties in end-stage dementia and a QOL appraisal of risk and benefit of an intervention. Katarin’s SLP recalled, “When I started working at SVP, I used to take the safest option, but with time I started to get to know better my patients, and I started to risk a bit more.” The virtues of prudent practice (Ogunbanjo & van Bogaart, 2014), and wisdom in care (Beauchamp & Childress, 2013) are documented in the literature, as such practice does help provide a more serene decisional process that better safeguards the dignity of the patient in care and avoids defensive approaches in clinical decision-making (Ogunbanjo & van Bogaart), leading to better rational judgement (Aries & Cur, 2005).

Furthermore, the interview responses showed that a compassionate approach to care was another virtue that was given due consideration in decision-making. In this approach, patience and dedication were active promoters of good care, leading to a better decision-making process. This virtue was shown in the patience necessary to provide appropriate care: “A patient with a swallowing problem needs more time to feed than a normal person without dysphagia” (Rosa’s SLP); or in trying to avoid untoward suffering: “For me personally in that poor state that she is in, I would decide to let nature take its course… the time has passed for drips, tubes” (Lorenza’s daughter).

The conversion of curative care to palliative/terminal care required the involvement of the virtue of character. For instance, Gina’s SLP showed a strong sense of compassion and personality in the provision and acceptance of EOL care by stating, “[In the EOL] My professional opinion is to go for oral feeding, as long as you do not have a patient who does not show an interest in feeding. In such cases, it does make sense to go for nil by mouth.” These virtuous traits of compassion (Beauchamp & Childress, 2013), patience, care (Vaughn, 2011), and character (Hursthouse, 1997), are fundamental qualities in the provision of EOL care.

Consideration away from curative care towards palliation requires a virtuous process of critical reflection (Day, 2006) that accepts the morality of the situation by focusing solely on current needs, which is that of a person in the last phase of life (Shah & Lloyd-Williams, 2003; Hertogh, 2006) (see also in Chapter, Section 6.A). Such approach invokes an emotional judgement which is necessary, for both family members and clinicians, to accept the reality in EOL care (Aries & Cur, 2005) (see in Chapter, Section 4.C) in a way to facilitate that all involved do follow the right action at that point in time (Beauchamp & Childress, 2013).

In conclusion to this section, it is evident that virtue theory holds a strong hold in the process to develop an ethical framework to help resolve an ethical dilemma in dementia care. However, as Hursthouse and Pettigrew (2018) remarked in normative ethics, virtue theory may not be the only ethical theory involved in decision-making, and they added that one such theory that is often implied is that of deontology theory.

8. Paternalism, the Forgotten Stakeholder and Deontology

This section looks at the loose relationship between paternalism and duty based care in deontology. Attention is also given to the observed phenomenon of stakeholders that were forgotten and thus excluded from participation in the decision-making process.

A. Paternalism.

The study findings indicated a widespread situation where paternalism left a significant deleterious impact upon the patient's autonomy to sustain control on their own EOL care. Such paternalism related to a common behaviour in clinicians and family members not to divulge a diagnosis of dementia to the patient who is afflicted with this condition. For instance, Berta's son stated, "I never talked with my mum about this." One of the consequences of this approach is that patients are denied the chance to declare their preferences for their EOL care earlier on in the disease process (see in Chapter, Sections 2.D & 3.C). Although in a number of responses such lack of veracity was related to a cultural inhibition in terms of beneficence to shield the patient from exposure to a devastating diagnosis of dementia (in Chapter, Section 2.D), this approach did potentially challenge the patient's dignity for involvement in decision-making for their EOL care (Linzer, 2002). Volicer and Ganzini (2003) remarked that this is a problem that is often experienced in patients with dementia lacking decisional capacity and living in long-term care settings, as frail aged persons are at increased risk of paternalism (Tuckett, 2006).

B. The forgotten stakeholder.

The study findings showed that in three of the six case studies, family members were not involved in the decision-making process to decide management of swallowing difficulties in dementia. This observation that family members were not always called to participate in the decision-making process regarding care for their relatives with dementia does not appear in the Maltese literature. These family members also said that they would have preferred to be involved in decision-making. For instance, Katarin's sister-in-law expressed her disappointment that she was not involved by clinicians in the decision process, "No, I was not involved in the discussion; they simply informed me what they had decided." This approach goes against what is stipulated in the Maltese *Mental Health Act* (2012), which states that in persons with mental incapacity, responsible relatives, "Shall, participate in the formulation of the multidisciplinary care plan." (Part: II, 4, 4c)

Likewise, it was observed that in many situations, there were clinicians who were excluded from the decision-making process. For instance Berta's nutrition nurse tried to explain why such exclusion happened, "I have no idea how to answer you, I do not think there was any particular reason why, probably it was more an oversight or a result of convenience, they just decide whoever is present to hurry it up, and let's go to patient number two." The problem of the forgotten stakeholder is rarely documented in healthcare literature, where it is seen as a form of decisional model where decision-making is made by authority without group discussion (Johnson & Johnson, 2000). However, it is evident that in Malta, the fact that there is lack of EOL care practice guidelines (*Consensus Document Endcare,* 2018), this deregulatory situation does expose the team decision-process to increased communication and relationship difficulties, leading to the exclusion of some stakeholders from the decision-making process (*Effective Decision-making,* n.d.). This fragmented approach renders decisions taken to be flawed, as they end up based on assumptions of what all the rest of team are thinking (Yrjönen, 2017), resulting in discord in consensus regarding decisions taken.

The disagreement that resulted from exclusion was observed in a clinician's response who stated, "When you meet, all stakeholders should be involved, so that at least you avoid double work, as you avoid going back to revise a decision once again through another grand meeting involving all those persons." At the same time, such exclusion from the decision-making process of family members does lead to potential threats to human dignity for the patient in care, as it is known that family members remain in a better position than clinicians to safeguard the best interests of their family members in care (Jones, 1997).

C. Deontology.

Many actions, as observed in the interview responses, found a strong correlation to a deontological approach to decision-making. Reference has already been made to a deontological approach where it concerned the provision of, proper care (see in Chapter, Sections 3.A & 5.A), safeguarding the patient's past wishes, and preserving human dignity (see in Chapter, Section 3.B).

The study findings showed that responses that favoured duty in care were often found to be profession specific. For instance, SLP's gave great importance to their professional duty to safeguard the principles of beneficence and non-maleficence through the promotion of safe swallowing: "Safety always wins!" (Berta's SLP) On the other hand, some nurses pushed their sense of duty for proper nutrition as a maxim in dementia management. For instance, such a nurse stated in terms of beneficence, "The aim is to prolong life… the guiding line is to continue (care) till the end, if necessary, pass another tube, and another tube".

The propensity and duty to prolong life through aggressive care based medicine has been documented before in the Maltese literature (*Consensus Document Endcare*, 2018). Hughes and Williamson (2019) remarked that the drive for tube feeding in advanced dementia rests on a deontology response that considers proper nutrition as a means to avoid suffering. Such a deontological approach to promote duty and rules is frequently associated with other ethical principles (Hursthouse & Pettigrove, 2018), where the focus in decision-making is aimed to provide consistent decisions (Chonko, 2012) that uphold the patient’s interests by satisfying a moral obligation to duty (Kitwood, 1997).

However, such a deontological approach was observed to expose some limitations in the drive to promote a patient-centred approach. While it is accepted that life-prolonging approach in the EOL is considered a deontological standard of rule of practice in institutional care, yet a clinician mentioned that there existed difficulty to convert to palliative approaches in the EOL, as the rule remains, “Saving lives, prolonging life, help those in our care who are doing poorly.” Pace et al. (2011) remarked that clinicians in end-stage dementia, unlike those in cancer care, do find it more difficult to convert curative approaches to palliative care. Furthermore, the regulatory scrutiny typically associated with long-term care settings, drives clinicians to persist in the provision of tube feeding, as in so doing the message is given to regulatory bodies that all possible is being done to feed the patient (Palecek et al., 2010). However, the difficulty of conversion to palliation and comfort hand feeding, exposes patients with dementia to a higher level of burden and suffering (Aminoff & Adunsky, 2006), leading to a situation where their dignity and interests end up being significantly threatened (Morris & Volicer, 2001).

Another observed difficulty was that certain clinicians in the rigidity of views to follow their professional duty, led to a compartmentalisation of ideas which hindered a team philosophy in the approach to care, this finding has not been debated locally before. For instance, Pina’s SLP remarked, “Our role as SLP is to assess safety in swallowing… the decision to tube feed or not should fall in the responsibility of the medical profession.” Arries and Cur (2005) too pointed out that it is a medical tradition for doctors to take the role of decision-makers regarding medical care.

This compartmentalised approach did not go down well with a number of other clinicians who felt that there was not being given enough attention to a shared team approach in the final decision regarding management of swallowing difficulties. In fact, the same SLP added, "Honestly I was not very happy when they told me that the patient was going to be fed via a nasogastric tube… If I was involved, I could have brought forward certain issues that could have been included in the discussion." This rigidity in rules and duty-bound approach in a non-consequentialist approach was described by Day (2006) as being a limitation of a deontological approach, where the moral rules set up by the categorical imperative leaves little room for manoeuvre and thus acts as a hindrance to the achievement of compromise leading to consensus. In fact, such rigidity to follow the rules does seem to lack an appreciation of the moral implications of personal relationships (Beauchamp & Childress, 2013), where morality, according to Moreland and Geisler (1996) is nothing more than a human development that responds to the needs and values of the human state.

In conclusion, it was evident that deontology theory was frequently applied in the resolution of ethical dilemmas in institutional care where its application was associated with other principles and values. However, the application of decision-making based solely on duty and rules does harbour considerable limitations as it denies a flexible care approach that safeguards an emotional morality of the vulnerable individual in care, in a drive to safeguard the patient's best interests. The next section will consider the importance and challenges associated with the application of the patient's best interests judgement in dementia care.

9. Patient's Best interests judgement

In this section, due reflection is made on those responses that promoted patients' best interests in dementia decision-making. What follows is an analysis of those study responses where patients' best interests were threatened by factors in care that challenged such ethical decision-making.

A. Patient's best interests decision-making.

In awareness of the difficulties faced in end-stage dementia care, many clinicians and family members understood the importance to work together through a patient's best interests approach. For instance, Rosa's son claimed that, "I do not know what my mother would have wanted …In the decision taken, the best way for my mother prevails." This account was one example of the many testimonies of a harmonious relationship observed in the interview responses between clinicians and family members. This approach in dementia is reflected in the literature as in the face of a situation where autonomy is lost and where substituted judgement finds rare application, in such situations many bio-ethicists do recommend that decision-making should be based on patient's best interests judgement (Gordon & Baker, 2011; Torke et al., 2008; *Mental Capacity Act,* 2005).

Family members contributed to best interests decision-making by giving attention to the patients' dignity, where respect was shown to the patient's values, beliefs and past expressed preferences for care (see in Chapter, Section 3). For example, Lorenza's daughter remembered, "Yes she did express the wish to die, especially when she was admitted her, you know in the past my mother was a vain person…" Dekkers, W.J.M., (2010) too said that the patient's best interests rests heavily on approaches in care where the patient's dignity and values have to be preserved.

Also, in seeking out the patient's best interests, attention was given to the risks and benefits of the various care options available in a virtue theory and QOL approach to decision-making. For instance, Lorenza's doctor remarked, "We decided to involve her relatives in the decision regarding the options to either go for comfort feeding or else go for a nasogastric tube or another form of enteral feeding like a PEG or RIG." This is echoed in the literature as in patients' best interests decision-making, consideration for risks and benefits of the various options is a balanced approach that helps to identify the best care for persons with dementia (*RCP,* 2010).

Furthermore, in appreciation of the patient's best interests, many family members and clinicians interviewed indicated the necessity to meet the patient's current and ongoing needs for the EOL, which for many aimed for a palliative approach to care. For instance, Lorenza's daughter stated, "We want her to continue living and die in a peaceful way." At the same time, Rosa’s SLP commented, “It is very important that the clients have the right care at every stage of dementia.” These comments do mirror what is written in the literature as best interests does respect and protect the vulnerability of the patient (Polden, 1989) by accepting their current and ongoing situation in care (Dekkers, W.J.M., 2010). These include attention to current behaviour, expressions, gestures, comfort and suffering (Welie, 2010). At the same time, consideration has to be given to the limited prognosis in end-stage dementia (Welie), which points towards the need to implement a palliative approach to care (Sloane & Zimmerman, 2010).

Some clinicians appreciated the importance of considering the relatives’ interests in decision-making, in a broader context of best interests judgement where the patient still retains the centre focus in care. For instance, Rosa’s doctor declared, “You must review how the team is feeling, how the patient is feeling, and how the relatives are feeling.” In Section 4.C of this chapter, an ample account has already been given of the emotional involvement of family members in dementia care and their needs for support. The approach in best interests judgement where clinicians give due consideration for the relatives’ best interests in dementia, is documented in the literature. In fact Reginald and Huntley (2006) stated that in best interests decision-making, apart from giving witness of the patient’s values and wishes, one must also give consideration to the interests of other involved players, as is the family, as they all participate in the journey of dementia progression, till the last breath of life (Beauchamp & Childress, 2013).

B. Threats to the patient’s best interests in decision-making.

In previous sections in this chapter (see 2, 5 & 6) attention was given to how decisional stakeholders utilised various ethical models to influence care decisions that favoured one of the two care strategies, namely prolonging life versus dying with dignity. The study findings showed that clinicians and family members did often disagree on what constitutes the best care strategy to follow that satisfies the patient’s needs, be it aggressive care or palliation. Caught in the middle of this conflict, this discord was observed to be of a potential threat to patient dignity and best interests in care (see in Chapter, Section 3). An analysis of the interview responses indicated two clear scenarios where the patient's best interests were challenged as a result of conflict between clinicians and relatives.

In the first case scenario of conflict between clinicians and family members, although both these stakeholders supported a patient's best interests approach, yet what was viewed as being of best interestss for the patient by the relatives, did not necessarily align with what clinicians recommended as being of best interests for the same person in care. For instance, in Gina's case study, her husband pushed for his wife's best interests, with a focus to promote a palliative approach to decision-making, "I suffer from heartache seeing her living a life of torture….Whatever is best for her, do it!" In the same case study, her doctor deemed that it was in the patient's best interests to seek an aggressive approach to care: "This patient to me is not for palliative care as she still has a life to live … I try to put the interests of the patient first" (Gina's doctor). This phenomenon was never reported before in Maltese Literature. The world literature has indicated the importance of agreement between clinicians and relatives in the process to achieve the patient's best interestss (Beauchamp & Childress, 2013). However, differences in personal and professional values between family members and clinicians did expose a clear limitation in promoting a patient's best interestss approach. As ultimately it rests on a personal interpretation of what is of best interests for another person (Welie, 2010) who is clearly living a different reality (*Nuffield Council Bioethics*, 2009) from both the clinician and the involved family members**.**

The second and more challenging situation of ethical and values-conflict between clinicians and relatives in swallowing difficulties was brought up by various clinicians who described situations of care where they experienced profound difficulty in reasoning with rigid-minded family members, who persisted in feeding the patient unaltered solid food that was unsafe to swallow. Such a situation was a dilemma where various ethical principles and values conflict were involved. Clinicians reasoned in terms of beneficence, non-maleficence and patient's best interests, to provide food/liquids that were safe to swallow to minimise the risk of choking hazard and aspiration. This opposed the often unwavering action taken by certain relatives, who in terms of beneficence, autonomy, substituted judgement, hedonistic ideals, QOL, and family emotional bonding, felt that it was in the patients' interests to disregard expert opinion and continue to provide unaltered food to patients, based more on food choices that gave the patient pleasure in eating, rather than safety. For instance, Katarin's sister-in-law remarked in substituted judgement to justify her behaviour in the provision of unrestricted feeding options in swallowing difficulties, "I used to bring her solid food she likes, and fruit boiled or fresh, a salad, chicken or beef, or fish and I would feed her slowly, slowly and coax her to eat the full plate." This approach was witnessed in other patients (not in this study) at SVP by the nutrition nurse who pointed out, "Relatives continue forcefully to give her [the patient] whatever she wants saying, 'Poor lady, what life does she have left!'" This behaviour by the relatives was opposed by many clinicians who in the patient's best interests remarked: "My concern always remains the safety of the patient; I look at the relative's needs, but safety always wins because that is always the patient's best interests" (Berta's SLP).

The stalemate created by the persisting conflict between stakeholders in what constitutes the patient's best interests in food choices led to much stress in clinicians. For instance, Katarin's SLP recalled such a past situation in care, "The relative wanted to bring him all types of food, her opinion was that if her family member in care were to die, he should die happy! …Staff members who were feeding him by mouth were very afraid that he would choke… and were very tense."

Such focus on values-conflict in swallow difficulty in end-stage dementia decision-making is something that has not been debated locally before, and it concerns a clash of wills and morals where family members, show high resolve to have their ideas for a QOL approach to care implemented. Van der Steen et al. (2014) pointed out that in many instances the central argument that underpins conflict between clinicians and family members is the difficulty in end-stage dementia to define a clear indication of survival time, thus rendering prognostication and proper management problematic. Karlawish et al. (1999) reported that litigation experienced in the management of swallowing difficulties does often concern a dispute between EOL feeding and safety, where disagreement does often rotate around rifts in "deep values about feeding, starvation and the meaning of care" (p. 835). Hughes and Williamson (2019) remarked that values-based practice helps to acknowledge such value-conflict, which with proper communication, evidence-based practice and compromise, helps lead to resolution of the problem in consensus.

Focusing on the particular situation that characterises care in nursing homes, Seymour et al. (2005) and Thompson Beckley (2017) pointed out that disagreement regarding care in dementia is common in long-term facilities. The literature showed that conflict between clinicians and family members does often relate to a different appreciation of values, ethics and beliefs (Agius, 2010; Sasson, 2000). Karlawish et al. (1999) remarked that these are compounded in long-term care where institutional regulations, weight loss and sustenance render the situation more complicated, thus leading to conflict in clinical judgement in dementia (Sasson, 2000).

Furthermore, family members do usually take up the role of bearers of patient values and wishes in substituted judgement when patients in dementia end up losing decisional capacity (Thompson Beckley, 2017; van der Steen et al., 2014). However, this role is often challenged once the patient is admitted to a nursing home, as institutional rules "limit self-determination, autonomy and freedom of action" (Sasson, 2000, p. 6). Thus admission to a nursing home generates additional complexity leading to a dispute in the various ethical models involved in decision-making, which potentially threaten human dignity and patient's best interests in care. To the extent that family members do favour benevolent care that respects the patient’s past wishes and values in substituted judgement and appreciation of QOL. However, such benevolence as interpreted by family members tends to find opposition in clinicians who in terms of beneficence, non-maleficence and virtue of care, are duty bound to weigh autonomy in contrast with patient’s best interests and safety in care (van der Steen et al., 2014).

Furthermore, another difficulty observed in the interaction with relatives, was that clinicians experienced uneasiness to confront relatives through legal methods. Gina’s doctor stated, “Going to court is the last thing I want to go to on this issue.” The literature did reflect on this difficulty, Monturo (2009) remarked that wherever clinicians resort to legal action to safeguarding the best interests of vulnerable persons in care, it ultimately turns out to be a Pyrrhic victory, as not only the professional relationship with family members ends up completely shattered, but also clinicians remain little at ease when dealing with court cases. At the same time, *Consensus Document Endcare,* (2018) remarked that clinicians should be given proper medico-legal support and the trust necessary, to act in fairness and independently to safeguard the dignity and personal interests of their patients (Beauchamp & Childress, 2013). Ultimately, it is to be acknowledged that clinicians do retain the moral right to act freely to intervene and decide for their patients’ best interests (Beauchamp & Childress; *BMA*, 2018).

i. Safeguarding personal interests.

The findings indicated past patients and one in the present study where family members did not acknowledge the risk of unsafe swallowing and persisted in feeding their relatives in care solid unaltered food that placed them at increased risk of choking and aspiration. At the same time, it was observed that clinicians once they became aware that the relatives ignored their recommendations for safety in swallowing, they stopped short of seeking patient protection under the *Mental Health Act* (2012) (see in Chapter, Section 9.B).

In a drive to safeguard their interests, some clinicians, with the support of SVP administration, tried to disassociate themselves from the potentially dangerous behaviour of relatives in feeding by asking them to fill out a *disclaimer form* and thus shifted responsibility on the shoulders of these relatives, “I do believe in the consent [disclaimer] forms particularly when the relatives bring food for the patient from home, so that we the professionals would be safe and safeguarded.” Such a reaction by this clinician in the study to safeguard personal interest is reported in the literature, where Ogunbanjo and Knapp van Bogaert (2014), remarked that out of fear of legal liability, balanced, prudent care practices are sidelined in favour of defensive medicine care practices.

On the other hand, other clinicians in terms of non-maleficence saw that such use of disclaimer forms was potentially exposing patients to harm and thus not in their best interests. At the same time, these clinicians remarked that wherever relatives signed such a disclaimer form, the caring clinicians and administrators do continue to shoulder legal, clinical and ethical responsibility in care:

> When these do happen [the disclaimer form], in most cases, they are going against the medical opinion to provide safer forms of feeding, and you are thus exposing the patient to additional harm. Finally, the responsibility falls on your lap, just the same. [And] the institution would suffer a bad name (an SLP remarked).

Furthermore, a doctor remarked that, “Use of such disclaimer forms poses strong ethical and legal implications on those delivering care to vulnerable patients under their care.” Thompson Beckley (2017) made reference to case law where such disclaimer forms are termed “*negotiated risk agreements*” (p. 2). Thompson Beckley remarked that such risk agreements are not protective and can interfere in the “provider-patient relationship” (p.2). On the consequences of defensive medicine, Ogunbanjo and Knapp van Bogaert (2014) remarked that such procedures offer little to no benefit to patients who in their vulnerability are exposed to more harm as they are abandoned to care practices that defy their best interests.

Knowing the above, at the time of writing this thesis, I am aware that the administration at SVP is considering a revision of the whole process underpinning the relationship between clinicians and family members, with a focus to safeguard the best interests of residents in care.

In conclusion, patient's best interests judgement in swallowing difficulties in dementia was found to be an ethical model that showed promise to safeguard those vulnerable in care. However, in the Maltese social, medical and legal scenario, best interests decision-making was observed to suffer from significant lacunae that left patients exposed to threats to their dignity and interests in care. To this end, an ethical model of decision-making in dementia needs to be identified that favours a patient-centred care approach that also promotes an agreement-seeking process that respects clinicians and family members. The next chapter will consider the pros and cons of implementing a consensus-building approach as a means to promote inclusivity of all parties in the decision-making process, while at the same time safeguarding the patient's dignity and interests in care.

10. Consensus-Building Approach

This section deliberates if the complex ethical difficulties in decision-making observed in the study, could find resolution through the implementation of a consensus-building approach, as an ethical model of choice to support end-stage dementia decision-making in Malta. To address this question, those interview responses that promoted a team approach will be considered in perspective of a decision-making process where respect and agreement for all stakeholders are reached through a consensus-building approach. An additional reflection is carried out to see if consensus-building approach could serve as an ethical model that draws in line the various ethical theories and principles involved in decision-making and consequently helps to safeguard the dignity and interests of the person with dementia in care.

A. A team approach to decision-making in dementia.

Many clinicians and family members believed that managing complex EOL decision-making in dementia was best carried out through a team approach: “We work in a multidisciplinary team … with the relatives being on board.” (Katarin’s Doctor) This team approach in decision-making is widely celebrated in the literature. It is known that a multidisciplinary team approach is the most recognised model of geriatric practice in nursing homes for persons in end-stage dementia (Allison, Balbino & Covinsky, 2019). Through such approach of shared decision-making, clinicians plus surrogates do work together as a team to help improve the quality of comprehensive care that is offered to institutionalised older adults suffering from chronic conditions (Boult et al., 2009).

However, the study findings showed that the application of a team approach by clinicians was strongly influenced by the prevalent unregulated process in end-stage dementia (see in Chapter, Sections 2 & 3), with the consequence that different teams took up different strategies in the process how to manage the patients under their care. This loose approach was explained by the nutrition nurse, who remarked that,

> Some wards do multidisciplinary team meetings and others do not do them. You find some who have the opportunity to take and be involved in the decision, while others do not have this opportunity.”

This deregulatory approach in end-stage dementia decision-making was described in the Maltese literature, with particular reference to EOL nutrition and hydration (*Consensus Document EndCare,* 2018). In fact, this document remarked that the dire consequences, of lack of care guidelines, does leave clinicians orphaned of a regulatory framework to help safeguard the interests and wishes of persons with dementia.

On the other hand, wherever it was observed that clinicians and family members worked together to achieve the overall benefit of the patient this led to a better outcome: “The relatives are very involved in the management of this patient in care, and even they themselves do feel that what is carried out should be done for the good of the patient." (Katarin's nurse) The literature did indicate that although team members and relatives do harbour different personal and professional values (Sasson, 2000), wherever agreement is reached through a team approach, the patient's best interests would stand to benefit.

Yet the study findings showed that reaching such agreement was not always easy, as one of the major difficulties to reach an understanding between clinicians and family members related to the differences in values in what these stakeholders respectively believed to be benevolent care in the best interests of the patient in care (see in Chapter, Sections 5.A & 9). On this dispute, the study findings indicated some interesting findings.

The first example of values-based conflict in decision-making did relate to a situation in care where the relatives pushed for a QOL approach in opposition to the medical decision that sought aggressive life-prolonging care. Gina's husband indicated such disagreement by saying. "They told us they were going to insert a tube. For us this would be unnecessary additional torture on her!"

On the other hand, the study findings exposed other cases where a values-based dispute between clinicians and the relatives indicated an inverse situation of conflict, with the relatives pushing for aggressive intervention even though clinicians firmly believed that the patient was close to dying and needed only comfort care. Such example was highlighted by Berta's son, who declared, "All they offered was that they were going to keep my mum comfortable… Feeding was very important, for us food is life!"

Values dispute was not only experienced at the level of clinicians versus family members alone. In fact, in one case study, such values dispute was observed between family members themselves, where Katarin's sister-in-law remarked, "I informed all her close relatives living abroad on the deterioration of her condition, some told me, 'Tell them to give her whatever she wishes'...While others told me, 'Do what is best and safe for her.'" Likewise, values dispute was also observed between clinicians in the same team, where in one case study a clinician objected to tube feeding in disagreement with the other team members by saying. “We are supposed to be there to help improve QOL and extend life; there is no QOL here!”

This conflict in values between stakeholders was further compounded by observations where certain stakeholders were excluded from involvement in the decision-making process (see in Chapter, Section 8.B), creating a problem of lack of participation and disagreement (see in Chapter, Sections 3.B & 4.C) between parties. To these disputes in values and fragmented decision-making between stakeholders, one must also make reference to the silence of Maltese law regarding advance directives (Cassar, 2010), which did seemingly lead to an exacerbation of patient vulnerability in late life dementia care (Tuchett, 2006), as patient’s past wishes were rarely given value in decision-making (see in Chapter, Sections 2 & 3).

Conversely, it was observed that in some case studies, the resolution of such values-dispute was attained when stakeholders came together to an agreement in consensus on a patient’s best interests approach: “When we take a decision we agree together to take it in the best interests of the patient” (Katarin’s nurse). This approach to decide in agreement between parties on which feeding strategy to follow was reported in the literature (Dekkers, W.J.M., 2010). The *BMA* (2018) guidelines in fact recommended that in cognitive decline decisional dilemmas, a patient’s best interests approach should be followed, where all stakeholders need to be involved to come to agreement in consensus to ensure that the patient’s past wishes, values and dignity are safeguarded (Eggenberger & Nelms, 2004; Chun-yan & Tao, 2004; Karlawish et al., 1999). At the same time, Hughes and Williamson (2019) remarked that a better way to resolve values-dispute is to institute values-based practice, which acknowledges such differences in values, encourages communication between all parties, and promotes negotiation and mutual respect, leading to consensus.

B. Conscientious objection.

It is worth mentioning that disagreement within the team regarding care decision-making brought up a case of possible unaddressed conscientious objection when a clinician in Gina' case pointed out, "Let us say, I truly do not agree with a decision, the consultant if he commands you to do it you have to do it. If you refuse, you are insubordinate, and this is another issue." One needs to point out that in the *Maltese Health Act* (2013) there is no provision to regulate conscientious objection (J. Cachia, personal communication, January 8, 2019), which is a right of health professionals (*RCP*, 2010) to practice according to their religious, personal or moral beliefs (Agius, 2010). This appreciation and respect of persons holding different beliefs and values in society, finds ever-increasing meaning in Malta following its accession within the European Union (Verhofstadt, 2012). In fact, the resulting reality of the opening of borders between countries has led to a progressive expansion of multi-culturalism in the Maltese population (Doublesin, 2016).

C. Setting the ethical arguments that favour a consensus-building approach.

In consideration of the above difficulties to sustain a collaborative process through a team approach, certain clinicians pushed for an agreement seeking approach where all parties are involved in the decision-making process that respects the patient's dignity and interests. Katarin's SLP supported the application of a consensus-building approach by saying, "I believe that taking a joint decision, where all are in agreement is the best way, the middle ground… [where] the dignity of the person is being given importance." Further to the above Rosa's SLP gave value to the important contribution of individual stakeholders in reaching a final decision in agreement between parties, "It has to be a team decision because you do not have all the information. You can only help decide by giving your perspective of it and coming to a common ground regarding feeding strategy." This collaborative approach is reflected in the literature, as decision-making in end-stage dementia care, is best taken through a holistic appreciation of all ideas that are best achieved through a consensus-building approach (Yean & Anantham, 2015). Chun-yan and Tao (2004) added that through a consensus-building approach the patient's dignity, interests, and preferences for care do end up being respected even when the patient's past wishes are not reported, a situation that is commonly found in Maltese practice (see in Chapter, Sections 3 & 4). Furthermore seeking consensus does relate to finding a middle ground (see also in Chapter, Section 7), where through virtue theory, the right decision of character and trust holds strength in the decision-making process (Hartnett, 2011). Such an approach leads to a process where, despite the patient's current vulnerable condition, their past wishes, life history and respect for values in authenticity, are given prominence (ten Have, 2010; Gefenas, 2010).

In the process to reach optimal care for the person with dementia, the study findings indicated awareness in clinicians and family members to work together in a virtuous relationship based on mutual trust and shared decision-making. In fact, on the importance of building a trusting relationship, Rosa's son remarked, "Regarding EOL decisions, I have full confidence in the doctors." At the same time, Berta's nutrition nurse acknowledged in trust that the relatives do mean well for their elders by stating, "Such idea has to be brought forward with the relatives." It is relevant to point out that many clinicians showed appreciation that reaching consensus with the relatives does, in the end, safeguard the best interests of the patient. The importance of building a virtuous relationship is reflected in the literature, where a virtue approach when based on mutual trust, integrity and benevolence, do end up all being of importance in the provision of a moral approach to health care (Beauchamp & Childress, 2013). The value of such trusting relationship is further highlighted in the fact that it is a fundamental component to help resolve an ethical dilemma through consensus (Jones & Harper, 1995), where all parties work together in agreement in decision-making (*NICE,* 2006, March).

The importance of prudent practice and having the patience to deal with family members was observed in Rosa's SLP statement, "You have to be extremely patient because they are usually quite traumatised and they cannot take in much information. So you have to repeat it again and again.” Such an approach to avoid rushed decisions is a feature of consensus-buildings approach (Agius, 2010) leading to a decision that harbours good care that is of benefit for the patient (Yean & Anantham, 2015)

On the other hand, in various sections in this chapter, (see 2.E; 5.A, 6 & 10.A) reference has been made to the observed conflict between stakeholders regarding which treatment strategy (prolonging life versus dying with dignity) to follow in end-stage dementia care. In appreciation of these value-conflicts, consensus does help all parties to focus on reaching an agreement, in terms of beneficence and non-maleficence; on matters of safety, dignity, values and avoidance of suffering (Agius, 2010). A consensus approach does also facilitate the incorporation of an appraisal of the patient’s lived values, the relatives’ values, care needs and beliefs (Nelson & Nazareth, 2013), and in so doing consensus helps to safeguard the patient’s dignity and best interests in the dying phase of life (Agius; Swedish National Council, 2008; Chun-yan & Tao). Thus Katarin’s sister-in-law remarked, “Yes I believe our values and wishes are being respected in decisions … I know that she would always prefer to eat normally through her mouth. These are her wishes.”

Furthermore, it was observed that agreement through consensus between stakeholders helped to sustain the duty of stakeholders to respect the person in care. Lorenza’s daughter pointed out this issue by saying, “With the doctor, we the relatives all agreed, to let her go with the minimal intervention possible… We want her to live and die in a peaceful way, die a peaceful death with dignity.” This is reflected in the literature as in the formulation of a consensus-based management plan, respect of the patient’s dignity and best interests does help to sustain a deontological approach, where the duty is to support those vulnerable in care, including persons in end-stage dementia care (Chun-yan & Tao, 2004; Karlawish et al. 1999).

In an inclusive approach based on consensus, the relatives hold a strong say in the decisional process, yet it was observed that family members need to be guided to help reach agreement on what constitutes the best decisions for their kin in care. Rosa's SLP mentioned, "[You need to] explain to the relatives… and then they realise that they have a role to play in this." To this argument, Rosa's doctor added, "Wherever the relatives might not agree, you try to arrive at a consensus always keeping the best interests of the patient as your goal… [where] my focus would be to meet the patient's wishes, values and desires." These responses are reflected in the literature, as consensus-building approach does hold to task the inclusivity of all stakeholders including family members, where through a consensus process the focus in care aims to respect the patient's values and preferences in care, even in those instances where advance directives hold no legal title (Chun-yan & Tao, 2004). This approach does affirm the idea that consensus-building approach could serve as an ideal ethical model of decision-making in a Maltese situation where advance directives lack legal backing in the decision-making process.

Further to the above, it was appreciated from the study findings that the relatives are the best source of input regarding the patient's views, values, and wishes (see in Chapter, Section 4.A). Consequently, through a structured dialogue in consensus, properly guided relatives can help push forward the patient's values (Yean & Anantham, 2015), as a means to safeguard the patient's autonomy and dignity, as ultimately the decision belongs to the patient (Beauchamp & Childress, 2013). In helping family members and clinicians come to an agreement in accordance with beneficence on a plan of care (Agius, 2010), such consensus decisions, when guided by a patient's best interests approach, do promote the achievement of a favourable outcome as the person with dementia would stand to gain (*RCP*, 2010; "American Heart Association", 2010).

At the same time, it was observed that spirituality was given value by both clinicians and family members in decision-making. For instance, Gina's doctor remarked, "These elderly, many of them were practising Catholics, they have the faith not to let themselves die and do respect life.” Likewise, Lorenza’s daughter gave an account of the Christian values that were ingrained in her mother’s beliefs, “For her, the Church was her second home.” These values in safeguarding the sanctity-of-life, contrasted with QOL ideals as offered by other stakeholders. For instance, Pina’s SLP was categorical “Geriatrics is about QOL.” Likewise, Gina’s husband questioned the benefit of tube feeding in his frail wife by saying, “They were going to insert a tube…For us this would be additional torture on her.” This dispute in principles and values regarding sanctity-of-life and QOL is often a decisional nightmare as it often relates to the difficulty to reach agreement regarding the withholding or withdrawal of potentially burdensome futile treatment, as is tube feeding.

For this reason, Rosa’s doctor as a facilitator in seeking agreement through a consensus-building approach showed the necessary leadership by saying,

> If you give the right picture … it is quite easy for those involved, to come to an agreement without having any problems in the team taking decision…. [In this you need to] negotiate very wisely between all stakeholders to come to a common agreed decision that reaches consensus.

The deliberation of this statement opens multiple ethical arguments that need appropriate reflection in the context of a consensus-building approach.

The first consideration relates to the observation that the doctor held a central role in guiding the consensus-building process. On this approach, Rosa’s doctor added, “I feel that my role in the decision process is that not to be paternalistic, I think my role as the lead person is to guide the process.” This is reflected in the literature as the physician usually carries the duty of facilitator in consensus-building approach, which role is crucial in the process to set up the ground rules to bring stakeholders to an agreement (Karlawish et al., 1999). Such guidance by the facilitator helps avoid group domination (Jones & Hunter, 1995) and overcome paternalistic approaches (Chun-yan & Tao, 2004).

Secondly, it was appreciated from the study findings that as the EOL loomed close, sanctity-of-life and QOL worked closer together, a consideration that served as a point of convergence. This was pointed out by Berta's nutrition nurse, who said, "Her condition is not very good. I do not want to start a very uncomfortable intervention [in reference to NG tube feeding]; it is invasive and uncomfortable." In an appreciation of the literature, Karlawish et al. (1999) pointed out that consensus-building approach helps put on the table for deliberation, matters that need to be discussed and agreed upon, these include matters of patient wishes, suffering, comfort, dignity, and QOL. In so doing consensus does delineate a course of action that focuses the correct path to follow concerning an appraisal of QOL, while at the same time, the spirituality of family members and patients involved is given value (Agius, 2010).

Reaching agreement in consensus was observed to be strongly influenced by the ability to respect the values of all stakeholders involved, plus the team should discuss with relatives those options in care that are evidence-based. This approach was proposed by Rosa's doctor, who remarked, "To come to an agreement…you give the right picture which is realistic, evidence-based …. my focus would be to meet the patient's wishes, values & desires." This approach in consensus-building approach, where decisions give importance to the respect for values, is evidenced in the literature (Hughes & Williamson, 2019; Nelson & Nazareth, 2013). At the same time, Hughes and Fulford (2005) remarked that wherever consideration of values is done in synergy with evidence-based medicine, this does help to guide the decision process in the right path to reach agreement.

D. Blockers to consensus-building.

Despite all efforts to the contrary, a consensus-building approach remains vulnerable to situations where a blocker or blockers to consensus deny the possibility of reaching agreement in decision-making. Various clinicians highlighted this difficulty: "The relatives …want to decide for everybody…. At times even doing a trial period of intervention can be of help to get the relatives on board." (The nutrition nurse) The phenomenon of persisting disagreement hindering consensus between clinicians and relatives is a situation in care that is not unknown in the management of patients who lack decisional capacity (Chun-yan and Tao, 2004). One possible solution is to agree about a trial intervention with clear time and end-point objectives (RCP, 2010).

In the face of notable disagreement between stakeholders, one must reflect in how clinicians can help relatives, through appropriate communication and guidance (see in Chapter, Section 3.B), to focus their approach to decision-making by giving testimony of the patient's wishes, values and feelings (Reginald & Huntley, 2006) (see in Chapter, Section 4.A) and not decide on their own personal values (Gastmans, 2016).

Furthermore, Richardson (2009) pointed out that in the face of possible deep rift in beliefs and moral disagreement between stakeholders. In such cases, an in-depth appraisal of each conflicting issue is necessary in order to apply a holistic approach that is based on "reflective equilibrium" (p. 26), where patient's best interests have to be agreed upon by all parties in a consensus-building approach (Agius, 2010). One of the many issues that clinicians and family members have to face in the road to find agreement is to consider what are the patient's current needs (*RCP,* 2010) (see in Chapter, Section 3.E), and not base interventions and feeding needs in a celebration of the past.

At the same time, wherever possible, a more accurate appraisal of survival time could be of help to put in perspective the true needs from now until the end of life (Bayer, 2006). In so doing this could be of help to delineate a point of focus for decision-making through consensus. However, estimation of survival time remains unpredictable in end-stage dementia (see in Chapter, Section 2.C) even though the use of tools to estimate survival, such as stage 7c on the FAST score + co-morbidities can indicate six months survival ("Hospice Eligibility Criteria", 2008) with moderate accuracy (Hanrahan et al.,1999).

In a persisting situation of disagreement one possible solution that was suggested by Gina’s nutrition nurse was to refer problem situations to the attention of an ethics committee, “I believe there should be created a type of ethics committee that in such complex decision-making situations, this ethics committee is called in to be involved.” The intervention of such ethical bodies to help resolve a stalemate in decision-making to withhold or withdraw tube feeding (Monturo, 2009), is a necessary measure to be taken by physicians in order to safeguard the best interests of the patient under their care (*RCP,* 2010). What complicates matters in Maltese practice is that the *Maltese Health Act* (2013) is silent regarding ethics committees in bedside clinical situations of care (J. Cachia, personal communication, January 8, 2019) (see also in Chapter, Section 5.B). So in persisting discord with family members, Maltese physicians are denied the support of an ethics committee that holds a legal basis for intervention.

In those instances where it remains impossible to reach consensus in the best interests of the patient, the clinical team has to seek judicial and bioethical levels of intervention beyond the bedside in order to attain decisional resolution (Monturo, 2009). This could include taking appropriate action to place the patient under protection (*BMA*, 2018; *Mental Health Act*, 2012) (see in Chapter, Sections 3.C & 9.B).

Although with some limitations, a consensus-building approach does offer a holistic approach to decision-making, as it encompasses all ethical theories and principles. At the same time, it helps diminution of conflict by ensuring that both clinicians and family members do have a significant say in the decision-process. Furthermore, consensus-building approach helps to draw up a process for an agreed plan of care in end-stage dementia that safeguards the patients’ dignity and interests, by sustaining their values, beliefs, needs and preferences for care.

11. The Conclusion to the Chapter

The study findings indicated considerable variation in the attitudes and behaviours of clinicians and family members, leading to significant tension in decision-making to manage swallowing difficulties in end-stage dementia. An analysis of the interviews indicated that causes of this variance were multi-factorial and involved a complex array of variance in personal values and knowledge on end-stage dementia care in family members; and also concerned differences in professional values, personal beliefs, and practices in individual clinicians involved in the six case studies. These had to be factored in a clinical situation in end-stage dementia where the patient's lack of mental capacity for autonomous decision-making rendered them vulnerable as passive often forgotten bystanders in decision-making.

The variance in approach to decision-making between stakeholders was also observed to show a strong relationship to the fragility created by the lack of a legal framework in Malta to legitimise the patient's past wishes in the decision-process in end-stage dementia. Additionally, the absence of structured EOL guidelines to guide clinical management in dementia was also noted to complicate the already complex decision-making process in end-stage dementia.

The consequence of these factors led to the application of various ethical models in the decision-making leading to a liberal application of EOL strategy frameworks. Noteworthy to recall was the observation that in three out of the six case studies, the persons in end-stage dementia ended up being exposed to aggressive life-prolonging approaches to care through tube feeding, while in the other three situations in care, decisions favoured comfort feeding in a dying with dignity approach.

To this end, the cardinal decisional dilemma observed in the case studies was the difficulty faced by clinicians and family members to choose in swallowing difficulties between the following two care strategies, namely:

1. Aggressive *life-prolonging* intervention where pushing for proper nutrition, included as a valid option, measures to start tube feeding.
2. An appreciate that the EOL was near and thus instituting a *dying with dignity* approach, where QOL was giving value with measures taken for comfort care and avoidance of tube feeding.

In deliberation of the above cardinal dilemma in decision-making, the research findings provided a rich account of the ethical models and values involved in the management of swallowing difficulties in end-stage dementia.

The diversity in views regarding EOL management led to a revival of the debate between QOL and sanctity-of-life. While one case study gave primacy to vitalism and life-sustaining approach, on the other hand, many stakeholders in other case studies supported the approach to safeguard dying with dignity though sanctity-of-life, where a QOL approach was given consideration. On the other hand, some stakeholders focused their decisions solely on QOL considerations through an appraisal of the burden of care, in an EOL situation of severe physical and mental frailty, and suffering. In this deliberation, it was also observed that none of the stakeholders openly promoted arguments that favoured euthanasia.

One difficulty created by lack of EOL guidance was that various stakeholders showed wide variation in how, in terms of beneficence and non-maleficence, they opted to manage swallowing difficulties in end-stage dementia. The main argument of disagreement in the application of these principles often related to the importance given to the application in practice of three clinical procedures/attitudes [good nutrition, safety in swallowing and avoidance of burdensome futile care] that often complemented each other, but at times seemed contradictory to one another.

This variance in views regarding what constitutes benevolent care provoked considerable difficulty in some of the case studies to define what constitutes virtue in care that safeguards the patient's interests in the decision process. The difficulty to reach agreement on what constitutes optimal care through a virtuous approach that safeguards the patient’s best interests, led in some cases to reactive behaviours in certain stakeholders, with clinicians reverting to defensive practices in the face of situations where relatives remained inflexible in their persistence to feed patients unsafe to swallow food choices.

These rigid approaches to management taken by clinicians and family members rendered patients in care more vulnerable given the doubt created if their best interests still held primacy in care in such situations.

One of the major difficulties underpinning such confrontation between clinicians and family members in decision-making was related to ineffective communication between these two parties. This started with rarely utilised advance care planning in early dementia, leading to inappropriate exchange of ideas and knowledge that is needed to set up a joint plan of care as dementia progresses to the EOL. In fact, the lack of information regarding the manifestations of end-stage dementia resulted in increased difficulty in family members to accept an EOL approach to care. This was compounded by a paternalistic approach taken by most clinicians and relatives in early dementia, where the patient was denied a diagnosis; this led to inability of the patient to participate in discussions on future care and therefore the patients’ preferences for their EOL remained unknown.

Concerning shared decision-making through a team response in the management of swallowing difficulties, most clinicians involved valued the idea of a team approach with the active involvement of the relatives to promote the development of a joint plan of care. However, in various case studies, certain stakeholders were left out from the decisional process even though these forgotten stakeholders felt that they could have contributed positively to the decision taken.

Of interest was that many SLP’s provided input in the decision-making process that focused only on performing their duty to ensure safety in swallowing, while many nurses brought to the team decision a deontological approach where the nurse did his/her duty and obeyed medical orders. Such responses in deontology seemed to hinder a true exchange of ideas in the development of consensus-building in decision-making.

These findings led to the conclusion that under the complex circumstances experienced in end-stage dementia, a consensus-building approach seemed to uphold the role of the most suitable ethical decision-making model. Consensus-Building approach facilitated an honest, collaborative, decisional environment of compromise between clinicians and family members, while it safeguarded the dignity and interests of the person in care. Furthermore, a consensus-building approach appeared to encompass the major ethical theories and principles that were observed from the interview responses.

The next concluding chapter will summarise the rationale, the methodology used, and outcome derived from the study. At the same time an account will be given of the implications of the findings for future research; but also due attention will be given to any practical care applications that could be of benefit for persons with swallowing difficulties in end-stage dementia.

Chapter 7: Concluding Reflections

The concluding chapter rounds up the whole thesis through an appraisal of the reasoning underpinning the research question. This is followed by a brief overview of the main outcomes of the study and their significance concerning institutional care for persons in end-stage dementia in Malta. Furthermore an account is given of the limitations of the study followed by consideration for the implications of the findings for future research.

1. The Reasons Underpinning the Research

The progression of dementia to the end-stage of the disease process severely hinders the affected person's physical capabilities (ten Have, 2010), but also does ends up robbing their cognitive functions (Gefenas, 2010). Of these losses, none is more detrimental than the loss of control to decide matters that concern personal views and values regarding current and future welfare and care (Hall et al., 2009).

Additionally, it is known that no situation of care in end-stage dementia is more heart wrenching than taking decisions to manage swallowing difficulties. Such difficulty relates to the problem to deal with the close bonding and emotional interpretation of the management of suffering, survival, QOL, starvation and hunger in the EOL (Cunningham, 2012; Eggenberger & Nelms, 2004; Karlawish et al., 1999). In the resolution of the dilemma concerning management of swallowing difficulties, the question of who takes up the role of decision-maker (*RCP*, 2010) demands a moral response with the intent to facilitate an ethical approach to clinical decision-making.

Maltese researchers have over the past fifteen years considered the regulatory, clinical and social problems associated with dementia (*Consensus Document Endcare*, 2018; *Empowering Change*, 2015; Innes et al., 2011). However, little in-depth analysis has been done of how the various ethical models of decision-making hold a role in the management of swallowing difficulties in end-stage dementia in institutions, and how such decisions are influenced by the interaction of clinicians with family members involved in resolving dilemmas of EOL care in dementia.

In the face of the complex factors influencing decision-making in dementia, my research question was: *What ethical models are being used and underpin the decisions of clinical teams and other stakeholders in relation to swallowing difficulties in end-stage dementia?* To this end, the resolution of this ethical query aimed to help pave the way to explore, through moral reasoning (Ursery, 2005), new avenues of EOL care processes that could lead to a more balanced decision, which better safeguards the dignity and interests of the person with dementia in care (Agius, 2010).

The context that needed resolution in this ethical dilemma related principally to an appreciation of the complex conflicts involved in choosing between curative versus palliative approaches to care (Sampson et al., 2009). In this research, this conflict boiled down to a resolution of the dilemma between *prolonging life* and *dying with dignity.* To this end, in the clinical management of swallowing difficulties, decisions to prolong life did tend to favour the commencement of tube feeding, whilst in a dying with dignity approach, comfort feeding was preferred.

2. A Summary of Findings

A. The influence of ethical models in decision-making.

The observed findings reflected reports in the literature that decision-making in end-stage dementia is a complex process (Cummings, 2009). The effect of such complexity did replicate Hursthouse and Pettigrove (2018), in the sense that this led to the interplay of various ethical models in the decision-making process. It was observed that the relative importance of the ethical models involved in decision-making did vary from case to case. This variance was noted to depend mainly on the often conflicting perceptions of stakeholders on the prognostic estimation of the patient in care, and also related to a difference in opinion on how such patient's remaining life course should be managed. The study findings showed that some clinicians and relatives managed to find consensus in defining a balanced decision, drawing more or less consciously on virtue theory, through which optimal care was achieved that respected the patient's dignity and their best interests. However, in some situations, the achievement of such agreement was observed to be seriously challenged.

In a general overview of responses derived from clinicians and family members, the main focus in decision-making did usually consider human dignity concerns. Consequently, sanctity-of-life was respected, whatever decision was taken - be it aggressive management or palliation- in end-stage dementia care. However, there was an instance where vitalism was given prime importance in a show of absolute value being given to life. On the other hand, some clinicians and family members did pose primary importance to a QOL approach irrespective of remaining survival time. Of note was that none of the stakeholders showed support for euthanasia, the practice of which is illegal in Malta.

Further to this, the principles of beneficence and non-maleficence left their imprint in all case studies. As Arries and Cur (2005) remarked, these two principles were often found to be in conflict in their interpretation between stakeholders. Decisions upholding these principles were observed to be dependent on the relatives' values and beliefs in care but also were influenced by clinicians' values and attitudes to care. To this approach, it was noted that the emerging themes showed little appreciation of the notion of substituted judgements, both by clinicians who showed little interest in the application of this principled approach and also by many family members who instead preferred to apply their values in the decision-making process.

The study findings showed that at the root of the problem behind such variance in views between stakeholders, in accordance with beneficence and non-maleficence was the dilemma between choices for prolongation of life as opposed to a dying with dignity approach. Commonly, in the deliberation of which strategy framework works best for the patient, one observed that the clinical procedures/attitudes for, proper nutrition, safety in swallowing, and avoidance of burdensome futile care in the EOL, were involved at varying levels of priority, depending on the focus chosen in decision-making.

In the delivery of a response by clinicians and relatives to resolve the decisional dilemma in swallowing difficulties, it was observed that in many case studies, the decision-making process was based on an inappropriate team response, where commonly certain stakeholders, particularly relatives, were forgotten from inclusion in the decision process. Furthermore, the study findings showed some paternalistic approaches by some physicians, but more commonly it was observed that nurses and SLP's tended to follow a rather strict deontological approach to respect institutional rules and duty inherent in their profession. Such restricted view led to an inappropriate team approach and fragmentation in the decision-making process, where the true meaning of aiming for a shared response was often found to be challenged.

In appreciation of the above difficulties, an analysis of the findings showed that respect for the patients' past wishes in end-stage dementia care left much to be desired. Such lack of attention to precedent autonomy was a serious challenge to the safeguarding of dignity and interests of the person in end-stage dementia care, the causation of which was observed to be multi-factorial. One of the prime difficulties was that Maltese law is silent regarding advance directives. Another regulatory deficiency derives from the fact that in Maltese medical practice, there remains the absence of a national strategy to regulate EOL care in dementia. The study findings showed that these two medico-legal deficiencies severely hindered, not only respect for patient preferences for EOL but also ended up making it quite challenging to withhold or withdraw tube feeding in end-stage dementia, when such intervention was deemed to be futile and burdensome in the EOL.

Also, the difficulty created by the Maltese cultural response to refrain from divulging a sinister diagnosis to patients and the observed difficulty of Maltese people to plan their future care, both led many clinicians in the study to practice and concentrate on current issues, while showing little attention to future planning in dementia.

Moreover, these medico-legal difficulties and attitudes to care resulted in an emerging theme where all clinicians refrained from bringing up for discussion in end-stage dementia, any form of communication with relatives to reveal if in the past the patient had expressed preferences for or against tube feeding in end-stage dementia care. In this complicated situation, relatives were observed to be poorly supported and inadequately informed regarding appropriate responses to guide decision-making in end-stage dementia care, as is substituted judgement. This lack of support for relatives, plus the difficulty of clinicians to appropriately communicate with relatives, did contribute to further difficulty for these two stakeholders to interact together to seek and respect the patients' past wishes for their EOL. In fact, in most responses, the patient's role was observed to be entirely passive, frequently forgotten, and their past expressed views and wishes neither sought out nor considered in the decisions taken.

In appreciation of these conflicts, some clinicians and family members stated that taking decisions to manage swallowing difficulties in end-stage dementia should follow a team approach that includes relatives. In this response, the primary aim of team decision-making was to promote a consensus-building approach as a preferred ethical model of decision-making. These clinicians remarked that consensus-building helps to overcome the fragmentation of ideas leading to agreement and involvement of all stakeholders in a decision that seeks and respects the patients' wishes and interests in care. Clinicians believed that through consensus, the decision-making process could embrace the ideals of shared-decision-making where all work together to derive an approach that is more likely to uphold virtues and meet patient's best interests in the decision-making process. At the same time, a consensus-building approach was observed to respect in its process the major ethical models that were involved in the management of swallowing difficulties in end-stage dementia care.

3. Implications of the Study for local Geriatric Practice

The thematic analysis of the six cases studies revealed significant findings, which present a new contribution to the literature. The main finding was that for the first time, particular attention was focused on the attitudes and behaviours of Maltese clinicians and family members involved in decision-making to manage swallowing difficulties in end-stage dementia in institutional care. Such focus on attitudes and behaviours in decision-making was done in light of how this relationship affected the dignity and interests of persons with dementia in care.

In appreciation of the findings, the implications of this thesis appear to hold strong arguments for a re-appraisal of dementia care in Malta. It needs to be appreciated that in the past fifteen years, the introduction of the dementia strategy (*Empowering Change*, 2015), the revision of the *Mental Health Act* (2012) and the increased awareness of Maltese society in general (*Consensus Document Endcare,* 2018; Formosa, 2016) have led to great strides forward in terms of better safeguarding respect for persons with dementia. However, this thesis has revealed certain significant lacunae in Maltese medico-legal interventions that need appropriate resolution to promote a better person-centred response throughout the life course of persons with dementia, from diagnosis to the terminal stage of the disease process.

- **Recommendation 1: The Maltese Government should employ Public Guardians to help support vulnerable persons with dementia in decision-making regarding their welfare and care.**

Persons in end-stage dementia are in a vulnerable state in view of loss of autonomy to make decisions about their health. In an ideal situation, a family member should take up the role of guardian to safeguard the patient’s welfare in decision-making. This is often unrealistic to achieve. My study findings indicated that, to help minimise this vulnerability in decision-making in dementia, there is the need for the State to appoint Public Guardians to take up an official role of proxy decision-maker. This is particularly relevant in situations where patients do not have relatives who are willing to take up a guardianship role, in the presence of in-family conflict, and in situations where an urgent clinical decision needs to be taken in the absence of a guardian.

- **Recommendation 2: The Maltese *Health Act* needs to incorporate provision for the appointment of Ethics Committees for clinical settings.**

EOL clinical decision-making to manage swallowing difficulty in end-stage dementia is a situation of care where decision-making is complex and is frequently compounded by values-dispute between clinicians and family members. In situations where these stakeholders remain in strong disagreement about management, the intervention of a legally backed ethics committee can help promote solution of such dilemmas and safeguard the best interests of the person in care.

- **Recommendation 3: As recommended in the *National Dementia Stra*tegy (*Empowering Change*, 2015, p. 14), the Maltese Parliament should draft up a bill to be enacted into law to regulate Advance Directives regarding treatment decisions in the EOL.**

The study findings clearly showed that the patients' past wishes for EOL care in end-stage dementia are most often not being considered in clinical decision-making. The major reason why such preferences for care are often disregarded, relate to the lack of a legal framework to regulate Advance Directives, where the clinician, as is now, lacks legal support to safeguard the patient's wishes and values in EOL care. The enactment of such a law to regulate advance directives would help uphold better the dignity and interests of vulnerable persons in dementia decision-making, by giving value to their autonomy in the EOL.

- **Recommendation 4: With the backing of appropriate endorsement by the Medical Council, the Maltese Medical community and Allied Professionals should take concrete steps to develop practice guidelines to regulate EOL care in dementia**

Clinicians in the study were clearly in difficulty to practice appropriate EOL management that safeguards the best interests of their patients in dementia. This problem is often experienced in view of lack of National Guidelines to help regulate EOL care in patients with dementia. A medico-legal framework regulating EOL care is in fact essential to help safeguard the true needs, dignity and interests of persons with dementia who are most vulnerable in the late stages of their lives. Such a framework should include the acceptance of the finality of life, measures to safeguard precedent autonomy and a best interests approach in cognitive decline, the regulation of advance care planning, the regulation of decisions that concern withholding and withdrawal of extraordinary treatment in the EOL, and to help promote increased knowledge on the EOL in clinicians and relatives.

- **Recommendation 5: Nursing Home Physicians and Allied Professionals need to be better supported by Palliative Specialists and Hospice.**

The study findings did show that many clinicians were observed to be quite hesitant and ill-equiped to institute palliative approaches in end-stage dementia care. It is thus recommended that Maltese nursing homes work more closely with the Palliative department and Hospice. The appointment of practice palliative nurses that visit regularly the nursing homes would be a strong first step in achieving this objective.

- **Recommendation 6: Nursing Home Physicians and Allied Professionals need to be exposed to training to develop improved communication skills and learn appropriate procedures how to deal with problem family members.**

Clinicians need to be exposed to training in communicative skills, including instruction on how to follow a process of consensus-building appropriately. Such initiatives would help to define better decision-making that is inclusive of all stakeholders.

- **Recommendation 7: Family members need to be exposed to psychological support to deal with the emotional losses faced in dementia; and also be better assisted by clinicians to be empowered to take up the role of proxy decision-makers for their elders with dementia in care.**

The study showed that family members do play an essential part in the decisional process at a time in life when their kin are faced by a devastating diagnosis and prognosis. It is recommended that family members would benefit from the provision of psychological support to deal with their fragile emotions. At the same time, clinicians can do more and be more receptive of their needs by providing better information and a higher level of involvement and support in decision-making.

Strengthened with the results of this research, I have started various representations with the relevant stakeholders explaining the implications of my findings and promoting feasible improvements. Noteworthy is the project launched in April 2019, in collaboration with St. Vincent de Paul LTCF authorities, called *Relatives' Day* (taking a leaf from Parents' Day meetings in education), which has led to the implementation of regular scheduled meetings between the respective multidisciplinary teams, residents and their relatives in this institution. Such meetings aim for a better understanding of the lived experience of the patient as a person in care, a better explanation of the current active medical problems and future projections in care. Furthermore, during such meetings, the patient's and relatives' values are identified and documented in a process that promotes values-based care planning.

4. Limitations of the Study

The following is an additional account of study limitations (see also Chapter 4, Section 13).

Whilst the co-morbid criteria listed by Mitchell et al. (2010) to determine six-month mortality included the need for regular weight measurement, measurement of a plated meal eaten, and a serum albumen assay, the inclusion of these variables in this study was found to be problematic as such measurements were not routinely recorded at SVP. Consequently, these criteria were withdrawn in the determination of inclusion criteria in my study. Knowing this, the exclusion of such optional requisites for identification of six-month mortality could potentially have led to the study of a different group of patients that differed from those listed under the international criteria listed above.

Moreover, the fact that the case studies were retrospective in nature exposed the researcher to the possibility of missing valuable information that could only be obtained if I were to be present during the actual decisional process taken regarding the management of swallowing difficulties in end-stage dementia.

5. Suggestions for Future Research

In reflecting on the study findings, what was significantly absent in the deliberation between stakeholders was the active voice of the person with dementia in care. Gheorghe at al. (2011) reported that views of older people regarding EOL decision-making depended on the perceived closeness to their EOL, and also depended on, whether or not in a hypothetical future situation, the persons in care was still capable of holding cognitive abilities. I do firmly believe that such a similar study should be carried out to identify better what Maltese older persons prefer for themselves in their EOL. The findings of such a study could help delineate the aged population's attitudes to EOL care in response to a sinister diagnosis as is dementia. Such information would help decision-makers to set up guidelines for the EOL in Malta, based on population attitudes to EOL care (Abela, 2015) in end-stage dementia care.

The second suggestion for further study was derived from the observation that Maltese people do generally refrain from planning for their EOL. It would be interesting to do a multi-generation study of how Maltese people look at their future health issues and planning of difficult health decisions for their EOL. Making a comparison of attitudes between generations regarding social, spiritual and cultural challenges in planning ahead would be an interesting sociological study to delineate attitudes and behaviours regarding how we as a population look at our future health care and decision-making.

In conclusion, decision-making to manage swallowing difficulties in dementia is a complex process that causes great concern for clinicians and family members in deriving decisions that safeguard the patient's best interests. This decisional complexity seems to be particularly challenging in Malta given the unique medico-legal lacunae and cultural attitudes that all leave their mark to define a moral solution to decisions concerning EOL care in end-stage dementia care. However, I remain firmly convinced that clinicians and family members, despite their differences in views and values regarding care, do retain the welfare of persons with dementia at heart. To this end, implementing of ethical models to facilitate clinical decision-making, particularly consensus-building approaches, does help to enable agreement and inclusivity between stakeholders. The fact that consensus-building respects other ethical models involved in end-stage dementia care ensures that the patient's dignity and best interestss are safeguarded at a time in life when in their vulnerability, they need it most.

8. Bibliography

Abbey, J., Wilson, J., Chang, P., & Abbey, B. (2007). *Advances in the Management of Severe Dementia*. Dementia Collaborative Research Centre Australia.

Abela, S., Mamo, J., Aquilina, C., & Scerri, C. (2007). Estimated prevalence of dementia in the Maltese Islands. *Malta Medical Journal. 19*(2), 23.

Abela, J. (2015). GP's and EOL decisions: Views and Experiences. *Malta Medical Journal. 27*(2), 31-36.

Abela, J., Mallia, P. (2010). An evaluation of palliative care education in the specialist training programme in family medicine. *Malta Medical Journal, 22*(4), 26-33.

About Thematic Analysis (2006). The University of Auckland. New Zealand.

Active and Passive Euthanasia. (2014). BBC Ethics Guide.

Admissions Policy to St. Vincent de Paul Long-term care Facility. (2015, February). St. Vincent de Paul LTCF, Malta.

Advance Care Planning. (2009, February). National Guidelines. Royal College of Physicians. Number: 12.

Agich, G. J. (2003). *Dependence and Autonomy in Old Age.* Cambridge: Cambridge University Press.

Agius, E. (2002). Withholding and withdrawing treatments: ethics at the bedside. In M. N. Cauchi. (Ed.), *Bioethical issues at the beginning and end-of-life* (pp. 125-134). The Bioethics Consultative Committee. Malta: Government Printing Press..

Agius, E. (2010, November). *Safeguarding the unconscious patients' overall benefit: towards a 'consensus-building' approach*. Seminar on Decision-Making Process. regarding Medical Treatment in *EOL* situations. Council of Europe Strasbourg.

Allison, T.A., Balbino, R.T., & Covinsky, K.E. (2019) Caring community and relationship centred care on an end-stage dementia special care unit. *Age and Ageing.*

Alzheimer's Association. (2007). *Dementia care practice recommendations for assisted living residences and nursing homes. Phase 3: EOL Care*. J. Tilly, & P. Reed (Eds.).

Alzheimer’s Association. (2010, July 5). *End-of-Life care. Ethical issues in Alzheimer’s disease: Care and Patients’ Rights.*

Alzheimer’s Association. (2011, September). *Assisted oral feeding and tube-feeding*.

Alzheimer Europe. (2008). *EOL Care for People with Dementia.*

Alzheimer Europe. (2008b). *Dementia in Europe.*

Alzheimer Europe. (2009, October). *Beneficence and Non-Maleficence*.

Alzheimer Europe (2009b). *Ethical principles in relation to advance directives and personhood*.

Amella, E.J., Lawrence, J.F., & Gresle, S.O. (2005). Tube feeding: Prolonging life or death in vulnerable populations? *Mortality, 10*(1), 69-81.

American Geriatrics Society feeding tubes in advanced dementia: Position statement of the American Geriatrics Society Ethics Committee and Clinical Practice and Models of Care Committee (2014). *Journal of the American Geriatrics Society, 62,* 1590-1593.

American Psychological Association. (2010). *Publication manual* (6th. ed). Washington: American Psychological Assocation.

American Psychiatric Association. (2013). *Highlights of changes from DSM-IV-TR to DSM-5.*

American Heart Association (2010). *Consensus-based decision-making processes*. Mission Lifeline.

Aminoff, B. Z., & Adunsky, A. (2006). Their last 6 months: suffering and survival of end-stage patient with dementias. *Age and Ageing*; *35*, 597-601.

AMT Bridle (2011). *Nasal tube retaining bridle*. Applied Medical Technology Inc. USA: Brecksville.

Arenella, C. (2005). Artificial Nutrition and Hydration: having the conversation. *Today's Geriatric Medicine, 7*(5), 24.

Aristotle. (n.d.). AZ Quotes.com. Retrieved October 20, 2017, from AZQuotes.com Web.

Arries, E., & Cur, M. (2005). Virtue ethics: an approach to moral dilemmas in nursing, *Philosophical Discourse, 28*(3), 64-72.

Asciak, M. (2010). *Ordinary and Extraordinary treatment – hydration and nutrition*. Bioethics Committee. Malta.

Azzopardi, J., Galea, D., Parker, P.A., Calleja, N., Sloan, J.A., & Zammit, R. (2017). Breaking bad news in cancer: an assessment of Maltese patients' preferences, *Malta Medical School Gazette, 01*(04), 36-46.

Balzan, D., Ferry, P., Mangion, S., & Zammit, P. (2015, January 24). *Mortality statistics at St. Vincent de Paul Residence, Malta*. [Power Point slides].

Bancroft Hecht, M., & Shiel, W.C. (2011). *Advance medical directives* (living will, power of attorney, and health care proxy). MedicineNet

Baron, J. (2012). The point of normative models in judgment and decision-making. *Frontiers in Psychology*, *3*(577), 1-3.

Barr, P. J., & Elwyn, G. (2015). *Measurement challenges in shared decision-making: putting the patient in patient-reported measures,* Health Expectations Online.

Barry, M. J., & Edgman-Levitan, S. (2012). Shared decision-making – the pinnacle of patient centered care, *New England Journal of Medicine*, *366*, 780-781.

Bayer, A. (2006). Death with dementia – the need for better care. Editorial. *Age and Ageing*, *35*, 101-102.

Beauchamp, T.L., & Childress, J.F. (1994). *Principles of biomedical ethics* (7th ed.). New York: Oxford University Press.

Beauchamp, T.L., & Childress, J.F. (2012/2013). *Principles of biomedical ethics* (7th ed.). New York: Oxford University Press.

Becker, G. (1994). The oldest old: autonomy and the face of frailty. *Journal of Aging Studies, 8*, 59-76.

Becker, H. S. (2000/2011). Cases, causes, conjuctures, stories and images. In R. Gomm, M. Hammersley, & P. Foster (Eds.), *Case Study Method* (pp. 223-233). London: SAGE Publications.

Bellelli, G., Frisoni, G.B. & Trabucchi, M. (2005). Feeding tube use in Italian nursing homes: the role of cultural factors. *Journal of the American Directors Association, 6,* 87-88.

Bennahum, D. A. (2010). The clinical challenge of uncertain diagnosis and prognosis in patients with Dementia. In R. B. Purtilo & H. A. M. J. ten Have (Eds.), *Ethical foundations of palliative care for Alzheimer disease* (pp. 48-58). Baltimore: John Hopkins University Press.

Bentham, J. (1780). *An introduction to the principles of morals and legislation*. (Re-published, 1988). New York: Prometheus Books.

Bentham, J. (2005). *Deontology or the science of morality.* (Reprinted, 1st Ed. 1834.). USA: Elibron Classics Series.

Birnbacher, D. (2007, May 31). Terminal sedation, euthanasia, and causal roles. *Medscape General Medicine, 9*(2), 48.

Bhat, A. (2019). *Consecutive sampling – definition, examples, advantages and disadvantages.* QuestionPro.

Birch, D., & Stokoe, D. (2010). Caring for people with end-stage Dementia. *Nursing Older People*, *22*(2), 31-36.

Black, N.A. (1994). Appropriateness of medical care in Europe: a commentary. *International Journal of Quality Health Care, 6,* 231-232

Blackford, J., Strickland, E., & Morris, B. (2007). Advance care planning in residential aged care facilities. *Contemporary Nurse, 27*, 141-151.

Blackford, R. (2009). Moral pluralism versus the total view: why Singer is wrong about radical life extension. *Journal of Medical Ethics, 35*, 747-752

Blasszauer, B. (1994, September/October). Institutional care of the elderly. *Hastings Center, 24*(5).

Bolsin, S., Faunce, T., & Oakley, J. (2005). Practical virtual ethics: healthcare whistleblowing and portable digital technology. *Journal of Medical Ethics*, *31*, 612-618.

Borg Xuereb, C. (2015). Long-term care. In M. Formosa, & Scerri, C. (Eds.), *Population ageing in Malta: multidisciplinary perspectives* (pp. 305-324). Malta: Malta University Press.

Botes, A. (2000). A comparision between the ethics of justice and the ethics of care. *Journal of advanced nursing, 32*(5), 1071-1075.

Boult, C., Green, A. F., Boult, L. B., Pacala, J. T., & Snyder, C. (2009). Successful models of comprehensive care for older adults with chronic conditions: evidence for the institute of medicine "retooling for an aging America" report. *Journal of the American Geriatric Society, 57*(12), 2348-2349.

Bowker, L. K., Price, J. D., & Smith, S. C. (2006). *Oxford Handbook of Geriatric Medicine.* New York: Oxford University Press.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77-101

Brauner, D.J., Muir, J.C., & Sachs, G.A. (2000). Treating nondementia illnesses in patients with dementia. *Journal of the American Medical Association, 283*(24), 320-325

Brayne, C., Gao, L., Dewey, M., & Matthews, F. E. (2006). Dementia before death in ageing societies - the promise of prevention and the reality. *Medical Research Council Cognitive Function and Ageing Study Investigators, 3*(10), 397.

Brincat, M. (2008). *Elder abuse within St. Vincent de Paul*. (Unpublished dissertation). University of Malta, Malta.

Brinkworth, M. M. (2015). Ageing population: life course transitions and demographic trends in Malta. In M. Formosa, & C. Scerri. (Eds.), *Population ageing in Malta: multidisciplinary perspectives* (pp. 3-22). Malta: Malta University Press.

British Geriatrics Society. (2012, November). *Dysphagia management for older people towards the EOL*.

British Medical Assocation (2018, December). *Clinically-assisted nutrition and hydration (CANH) and adults who lack the capacity to consent*. Guidance for decision-making in England and Wales. J. Chisholm et al. (Eds). British Medical Association and the Royal College of Physicians. UK.

British National Formulary. (2018, September). London: BMJ Group Publishers.

Bregje, D., Onwuteaka-Philipsen, H., Pasman, R. W., Kruit, A., van der Heide, A., Ribbe, M. W., & van der Wal G. (2001). Withholding or withdrawing artificial administration of food and fluids in nursing home patients. *Age and Ageing, 30*, 459-469

Brown, M.A., Sampson, E.L., Jones, L., & Barron, A. (2012). Prognostic indicators of 6-month mortality in elder people with advanced dementia. A systematic review. *Palliative Medicine, 27*(5), 389-400.

Buff, D. (2006). Against the flow: tube feeding and survival in patients with dementia. *American Academy of Hospice and Palliative Medicine, 7*(1).

Byrd, S. (2004). The use of artificial hydration and nutrition in elders with advanced dementia. *Topics in Advanced Practice Nursing, 4*(2).

Cachia, J. (2019, January 8). Mental Health Commissioner. Department of Health. Malta

Camilleri, E. (2006). *Hydration in dependent elderly persons in an institution*. (Unpublished dissertation). University of Malta, Malta

Candy, B., Sampson, E. L., & Jones, L. (2009). Enteral tube feeding in older people with advanced dementia: findings from a Cochrane systematic review. *International Journal of Palliative Nursing, 15*(8), 396-404.

Cantor, N.L. (2003). QOL in legal perspective. In S.G., Post (Ed.), *Encyclopedia of Bioethics* (3rd. ed.) (pp. 1396-1402). USA: Gale.

Caplan, G. A, Meller, A., Squires, B., Chan, S., & Willet, W. (2006). Advance care planning and hospital in the nursing home. *Age and Ageing*, *35*, 581-585.

Carey, T. S., Hanson, L., Garrett, J. M., Lewis, C., Phifer, N., Cox, C. E., & Jackman, A. (2006). Expectations and outcomes of gastric feeding tubes. *American Journal of Medicine, 119*(6), 527.

Caring for dying, deceased residents and their relatives. (2018, April, 12). St. Vincent de Paul LTC Facility. Nursing Department. (Unpublished).

Carmel S., Werner, P., & Ziedenberg, H. (2007). Physicians' and nurses' preference in using life-sustaining treatments. *Nursing Ethics*, 14, 5.

Caruana Pulpan, O. & Scerri, C. (2014). Practices in diagnosis, discloscure and pharmacotherapeutic management of dementia by general practitioners – a national survey. *Aging and Mental Health, 18*(2), 179-186.

Cassar, D. (2010). *Advance directives: the surrounding legal issues*. (Unpublished thesis). University of Malta, Malta,

Cassar, D. (2013, August). *EOL* decisions and advance directives. *Journal of the Malta College of Family Doctors*, *20*(2), 10–12.

Cassar, P. (1994). *St. Vincent de Paule's Residence for the Elderly: The medico-social record*. Malta: Parliamentary Secretariat for the Elderly.

Cassel, E. J. (1982). The nature of suffering. *The New England Journal of Medicine, 306*, 639-645.

Cassel, C. K. (2010). Forward. In R. B. Purtilo & H. A. M. J. ten Have (Eds.), *Ethical foundations of palliative care for Alzheimer disease* (pp. ix-xi). Baltimore: John Hopkins University Press.

Cervo, F.A., Bryan, l., & Farber, S. (2006). To PEG or not to PEG. A review of evidence for placing feeding tubes in advanced dementia and the decision-making process. *Geriatrics, 61*(6), 30-35.

Chadwick, D., Kelly, A., & Watson. (2007, July). *Problems Swallowing?* NHS National Patient Safety Agency.

Chalmers-Watson, T., McKenzie, C.A., Burnham, S.P. (2002). An audit of the percutaneous endoscopic gastrostomy (PEG) service provided by a nutrition team in a district gerneal hospital over a three year period. *Proceedings of the Nutrition Society Nutrition Society, 61*, 17.

Cherishing Life (2016, August 6). *Bishops Pastoral Letter.* Malta. ChurchinMalta.org

Chircop, K. (2017, November 18). *RIG feeding* [Power Point slides].

Chochinov, H.M., Hack, T., Hassar, T., Kristjanson, L.J. et al. (2002). Dignity in the terminally ill: a cross-sectional, cohort study. *The Lancet, 360*, 2026-2030.

Chochinov, H.M. (2007). Dignity and the essence of medicine: the A, B, C, and D of dignity conserving care. *British Medical Journal, 335*(7612), 184-187.

Chonko, L. (2012). *Ethical Theories*. Arlington: The University of Texas.

Chun-yan, T., & Tao, J. (2004). Strategic ambiguities in the process of consent: role of the family in decisions to forgo life-sustaining treatment for incompetent elderly patients. *Journal of Medicine and Philosophy*, *29*(2), 207-223.

Code of Organisation and Civil Procedure (1855, August 1). Malta.

Code of Organization and Civil Procedure and the Civil Code (ACT No. XXIV of 2012). Malta.

Coetzee, R.H., Leask, S.J. & Jones, R.G. (2003). The attitudes of carers and old age psychiatrists towards the treatment of potentially fatal events in end-stage dementia. *International Journal of Geriatric Psychiatry. 18*(2), 169-173.

Commission for Social Care Inspection. (2008, June). *See me, not just the Dementia*.

Congregation for the Doctrine of the Faith (2007). *Commentary on "Responses to Certain Questions of the United States Conference of Catholic Bishops Concerning Artificial Nutrition and Hydration."*

Consensus Document EndCare (2018). Erasmus+ Project of the Bioethics Research Programme. (Unpublished). University of Malta. Malta

Copp, D. (2007). *Oxford Handbook of Ethical Theory.* Oxford: Oxford University Press.

Craig, G.M. (1994). On withholding nutrition and hydration in the terminally ill: has palliative medicine gone too far? *Journal of Medical Ethics, 10*, 139-143.

Creswell, J. W., & Plano Clark, V. L. (2004). *Principles of qualitative research: designing a qualitative study.* [Power Point slides].

Cultural Evolution (2013, Feb). *Stanford Encyclopedia of Philosophy*. Stanford: Metaphysics Research Lab.

Cummings, S. M. (1999). Adequacy of discharge plans and rehospitalisation among hospitalised Patient with dementias. *Health and Social Work, 24*(4), 249-259.

Cunningham, C. (2012 May, 3). *In-patient feeding challenges. Tube feeding in dementia: ethics and evidence.* The Society for Acute Medicine. Dublin.

Dalli, M. (2016, July 25). Euthanasia 'could never be in a person's best interests', Bishops warn MP's. *Malta Today online*.

Davies, A. (2009). *The case of Tony Bland.*

Davis, A. (1994). All babies should be kept alive as far as possible. In R. Gillon (Ed.). *Principles of Health Care Ethics*. (pp. 629-641). John Wiley & Sons. England

Day, L. A. (2006). *Ethics in media communications. Cases and controversies*. California: Thomson Wadsworth Publications.

Darzins, D., Molloy, P., & Strang, D. (2000). *Who can decide: the 6 step capacity assessment process.* Cork: New Grange Press.

DeGrazia, D. & Rowan, A.N. (1991). Pain, Suffering, and Anxiety in animls and humans. *Theoretical Medicine, 12*(3), 193-211.

Deguara, S. (2011). *Withholding and withdrawal of artificial nutrition and hydration: is it a permissible omission*. (Unpublished thesis). University of Malta, Malta

Dekkers, W. J. M. (2010). Autonomy and the lived body in cases of severe Dementia. In R. B. Purtilo & H. A. M. J. ten Have (Eds.), *Ethical foundations of palliative care for Alzheimer disease* (pp. 115-130). Baltimore: John Hopkins University Press.

Dekkers, W. (2010). Persons with severe dementia and the notion of bodily autonomy. In J. C.Hughes, M. Lloyd-Williams & G. A.Sachs (Eds.). *Supportive care for the Person with Dementia* (pp.253-262). New York: Oxford University Press.

DeLegge, M.H., Borak, G., Moore, N. (2005). Central venous access in the home parenteral nutrition population-you PICC. *Journal of Parenteral and Enteral Nutrition, 29*(6), 425-428

Dementia information for carers, families and friends of people with severe and end-stage dementia. (2007). 2nd Edition. *Palliative Care Dementia Interface*. University of West Sydney, Sydney.

Dementia in the Long-term Setting. (2009). Guideline summary NGC-7639.

Department of Health (UK). (2008, July). *EOL Care strategy*.

Department of Health (Malta). (2013). *St. Vincent de Paul Residence*. Malta Government website.

Describing Death in America. What we need to know. (2003). Institute of Medicine National Research Council, USA.

Dewing, J. (2008). Personhood and dementia: revisitng Tom Kitwood's ideas. *Int Journal of Older People Nursing, 3*(1), 3-13.

Diacono, T. (October 14, 2015). *Malta Today Online*.

Diehl, M., & Stroebe, W. (1987). Productivity loss in brainstorming groups: towards the solution of a riddle. *Journal of Personality and Social Psychology, 53,* 497-509.

Dillon, S. M. (n.d.) *Descriptive decision-making*: comparing theory with practice.

Dimech, J. (2012). *The development of statutory LTC in Malta: a historical record. Malta* [Power Point Slides]. June 4, 2012.

Donmoyer, R. (2000/2011). Generalizaility and the single-case study. In R. Gomm, M. Hammersley, & P. Foster (Eds.), *Case Study Method* (pp. 45-68). London: SAGE Publications.

Doublesin, M.G. (2016). *The impact of multicultural exposure on Maltese society in the late 20th and early 21st century and its challenge for counsellors: a narrative ethnographic approach.* (Unpublished). University of Malta, Malta.

Dovey, D. (2015, February 9). *Canada legalizes euthanasia.*

Downing, J. & Larkin, P. (2009). Building consensus. *International Journal of Palliative Nurses, 15*(1), 3.

Drake, S. (2001, November). End of life Planning: Questions and Answers with Disabilities *Advocates Gazette Journal*

Dresser, R. (2004). At law: Schiavo: a hard case makes questionable law. *Hastings Center Report, 34,* 8-9.

Druml, C., Ballmer, P.E., Druml, W., Oehmichen, F., Shenkin, A., Singer, P., Soeters, P., Weimann, A., & Bischoff, S. C. (2016). ESPEN guideline on ethical aspects of artificial nutrition and hydration. *Clinical Nutrition, 1*(12).

Duijnstee, M.S.H. (1994). Relatives of Persons Suffering from Dementia: Differences in the Burden. Ageing and Society, 14(4), 499-519.

Dunlop, R. J., Ellershaw, J. E., Baines, M. J., Sykes, N., & Saunders, C. M. (1995). On withholding nutrition and hydration in the terminally ill: has palliative medicine gone too far? A reply. *Journal of Medical Ethics, 21,* 141-143.

Dunlop, J.T. (2006, January 27). *The feeding tube dilemma: key questions*. The Centre for Bioethics and Human Dignity. Trinity International University.

Dworkin, G. (1988). *The theory and practice of autonomy.* Cambridge University Press.

Dworkin, R. (1994). *Life's Dominium.* New York: Random House.

Dyer, K. A. (n.d.). *What are end-of-life and end-of-life care?*

Effective decision-making in teams. (n.d.). The Foundation Coalition.

Eggenberger, S.E. & Nelms, T.P. (2004). Artificial hydration and nutrition in advanced Alzheimer's disease: facilitating family decision-making. *Journal of Clinical Nursing, 13,* 661-667.

Ellul, J. (2014). *The Catholic identity of Malta after ten years of membership in the European Union. Occasional paper*. (Unpublished). Institute for European Studies, University of Malta, Malta.

Elstein, A. S. (2001). Naturalistic decision-making and clinical judgment. *Journal of behavioural decision-making. 14*, 354-384.

Elwyn, G., Edwards, A., Gwyn, R., & Grol, R. (1999). Towards a feasible model for shared decision-making: focus group study with general practice registrars. *British Medical Journal, 319*, 753-756.

Elwyn, G., Frosch, D., Thomson, R., Joseph-Williams, N., Lloyd, A., Kinnersley, P., Cording, E., Tomson, D., Dodd, C., Rolinick, S., Edwards, A., & Barry, M. (2012). Shared decision-making: a model for clinical practice. *Journal of General Internal Medicine, 27*(10), 1361-1367.

Emanuel, L., & Scandrett, K. G. (2010). *Decisions at the EOL: have we come of age?* Buehler Center on Aging.

Emerald Publishing. (2019, May). *How to undertake case study research*

Empowering Change: *A National Strategy for Dementia in the Maltese Islands 2015-2023*. (2015). Parliamentary Secretariat for the Rights of Persons with Disability and Active Ageing.

End of Life Care Strategy. (2008, July). Department of Health, UK.

Epp, T.D. (2003, April). Person-centred dementia care: a vision to be refined. *The Canadian Alzheimer Disease Review,* 14-18.

Epstein, R. M., Franks, P., Fiscella, K., Shields, C. G., Meldrum, S. C., Kravitz, R. L., & Duberstein, P. R. (2005). Measuring patient-centered communication in patient-physician consultations: theoretical and practical issues. *Social Science and Medicine*, *61,* 1516-1528.

Erol, R., Brooker, D. & Peel, E. (2015). *Women and Dementia.* Alzheimer's Disease International.

European Charter of Patients' Rights (2002, November). Active Citizen Network. Rome.

European Charter of Patients' Rights. (2011, April). Active Citizenship Network. Malta Health Network.

*Euthanasia and Assisted Suicid*e (n.d.). Pros and Cons.com

Evans, G. E., and Robinson, L. (2010). The role of the family doctor in supportive care for people with dementia. In J. C. Hughes, M. Lloyd-Williams & G. A. Sachs (Eds.), *Supportive care for the Person with Dementia* (pp.139-148). New York: Oxford University Press.

Fagerlin, A., & Schneider, C.E. (2004). Enough. The Failure of the living will. *Hastings Central Repository. 34*(2), 30-42.

Farlex Partner Medical Dictionary. (2012). The Free Dictionary.com

Farrugia-Bonello, R. (2015). Community care. In M. Formosa, & C. Scerri (Eds.), *Population ageing in Malta: multidisciplinary perspectives* (pp. 263-282). Malta: Malta University Press.

Farrugia, R. (2008). *Family involvement in the care of older relatives at SVPR.* (Unpublished dissertation). University of Malta, Malta.

Fenech, M.A. (2001). *Abuse within a chronic care institutional setting for older persons in Malta*. (Unpublished master's degree). University of Malta, Malta.

Fink, A., Kosecoff, J., Chassin, M., & Brook, R.H. (1984). Consensus methods: characteristics and guidelines for use. *American Journal of Public Health, 74* (9), 979-983.

Finnes, J. (1994). Theology and the 4 principles: a Roman Catholic view. In R. Gillon (Ed.). *Principles of Health Care Ethics*. (pp. 31-44). John Wiley & Sons. England.

Finucane, T. E., Christmas, C., & Travis, K. (1999, October) Tube feeding in patients with advanced dementia. *Journal of the American Medical Association, 282,* 1365-1370.

Fiorentino, R. (2016, November 9). Medical Superintendent. St. Vincent de Paul LTC Facility. Department of Health, Elderly and Community Care.

Fiorini, A. (2002). The elderly patient and QOL judgements. In M. N. Cauchi (Ed.). *Bioethical issues at the Beginning and EOL* (pp. 101-108). The Bioethics Consultative Committee. Malta: Government Printing Press.

Fiorini, A. (2015). The development of the specialty of geriatric medicine. In M. Formosa, & C. Scerri. (Eds.), *Population ageing in Malta: multidisciplinary perspectives* (pp. 123-144). Malta: Malta University Press.

Flacker, J. M., & Kiely, D. K. (2003). Mortality-related factors and 1 year Survival in Nursing Home Residents. *Journal of the American Geriatric Society, 51*, 213-221.

Food and Nutrition Policy and Action Plan for Malta 2015-2020. (2014, September). Parliamentary Secretariat for Health. Malta.

Formosa, M. & Scerri, C. (2015). Introduction. In M. Formosa, & Scerri, C. (Eds.), *Population Ageing in Malta: Multidisciplinary perspectives* (pp. xxxi-xlviii). Malta: Malta University Press.

Formosa, M. (2016). *Ageing and later life in Malta. Issues, policies and future trends*. Malta: Gutenberg Press.

Franklin, L.L., Temestedt, B.M., & Nordenfelt, L. (2006). Views on dignity of elderly nursing home residents. *Nursing Ethics, 13*, 130-146.

Frendo, M. (2017). *Death with dignity for the irremediably ill: Physician-assisted dying from a Maltese perspective within a comparative review.* (Unpublished thesis). University of Malta, Malta

Frey, R.G. (2014). The fear of a slippery slope. In G.Dworkin, R.G. Frey, & S. Bok (Eds.), *Euthanasia and Physician-assisted Suicide.* Cambridge University Press.

Froggatt, K., & Parker, D. (2010). Care homes and LTC for people with dementia. In J. C.Hughes, M. Lloyd-Williams & G. A.Sachs (Eds.), *Supportive care for the Person with Dementia.* (pp.181-188). New York: Oxford University Press.

Functional Assessment Staging Test. (n.d.). Medical Care Corporation.

Furlong, E. (2010). The role of nurses and nursing education in the palliative care of patients and families. In R. B. Purtilo & H. A. M. J. ten Have (Eds.), *Ethical foundations of palliative care for Alzheimer disease* (pp. 243-260). Baltimore: John Hopkins University Press.

Gafa, B. (2011, October 24). Legal. Advisor. Department of Health, Elderly and Community Care. Malta.

Gallagher, R. (2011). Swallowing difficulties. A prognostic signpost. *Palliative Care Files,* 1407-1420.

Gardiner, C., Cobb, M., Gott, M., & Ingleton, C. (2011). Barriers to providing palliative care for older people in acute hospitals. *Age and Ageing*, *40*, 233-238.

Gastmans, C. (2016). Dignity enhancing care for person with dementia and its application to advance euthanasia directives. In J. Platzer, F. Grossschadl (Eds.). *Entschiedungen am Lebensende* (pp. 145-164). Nomos: Baden-Baden

Gefenas, E. (2010). Changing patterns of protection and care of incapacitated adults. In R. B. Purtilo & H. A. M. J. ten Have (Eds.), *Ethical foundations of palliative care for Alzheimer disease* (pp. 278 -289). Baltimore: John Hopkins University Press.

General Medical Council. (2010, May 20). *Treatment and care towards the EOL: good practice in decision-making.*

General Medical Council. (2012, March 12). *Leadership and management for all doctors.*

Gheorghe, C., Vasquez, R., Casanegra, A., Argento, V., et al. Elders' environs and their *EOL* preferences. (January, 2011). *Journal of the American Medical Directors Association*, *12*, 22-28

Giantin, V., Siviero, P., Simonato, M., Lasevoli, M., Pengo V., Andrigo, M. (2012). Physicians' and nurses' experiences of EOL decision-making in geriatric settings. *Aging Clinical Expertise Research. 24*(5), 537-547.

Gibson, L., et al. (2009). *The power of partnership: palliative care in dementia*. UK: SCIE.

Gillick, M. R. (2000, January). Rethinking the role of tube feeding in patients with advanced dementia. *The New England Journal of Medicine, 342*(3), 206-210.

Gillick, M. R. (2010). Advance care planning: an American view. In J. C.Hughes, M. Lloyd-Williams, & G.A.Sachs (Eds.). *Supportive care for the Person with Dementia*. (pp. 263-270). Oxford University Press. New York

Gillon, R. (1994). *Principles of Health Care Ethics*. England: John Wiley & Sons.

Gilmore, A. (1984). Sanctity-of-life versus QOL – the continuing debate. *Canadian Medical Association,* (130), 180-181.

Givens, J. L., Kiely, D. K., Carey, K., & Mitchell, S. L. (2009). Healthcare proxies of nursing home residents with advanced dementia: decisions they confront and their satisfaction with decision-making. *Journal of the American Geriatric Society*. *57*, 1149-1155.

Glover, G. (1977). *Causing death and saving lives.* Harmondsworth: Pelican.

Gobey, A. (2016, June 6). *Dementia intervention team*.

Godfrey, M., & Hackett, J. (2015). Advance care planning: policy and real-life decision-making? *Age and Ageing*, 44, 348-350.

Goffman, E. (1961). *Asylum: essays on the social situations of mental patient and other inmates*. New York: Doubleday.

Gomm, R., Hammersley, M., & Foster, P. (2011). *Case Study Method.* London: SAGE Publications.

Goodchild, C. (2009). *Putting People First Living well with dementia* - the National Dementia Strategy. Joint Commissioning Framework for dementia. Department of Health. UK.

Goodman C, Evans C, Wilcock J, Froggatt, K., Drennan, V., Sampson, E., Blanchard, M., Bissett, M., & Lliffe, S. (2010, April). *EOL* care for community dwelling older people with dementia: an integrated review. *International Journal of Geriatric Psychiatry*, *25*(4), 329-337.

Gopalraj, R. K., Grooms, L. J., Setters, B. K., Kaundar, A., & Furman, C. D. (2012). Decision-making in older adults with serious illness: barriers to the goals of care discussion. *Aging Health, 4*, 367-376.

Gordijin, B. (2010). Alzheimer disease and Euthanasia. In R. B. Purtilo & H. A. M. J. ten Have (Eds.), *Ethical foundations of palliative care for Alzheimer disease* (pp. 226-239). Baltimore: John Hopkins University Press.

Gordon, M. (2002). Ethical challenges in EOL therapies in the elderly. *Drugs Aging, 19* (5), 321-329.

Gordon, M., & Baker, N. (2011). *Late-Stage Dementia: promoting comfort, compassion and care.* Indiana: iUniverse.com.

Gormally, L. (1994). Against Voluntary Euthanasia. In R. Gillon (Ed.), *Principles of Health Care Ethics* (pp. 763-775). UK: Bookcraft.

Gustafsson, J. (2017). Single case studies vs. multiple case studies: A comparative study. *Hamstad University, Sweden*.

Haber, N. (2015). The travails of informal care. In M. Formosa, & Scerri, C. (Eds.), *Population ageing in Malta: multidisciplinary perspectives* (pp. 263-282). Malta: University Press. Malta.

Hall, S., Longhurst, S., & Higginson, I. (2009). Living and dying with dignity: a qualitative study of the views of older people in nursing homes. *Age and Ageing*, *38*, 411-416.

Hammersley M., & Gomm, R. (2011). Introduction. In R. Gomm, M. Hammersley, & P. Foster (Eds.), *Case Study Method* (pp. 1-16). London: SAGE Publications.

Hammersley, M., Gomm, R., & Foster, P. (2011). Case study and theory case study. In R. Gomm, M. Hammersley, & P. Foster (Eds.), *Case Study Method* (pp. 234-258). London: SAGE Publications.

Hanrahan, P., Raymond, M., Mc Gowan, E., & Luchins, D. J. 1999. Criteria for enrolling patient with dementias in hospice: a replication. *American Journal of Hospital Palliative Care*, *16*(1), 395-400.

Hanson, L. C., Garrett, J. M., Lewis, C., Phifer, N., Jackman, A, & Carey, T. S. (2008). Physicians' expectations of benefit from tube feeding. *Journal of Palliative Medicine*, *11*(8), 1130-1134

Hanson, L. C., Carey, T. S., Caprio, A. J., Lee, T. J., Ersek, M., Garrett, J., Jackman, A., Gilliam, R., Wessell, K., & Mitchell, S. L. (2011). Improving decision-making for feeding options in advanced dementia: a randomized controlled trial. *Journal of the American Geriatrics Society, 59*(11), 2009-2016.

Hansson, S. O. (2005). *Decisional Theory. A brief introduction. Department of philosophy and the history of technology.* Stockholm: Royal Institute of Technology.

Harstell, Z.C. & Williams, J.S. (2010). Is it ethical to provide enteral tube feeding for patients with dementia? *Journal of the American Academy of Physicians Assistants, 23*(10), 55-56.

Hartnett, T. (2011). *Consensus-Oriented-Decision-Making*. USA: New Society Publishers.

Hartnett, T. (1995). *The basics of consensus decision-making.* Group Facilitation.net

Harwood, R. H. (2014). Feeding decisions in advanced dementia. *Journal of the Royal College of Physicians Edinburgh*, *44*(3), 232-237.

Health Act. (2013). E-Health, Malta.

Health Care Professions Act. (2003). Chapter 464, Act XII. Laws of Malta.

Hertogh, C. M. P. M. (2006). Advance care planning and the relevance of a palliative care approach in Dementia. Editorial. *Age and Ageing, 35*, 553-555.

Hertogh, C. (2010). Advance care planning and palliative care in dementia: a view from the Netherlands. In J. C.Hughes, M. Lloyd-Williams & G. A.Sachs (Eds.), *Supportive care for the Person with Dementia* (pp. 271-280). New York: Oxford University Press.

Higgs, P. & Gilleard, C. (2016). Interrogating personhood and dementia. *Ageing & Mental Health.20,* (8), 773-780.

Hofland, B.F. (1990, supplement). Introduction. Generations. *Journal of the Western Gerontological Society*, *14,* 5-8.

Hope, T. (1994). Personal identity and psychiatric illness. In A. Phillips Griffiths (Ed.), *Philosophy, Psychology and Psychiatry* (pp. 141-143). Cambridge: University Press.

Hospice Eligibility Criteria (2008). John A. Hartford Center of Excellence in Geriatrics. Texas.

Hollinger, D. (2003). Life, sanctity of. In S.G., Post (Ed.), *Encyclopedia of Bioethics* (pp. 1402-1406), (3rd. ed.). USA: Gale.

Howland, J. S. (2009, winter). A defense of assisted nutrition and hydration in patients with dementia. *National Catholic Bioethics Quarterly, 9*(4), 697-710.

Hoy, D. G., Rickart, K.T., & Durham, J. (2010). Working together to address disability in a culturally-appropriate and sustainable manner. *Disability and Rehabilitation, 32*(16), 1373-1375.

Hughes, C.P., Berg, L., Danziger, W.L., Coben, L.A., & Martin, R.L. (1982). A new clinical scale for the staging of dementia. *British Journal of Psychiatry,140*, 566-72.

Hughes, J. C. (2001). Views of the person with dementia. *Journal of Medical Ethics*, *27*, 86-91.

Hughes, J.C., Hope, T., Savulescu, J., & Ziebland, S. (2002). Carers, ethics and dementia: a survey and review of the literature. *International Journal of Geriatric Psychiatry, 17,* 35-40.

Hughes, J.C., & Fulford, K.W.M. (2005). Hurly-burly of psychiatric ethics. *Australian and New Zealand Journal of Psychiatry, 39*, 101-1007

Hughes, J. C. (2006). Ethical Commentary. In J. C. Hughes (Ed.), *Palliative care in severe Dementia in association with nursing and residential care* (pp. 113-115). London: Quay Books.

Hughes, J. C., & Baldwin, C. (2006). *Ethical issues in dementia care. Making difficult decisions.* Bradford Dementia Group Good Practice Guidelines. UK: Jessica Kingsley Publishers.

Hughes, J. C., & Dove, P. (2006). The ethics of EOL decisions in severe dementia. In J. C. Hughes (Ed.), *Palliative care in severe dementia in association with nursing and residential care* (pp. 45-54). Quay Books: London

Hughes, J. C., Lloyd-Williams, M. & Sachs, G. A. (2010). Characterizing care. In J. C.Hughes, M. Lloyd-Williams & G. A.Sachs (Eds.), *Supportive Care for the Person with Dementia* (pp. 1-9). New York: Oxford University Press.

Hughes, J.C., & Williamson, T. (2019). *The Dementia Manifesto: putting values-based practice to work.* UK: Cambridge University Press.

Human Righs Act. (1998). Chapter 42. Legislation UK.

Hume, D. (1739). *A Treatise of Human Nature.* J. Speaks (Ed.) 2006.

Hume, D. (1771). *Enquiries Concerning the Principles of Morals*. Online Library of Liberty

Hursthouse, R. (1997). Virtue theory and abortion. In R. Crispe & M. Slope (Eds), *On Virtue Ethics.* (pp. 217-381). Oxford: Oxford University Press.

Hursthouse, R. (2000). *On Virtue Ethics*. Oxford: Oxford University Press.

Hursthouse, R., & Pettigrove, G. (2018). Virtue Ethics. In E.N., Zala (Ed.), *The Stanford Encyclopedia of Philosophy.*

Innes, A., Abela, S., & Scerri, C. (2011, May 11). The organisation of dementia care by families in Malta. *Dementia, 0*(0), 1-20.

Innes, A., Kelly, F., Scerri, C., & Abela, S. (2016, January 20). Living with dementia in hospital wards: a comparative study of staff perceptions of practice and observed patient experience. (pp. 1-13). *International Journal of Older People Nursing.*

Janssens, R. (2010). The practice of palliative care and the theory of medical ethics. In R. B. Purtilo & H. A. M. J. ten Have (Eds.), *Ethical foundations of palliative care for Alzheimer diseas*e (pp. 147-160). Baltimore: John Hopkins University Press.

Jannsens, R., Zyliczm Z., & ten Have. (1999). Articulating the concept of palliative care: philosophical and theological perspectives. *Journal of Palliative Care, 15*(2), 38-44

Jaworska A. (1999). Respecting the margins of agency: Alzheimer’s patients and the capacity to value. *Philosophy & Public Affairs*, *28*, 105–138.

Jeffrey, S. (2009). Reporting on Dementia is a terminal illness, but palliative care often poor. *New England Journal of Medicine*, *361,* 1529-1538.

Jewell, P. (2005, September). Rationality, euthanasia, and the sanctity-of-life. *Australian Association for Professional and Applied Ethics 12th. Annual Conference*

Johnson, D.W., & Johnson, F.P. (2000). *Joining together: Group theory and group skills* (7th. ed.). Boston: Allyn and Bacon.

Jolley, D. (2010). An introduction to the dementias: a clinical overview. In J. C.Hughes, M. Lloyd-Williams & G.A.Sachs (Eds.), *Supportive care for the Person with Dementia* (pp. 11-19). New York: Oxford University Press.

Jones, J. & Hunter, D. (1995). Consensus methods for medical and health services research. *British Medical Journal, 311*(5), 376-280.

Jones, R. (1997). Ethical and legal issues in the care of demented old people. In C. Holmes & R. Howard (Eds.), *Advances in Old Age Psychiatry: Chromosomes to Community Care* (pp. 117-127). PA: Petersfield and Bristol.

Jonsen, A.R. & Toulmin, S. (1988). *The abuse of casuistry: a history of moral reasoning.* Berkeley: University of California Press.

Jonsen, A.R. (1994). Clinical ethics and the 4 principles. In R. Gillon (Ed.), *Principles of Health Care Ethics* (pp. 13-21). John Wiley & Sons. England.

Joy, E. (2013). Advancing multidisciplinary team care. *Family Practice Management, 20*(4), 8.

Karlawish, J.H.T., Quill, T., & Meier, D.E. (1999). A consensus-based approach to providing palliative care to patients who lack decision-making capacity. *Annals of Internal Medicine, 130*(10), 835-840.

Keen, J., & Packwood, T. (1995). Qualitative research: case study evaluation. *British Medical Journal, 311*, 444.

Kellett, U. M. (1998). Meaning-making for family carers in nursing homes. *International Journal of Nursing Practice.4*, 113-119.

Keown, J. (2015, October, 28*). How does vitalism differ from sanctity-of-life.*

Keyserlingk, E. (1979). *Sanctity-of-life or Quality of Life. Protection of Life Series.* Law Reform Commission. Canada.

Kimsma, G.K., & van Leeuwen, W. (2007). The role of family in euthanasia decision making. *Health Care Ethics Forum, 19*(4), 365-373.

Kirkendall, N., & White, J. (2018). *Improving health research on small populations.* Washington: National Academies Press.

Kirsch, N. R. (2003). *Ethical Issues and Residents with Alzheimer Disease /Dementia*. California: Ethical Decisions in Physical Therapy.

Kissell, J. L. (2010). The moral self as patient. In R. B. Purtilo & H. A. M. J. ten Have (Eds.), *Ethical foundations of palliative care for Alzheimer disease* (pp. 131-145). Baltimore: John Hopkins University Press.

Kitwood, T. (1997). *Dementia reconsidered. The person comes first*. Buckingham, Open University Press. UK.

Klein, G. & Calderwood, R. (1991). Decision models: some lessons from the field. *Transactions on Systems, Man, and Cybernetics, 21*(5), 1018-1026.

Klein, G. (2015). A naturalistic decision-making perspective on studying intuitive decision-making. *Journal of Applied Research in Memory and Cognition*, 164-168.

Kolbe, M., & Boos, M. (2009). Facilitating group decision-making: Facilitator’s subjective theories on group coordination. *Qualitative Research, 10*(1), 28.

Kohl, M. (1974). *The morality of killing, sanctity-of-life, abortion and euthanasia*. USA

Komarova, N. L., & Thalhauser, C. J. (2011). High degree of heterogeneity in Alzheimer’s disease progression patterns. *Computational Biology*, *7*(11), 1-6.

Kolbe, M., & Boos, M. (2009). Facilitating group decision-making: facilitator's subjective theories on group coordination. *Qualitative Research, 10*(1), 28.

Koopmans, R. T. C. M., van der Sterren, K. J. M. A., & van der Steen J. T. (2007). The natural endpoint of dementia: death from cachexia or dehydration following palliative care? *International Journal of Geriatrics and Psychiatry, 22*, 350-355.

Kumar, Aaker, & Day. (2009). *Essentials of marketing research (2nd edition).* [Power Point Slides].

Kumar, C. T. S., & Kuriakose, J. R. (2013). EOL *care issues in advanced dementia. Mental Health in Family Medicine, 10(3), 129-132.*

Kuraoka, Y., & Nakayama, K. (2014). A decision aid regarding long-term tube feeding targeting substitute decision makers for cognitively impaired older people in Japan: A small-scale before and after study. *Biomed Central Geriatrics*, 14-16.

Kushniruk, A. W. (2002). Analysis of complex decision-making processes in health care: cognitive approaches to health informatics. *Journal of Biomedical Informatics*, 34, 365-376.

Levy, C., Morris, M., & Kramer, A. (2008). Improving EOL outcomes in nursing homes by targeting residents at high risk of mortality for palliative care: program description and evaluation. *Journal of Palliative Medicine, 11*(2), 217-225.

Lewis, C. L., Hanson, L. C., Golin, C., Garrett, J. M., Cox, C. E., Jackman, A., Phifer, N., & Carey, T. S. (2006). Surrogates' perceptions about feeding tube placement decisions. *Patient Education and Counselling, 61*(2), 246-252.

Lieberson, S. (2000/2011). Small N's and Big conclusions: an examination of the reasoning in comparative studies based on a small number of cases. In R. Gomm, M. Hammersley, & P. Foster (Eds.), *Case Study Method* (pp. 208-222). London: SAGE Publications.

Lincoln, Y. S., & Guba, E.G. (2000/2011). The only generalisation is: there is no generalisation. In R. Gomm, M. Hammersley, & P. Foster (Eds.), *Case Study Method* (pp. 27-44). London: SAGE Publications.

Linzer N. (2002). An ethical dilemma in home care. *Journal of Gerontological Social Work. 37*(2), 23-34.

List, D. (2001). The consensus group technique in social research. *Field Methods, 13*(3), 277-290.

Locke, J. (1690). An essay concerning human understanding. *McMaster Online Publications.*

Lopez, R. P., Amella, E. J., Mitchell, S. L., & Strumpf, N. E. (2010). Nurses' perspectives on feeding decisions for nursing home residents with advanced dementia. *Journal of Clinical Nursing. 19*(5), 632-638.

Mack, N., Woodsong, C., MacQueen, K. M., Guest, G., & Namey, E. (2011, July). Qualitative research methods: A data collector's field guide. Module 1. *Family Health International*.

Macklin, R. (2003). Dignity is a useless concept. *British Medical Journal, 327*, 1419.

Mallia, P. (2010). Treat me right: the usefulness of advance directives. In *Essays in Bioethics* (pp. 169-173). Malta, Printwell Ltd.

Mallia, P. (2011, July 07). Advance directives and mental incompetence. *The Malta Independent online*.

Mallia, P. (2017, January 21). Something is going wrong with EOL care. *The Times of Malta online.*

Mallia, P. (2018, preface). *Consensus Document EndCare.* University of Malta. Erasmus+ Project of the Bioethics Research Programme. (Unpublished).

Malta Healthcare and Decision-making in Dementia (2011, April). Alzheimer Europe.

Mamo, D. (2012, August 17). Consultant Psychogeriatrician. Department of Health, Elderly and Community Care. Malta.

Mamo, D. (2015, September 26). *Lecture on Mental Capacity in older people*. Karin Grech Rehabilitation Hospital. Pieta, Malta.

Mantzavinos, C. (2005). *Hypothetic Deduction Method*. UK: Cambridge University Press.

Marker, R. L. (2012). *End-of-life decisions and double effect*.

Mason, S.E., McSHane, R., & Ritchie, C.W. (2010, August). Diagnostic tests for Alzheimer's disease: rationale, methodology and challenges. *International Journal of Alzheimer's Disease*.

Marker, R., & Hamlon, K. (2010). Euthanasia and Assisted Suicide: Frequently asked questions. *International Task Force on Euthanasia and Assisted Suicide.*

Martin, R.J. & Post, S.J. (1992). Human dignity, dementia, and the moral basis of caregiving. In R.H. Binstock (Ed.), *Dementia and Ageing* (pp. 55-68). Baltimore: John Hopkins University Press.

Mays, N., & Pope, C. (1995, July). Rigour and qualitative research. *British Medical Journal*, *311*, 109-112.

Mazzola, P. (2015). Attitudes towards EOL care in Italy: the need for education. *Palliative Medicine and Care, 2*(1), 1-7.

McCormack, B. (2004). Person-centredness in gerontology nursing: an overview of the literature. *Journal of Clinical Nursing, 13*, 31-38.

McCormick, R.A. (1978). The QOL, The sanctity-of-life. *The Hastings Center Report, 8*(1), 30-39.

McCormick, T.R. (2008). *The place of principles in bioethics.* Ethics in Medicine. University of Washington School of Medicine.

McWhinney, R.L. (1995, July). The “winer-loser syndrome.” *Family Court Review*

Measuring Shared Decision-making (2012, December). Shared decision-making programme: NHS.

Mental Capacity Act (2005, April).

Mental Health Act (Cap. 525) (2012). E-Health, Malta.

Mill. J.S. (1863). *Utilitarianism.* G. Sher (Ed.) Re-published (2012). Indianapolis: Hackett Publishing Company.

Miller, W., Robinson, L.A., & Lawrence, R. (2007). *Valuing Health for Regulatory Cost-Effectiveness Analysis.* Washington: The National Academic Press.

Miller, L., & Wolf, K. (n.d.). *Measuring in the affective domain,* [Power Point slides].

Missotten, P., Squelard, G., Ylief, M., Di Notte, D., Paquay, L, De Lepeleire, J., & Fontaine, O. (2008). QOL in older Belgian people: comparison between people with dementia, mild cognitive impairment, and controls. *International Journal of Geriatric Psychiatry, 23*, 1103-1109.

Mitchell, S.L., Kiely, D.K., Lipsitz, L.A. (1998). Does artificial enteral nutrition prolong the survival of institutionalised elders with chewing and swallowing problems? *Journal of Gerontology and Biological Science Medical Science, 53*(3), 207-213.

Mitchell, S. L., & Lawson, F. M. E. (1999). Decision-making for long-term tube-feeding in cognitively impaired elderly people. *Canadian Medical Association Journal, 160,* 1705-1709.

Mitchell, S. L., Tetroe, J. M., & O’Connor, A. M. (2001). A decision aid for long-term tube feeding in cognitively impaired older persons. *Journal of the American Geriatrics Society, 49*(3), 313-316.

Mitchell, S. L., Kiely, D. K., & Gillick, M. R. (2003). Nursing home characteristics associated with tube feeding in advanced cognitive impairment. *Journal of the American Geriatric Society, 51*, 75-79.

Mitchell, S, L., Kiely, D. K., & Hamel, M. B. (2004a, September 2). Dying with advanced dementia in the nursing home. *Archives of Internal Medicine*, *163*(3), 321-326.

Mitchell, S. L., Kiely, D. K., Hamel, M. B., Park, P. S., Morris, J. N., & Fries, B. E (2004b). Estimating prognosis for nursing home residents with advanced dementia. *Journal of the American Medical Association, 291*(22), 2734-2740.

Mitchell, S. L., Tetroe, J. M., O'Connor, A. M., Roston, A., Villeneuve, C., & Hall, B. (2008). *Making choices. Long term feeding tubes placement in elderly patients. Personal worksheet for feeding tube placement.* Ottawa Hospital, Canada.

Mitchell, S. L., Teno, J. M., Kiely, D. K. et al., (2009). The clinical course of advanced dementia. *New England Journal of Medicine, 361*(16), 1529-1538.

Mitchell, S. L., Miller, S. C., Teno, J. M., Davis, R. B., & Shaffer, L. (2010, November). The Advanced Dementia Prognostic Tool (ADEPT): A Risk Score to Estimate Survival in Nursing Home Residents. *Journal Pain Symptom Management, 40*(5), 639-651.

Mitchell, A.J., Beaumont, H., Ferguson, D., Yadegarfar, M., & Stubbs, B. (2014). Risk of dementia and mild cognitive impairment in older people with subjective memory complaints: meta-analysis. *Acta Psyhiatrica Scandinavica, 130*(6); 439-451.

Moe, C., Schroll, M. (1997). What degree of medical treatment do nursing home residents want in case of life-threatening disease? *Age and Ageing, 26,* 133-137.

Monger, B. (2014). *Qualitative research and attitude measurement techniques. Maanz International.* [Power Point slides].

Monturo, C. (2009). The artificial nutrition debate: Still an issue…After all these years. *Nutrition in Clinical Practice, 24*(2), 206-213.

Moreland, J. P. & Geisler, N. L. (1996). Ethical theories and ethical decision-making. In F. I. Beckwith (Ed.), *Do the right thing. A philosophical dialogue on the moral and social issues of our time*. Boston: Jones and Bartlett Publishers.

Murphy, L.M., & Lipman, Y.O., (2003). Percutaneous endoscopic gastrostomy doesnot prolong survival in patients with dementia. *American Medical Association, 163*, 1351-1397.

Morreim, E.H. (2003). QOL in healthcare allocation. In S.G., Post (Ed.), *Encyclopedia of Bioethics* (3rd. ed.) (pp. 1393-1396). USA: Gale.

Morris, J., & Volicer, L. (2001). Nutritional management of individuals with Alzheimer's disease and other progressive dementias. *Nutrition in Clinical Care, 4*(3), 148-155.

Mosby's Dictionary of Medicine, Nursing & Health Professionals. (2010). Brooker, C. (Ed.). Elsevier, UK.

Mukherjee, C., Ewins, K., Green, J., & Hodby, F. (2017, September). A new approach to assessing nutrition and hydration capacity in patients with dementia. *BGS Newsletter*

Murphy, M.K., Black, N.A., Lamping, D.L., McKee, C.M., Sanderson, C.F.B., Askham, J. & Mareau, T. (1998). Consensus development methods, and their use in clinical guideline development. *Health Technology Assessment NHS, R&E, HTA Programme*, *2*(3).

Nair, B., Dobson, A., McPhee, J., & Saul, P. (2008). Advance care planning in residential care. *Australian and New Zealand Journal of Medicine, 30*(3), 1-8

National Audit Office (2005). *Performance audit-QOL for the elderly at St. Vincent de Paul Residence*. Malta.

National Audit Office (2007). *National Audit Office findings on the Department of Health and NHS*. UK.

National Institute for Health and Clinical Excellence [NICE]. (2006, March). *Methods of development of NICE public health guidance. 9: Making group decisions and consensus.*

National Institute for Health and Clinical Excellence [NICE]. (2006, November). *Dementia. Supporting people with dementia and their carers in health and social care*. NICE clinical guideline 42.

National Institute for Health and Clinical Excellence [NICE] (2010, June). *End-of-life care for people with dementia.*

National Institute for Health and Clinical Excellence [NICE]. (2016, May update). *Dementia. Supporting people with dementia and their carers in health and social care*. NICE clinical guideline [CG42].

NICE-SCIE (2007). Dementia. *The NICE-SCIE guideline on supporting people with dementia*. National Collaborative Centre for Mental Health. The British Psychological Society.

National Minimum Standards for Care Homes for Older People. (2004, March). Ministry for health and social services. Welsh Assembly Government.

National Minimum Standards for Care Homes for Older People (2015, September). Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing. Malta.

National Statistics Office (2014). *Malta in Figures: 2014.* NSO, Malta.

National Statistics Office (2016). *Trends in Malta*: 2016. NSO, Malta.

National Statistics Office (2018, February, 12). *Population revision as on December 31,* 2016. NSO News Release.

National Strategic Policy for Active Ageing. Malta 2014-2020. (2014). Parliamentary Secretariat for the Rights of Persons with Disability and Active Ageing. Malta.

Nelis, M.N., Wu, Y.T., Matthews, F.E., Martyr, A., Qionn, C., Rippon, I., Rusted, J., Thom, J.M., Kopelman, M.D., Hindle, J.V., Jones, R.W., & Clare, L. (2019). The impact of co-morbidity on the quality of life of people with dementia: findings from the IDEAL study. *Age and Ageing, 48,* 361-367.

Nelson, R (2015, October). ‘Surprise’ question effective at prediction EOL. *Medscape Medical News.*

Nelson, C.M. & Nazareth, B.A. (2013). Non-beneficial treatment and conflict resolution: building consensus. *Permanente Journal, 17*(3), 23-27.

Nitschke, P. (2001). Euthanasia sets sail. *National Review Online Interview book review*.

Nordenram, G. (2010). The ethical challenge of treating pain in Alzheimer disease. In R. B. Purtilo & H. A. M. J. ten Have (Eds.), *Ethical foundations of palliative care for Alzheimer disease* (pp. 218-225). Baltimore: John Hopkins University Press.

Nuffield Council of Bioethics (2009, October). *Dementia: Ethical issues.* Cambridge Publishers. UK.

Nurses had clear instructions. (July 10, 2014). *The Malta Independent Online*.

Nussbaum, M. (2006). The moral status of animals. Frontiers of justice: disability, nationality, species membership. *The Chronicle of Higher Education, 52*(22)

Ogunbanjo, G. A., & Knapp van Bogaert, D. (2014). Ethics in health care: the practice of defensive medicine. *South African Family Practice, 56*(1), supplement 1.

Olde Rikkert, M. G. M., & Rigaud, A. S. (2010). Hospital-based palliative care and Dementia, or what do we treat patients for and how do we do it? In R. B. Purtilo & H. A. M. J. ten Have (Eds.), *Ethical foundations of palliative care for Alzheimer disease* (pp. 80-96). Baltimore: John Hopkins University Press.

Onwuteaka-Philipsen, B. D., Muller, M. T., & van der Wal. G. (1997). Euthanasia and old age. *Age Ageing,* 26, 487-492

Owen, T., & NCHRDF (Eds). (2006). *My home life. QOL in Care Homes*. Help the Aged. London.

Pace, V., Treloar, A., & Scott, S. (2011). *Dementia from advanced disease to bereavement*. New York: Oxford University Press.

Palecek, E.J., Teno, J.M., Casarett, D.J., Hanson, L.C., Rhodes, R.L. & Mitchell, S.L. (2010). Comfort feeding only: a proposal to bring clarit to decision-making regarding difficulty with eating for persons with advanced dementia. *Journal of the American Geriatric Society, 58,* 580-588.

Panke, J. A., & Volicer, L. (2002). Caring for persons with dementia. a palliative approach. *Journal of Hospice and Palliative Care, 4* (3), 143-152.

Pantilat, S. (2008). *Beneficence vs. Non-Maleficence.* University of California.

Pannucci, C.J. & Wilkins, E.G. (2010) Identifying and avoiding bias in research. *Plastic Reconstruction Surgery, 126*(2), 619-625.

Parker, M.F., Erlbaum-Zur, P., & Chichin, E.R. (2008, winter/spring). Ethics of everyday life in Geriatric Care 2008. *Journal of Jewish Communal Services*, *83* (2-3), 146-154.

Parfit, D. (1984). Reasons and persons. *Population and Development Review. 10*(3), 545-547.

Pasman, H. R. W., The, B. A., Onwuteaka-Philipsen, B. D., van der Wal, G., & Ribbe, M. W. (2003). Feeding nursing home patients with severe dementia: a qualitative study. *Journal of Advanced Nursing, 42*(3), 304-311.

Pavia, G. (2016, November 9). Assistant Director. Department of Health, Elderly & Community Care. Malta

Pekel, J. & Wallace, D. (2006). *The ten-step method of decision-making.*

Personal Values, Beliefs and Attitudes (2009). State of New South Wales, Department of Education and Training.

Pleschberger, S. (2007). Dignity and the challenge of dying in nursing homes: the residents' view. *Age and Ageing, 36,* 197-202.

Polden, E. R. (1989). Social work and people with Dementia: putting principles into practice. *International Journal of Geriatric Psychiatry*, *4,* 173-181.

Pope John Paul II (1995, March 25). *Evangelium Vitae,* The encyclical letter on abortion, euthanasia, and the death penalty in today's world.

Pope Pius XII (1944, November, 12). *Address to the Unione Medico Biologica di San Luca* (English version)

Pope, C., van Royen, P., & Baker, R. (2002). *Qualitative methods in research on healthcare quality*. Center for the Evaluative Clinical Sciences. Dartmouth Medical School. Hanover, USA.

Potack, J. Z. & Chokhavatia, S. (2008). Complications of and controversies associated with percutaneous endoscopic gastrostomy: report of a case and literature review. *Medscape Journal of Medicine, 10*(6), 142.

Pozzuolo, J., Lassoff, L., & Valentine, J. (2005, September). Why living wills/advance directives are an essential part of estate planning. *Journal of Financial Service Professionals.*

Purtilo, R. B., & ten Have H. A. M. J. (2010), *Ethical foundations of palliative care for Alzheimer disease*. Baltimore: John Hopkins University Press.

Purtilo, R. B. (2010). Social marginalisation of persons with disability. In R. B. Purtilo and H. A. M. J. ten Have (Eds.), *Ethical foundations of palliative care for Alzheimer disease* (pp. 290-304). Baltimore: John Hopkins University Press.

Purtilo, R. B., & ten Have H. A. M. J. (2010b), Appendix A: The Declaration of Berg en Dal on ethical principles guiding palliative care for persons with Alzheimer's disease. *Ethical foundations of palliative care for Alzheimer disease* (pp. 343-347). Baltimore: John Hopkins University Press.

Quality Markers for Care Homes. (2010, April). National EOL care programme. Support sheet 5.

Rabins, P.V., & Kasper, J. (1997). Measuring QOL in dementia: conceptual and practical issues. *Alzheimer Disease and Associated Disorders, 11*(6), 100-104.

Rait, G., Walters, K., Bottomley, C., Peterson, I., Liffe, S., & Nazareth, I. (2010). Survival of people with clinical diagnosis of dementia in primary care: cohort study. *British Medical Journal.* August 5, 341

Ramsey, P. (1978). *Ethics at the edges of life.* New Haven, USA.

Rawls, J. (1999). *A theory of justice.* Cambridge, Harvard University Press (revised edition).

Raymond, T. C. M., Koopmans, J. L. P., Ekkerink, & van Weel, C. (2003). Survival to Late Dementia in Dutch Nursing Home. *Journal of the American Geriatric Society*, *51*, 184–187.

Regnard, C. & Huntley, M. E. (2006). Managing the physical symptoms of dying. In J. C. Hughes (Ed.), *Palliative care in severe dementia in association with nursing and residential care* (pp. 22-44). London: Quay Books.

Reich, W. (1978). Life: QOL. In W.T. Reich (Ed.). *Encyclopedia of Bioethics.* (pp. 829-840). (2nd. Edition). Gale,

Reifsnyder, J. (2005, April). *Development of pressure ulcers in patients receiving home* hospice care. *Wounds*, *17*(5), 74-79.

Reisberg, B. (1988). Functional Assessment Staging (FAST). *Psychopharmacology Bulletin*, *24*, 653-659.

Reyna, V. F. (2008). Theories of medical decision-making and health: an evidence-based approach. *Medical Decision-Making, 28*(6), 829-833.

Richards, L. (2015). *Handling qualitative data*. A practical guide. Sage. Los Angeles

Richardson, H. S. (2009). Moral reasoning. *The Stanford Encyclopedia of Philosophy.* Zalta, E. N. (Ed.).

Rimon, E., Kagansky, N., & Levy, S. (2005). Percutaneous endoscopic gastrostomy; evidence of different prognosis in various patient subgroups, *Age and Ageing, 35,* 353-357.

Rosenfeld, K. E., Wenger, N. S., & Kagawa-Singer, M. (2001). EOL decision-making. A qualitative study of elderly individuals. *Journal of General Internal Medicine*, *15,* 620-625.

Rosin, A. J. & Sonnenblick, M. (1998). Autonomy and Paternalism in geriatric medicine. The Jewish ethical approach to issues of feeding terminally ill patient, and to cardiopulmonary resuscitation. *Journal of Medical Ethics*, *24,* 44-48.

Royal College of Physicians and the British Society of Gastroenterology (2010). *Oral feeding difficulties and dilemmas. A guide to practical care particularly towards the EOL.* Working party. Cambrian Printers ltd. Aberystwyth. UK.

Rudberg, M.A., Egleston, B.L., Grant, M.D., & Brody, J.A. (2000). Effectiveness of feeding tubes in nursing home residents with swallowing disorders. *Journal of parenteral and enteral nutrition, 24*, 97-101.

Ruggiero, V.R. (1992). *Thinking Critically about Ethical Issues.* (3rd. Edition). California: Mayfield.

Ruggunan, S. (2014). *Introduction to qualitative analysis and writing up your analysis: Thematic Analysis*. University of KwaZulu-Natal, South Africa.

Rurup, M. L., Onwuteaka-Philipsen, B. D., Pasman, H. R. W., Ribbe, M. W., & van der Wal, G. (2006). Attitudes of physicians, nurses and family towards EOL decisions concerning nursing home patients with Dementia. *Patient Education and Counselling*, *61*, 372-380.

Sachedina, A. (2005). End-of-life: the Islamic view. *Lancet, 366*(9487), 774-779.

Sachs, G. A., Shega, J. W., & Cox-Hayley, D. O. (2004). Barriers to excellent EOL care for patients with dementia. *Journal of General and Internal Medicine, 19,* 1057-1063.

Safeguard the Dignity of Human Life. (2016, July 25). Bishops open letter to MP's. *The Malta Independent online.*

Sampson, E. L., Candy, B., & Jones, L. (2009). Enteral tube feeding for older people with advanced dementia. *The Cochraine Collaboration*.

Sasson S. (2000). Beneficence versus respect for autonomy: an ethical dilemma in social work practice. *Journal of Gerontological Social Work, 33*(1), 5-16.

Satariano, B., Gauci, S., & Schembri, J.A. (2010). The family in Malta within the demographic transitions: a study of families-in-need.

Scerri, C. (2010). *Inspiring new frontiers*: Recommendations for a dementia strategy in the Maltese Islands. Malta.

Scerri, C. (2012). Challenges of developing a dementia strategy: the case of Malta. In A. Innes, F. Kelly, & L. McCabe (Eds.), *Key issues in evolving dementia care: International theory-based policy and practice* (pp. 153-175). London: Jessica Kingsley.

Scerri, C. (2015). Dementia in Malta: trends, policy and professional development. In M. Formosa, & C. Scerri (Eds.), *Population ageing in Malta: multidisciplinary perspectives* (pp. 169-191). Malta: Malta University Press.

Scheirton, L. S. (2010). Ethical dimensions of Alzheimer disease decision-making. In R. B. Purtilo & H. A. M. J. ten Have (Eds.), *Ethical foundations of palliative care for Alzheimer disease* (pp. 261-277). Baltimore: John Hopkins University Press.

Schembri Orland, K. (2016, July 24). 'Big difference between euthanasia, patient refusing treatment' Professor Pierre Mallia. *The Malta Independent online*.

Schroeder, D. & Gefenas, E. (2009). Vulnerability: too vague and too broad? *Cambridge Quarterly of Healthcare Ethics, 18*(2), 113-121.

Scholz, R. W., & Zimmer, A. (1997). *Qualitative aspects of decision-making* – a challenge for decision research.

Scolaro, A. (2016). *Dignity in care homes for older people. A qualitative study.* (Unpublished master's thesis). University of Malta, Malta

Scottish Council on Human Bioethics. (2010, October 19). *Withdrawing or withholding of nutrition and/or hydration.* Position Statement.

Sepucha, K. R., & Scholl, I. (2014, April). Measuring shared decision-making. *Health Division Sciences*.

Seymour, J., Witherspoon, R., Gott, M., Ross, H., & Payne, S. (2005). Messages from Research. In T. Owen (Ed.), *Dying in old age reflections and experiences: an old person's perspectives.* Help the Aged.

Shaban, R. (2005). Theories of clinical judgment and decision-making: a review of the theoretical literature. *Australasian Journal of Para-Medicine*, *3*, 1.

Shah, A. (2011, March 16). Manager, Malta Hospice Movement. Malta.

Shah, S. H. (2006). A patient with dementia and cancer: to feed via percutaneous endoscopic gastrostomy tube or not? *Palliative Medicine*, *20*, 711-714.

Shah, S., & Lloyd-Williams, M. (2003). EOL decision-making – have we got it right? *European Journal of Cancer Care, 12*, 212-214.

Shannon, T.A., & Walter, J.J. (2005). Implications of the Papal Allocation on feeding tubes. *Hastings Center Report, 34,* 18-20.

Shared decision-making: engaging patients to improve health care. (2013, May). *Families USA*.

Shega, J. W., Levin, A., Hougham, G. W., Cox-Hayley, D., Luchins, D., Hanrahan, P., Stocking, C., & Sachs, G.A. (2003). Palliative Excellence in Alzheimer Care Efforts (PEACE): A program description. *Journal of Palliative Medicine*, *6*(2), 315-320.

Shega, J. W., & Sachs, G. A. (2010). Offering supportive care in dementia: reflections of the PEACE programme. In J. C.Hughes, M. Lloyd-Williams & G. A.Sachs (Eds.), *Supportive care for the Person with Dementia* (pp. 33-44). Oxford University Press. New York

Should Euthanasia or Physician-Assisted Suicide be legal? (2013). Pro-con.org.

Schwarz, D.B., & O'Sullivan Maillet, J. (2013, June). Ethical and legal issues on feeding and hydration. *Journal of the Academy of Nutrition and Dietetics.*

Silberfeld, M., Grundstein-Amado, R., Stephens, D., & Deber, R. (1996). Family and physicians' views of surrogate decision-making: the roles and how to choose. *International Psychogeriatrician, 8*, 589-596.

Singer, P., & Kushe, H. (1985). *Should the baby live?* Oxford: Oxford University Press.

Singer, P., & Kuhse, H. (1988). Resolving arguments about the sanctity-of-life: a response to Long. *Journal of Medical Ethics, 14,* 198-199.

Singer, P. (1995). Is the Sanctity-of-life ethic terminally ill? *Bioethics, 9*(3-4), 327-42.

Singer, P., McKie, J., Kuhse, H., & Richardson, J. (1995). Double jeopardy and the use of QALY's in health care allocation. *Journal of Medical Ethics, 21,* 144-150.

Singer, P. (2005, September / October). The Sanctity-of-life. *Foreign Policy,* 40-41.

Skill Building – Group Decision-making. (2011, January). Mt Holyoke College.

Sloane, P. D., Zimmerman, S., Williams, C.S., & Hanson, L. C. (2008). Dying with dementia in LTC. *The Gerontologist, 48* (6), 741-751.

Sloane, P.D. & Zimmerman, S. (2010). Assisted living programmes providing supportive care for dementia. In J. C. Hughes, M. Lloyd-Williams & G. A.Sachs (Eds.), *Supportive care for the Person with Dementia* (pp.189-197). New York: Oxford University Press.

Smebye, K.L., Kirkevold, M., & Engedal, K. (2016). Ethical dilemmas concerning autonomy when persons with dementia wish to live at home: a qualitative hermeneutic study. *BMC Health Services Research, 16*, 21.

Soler, D. (2005). Telling patients the truth. *Malta Medical Journal, 17*(4), 56-58.

Stages of Alzheimer-type Dementia (2011, March). University of Iowa.

Stake, R. E. (2000/2011). The case study method in social enquiry. In R. Gomm, M. Hammersley, & P. Foster (Eds.) *Case Study Method.* (pp. 19-26). SAGE Publications. London.

Standing, M. (2010). *Perceptions of clinical decision-making: a matrix model.*

Stanford Encyclopedia of Philosophy. (1995). Stanford University, California.

Stewart, F., Goddard, C., Schiff, R., & Hall, S. (2011). Advanced care planning in care homes for older people: a qualitative study of the views of care staff and families. *Age and Ageing*, *40,* 330-335.

St Vincent de Paul. (2015, October). *Admission Criteria.* (Unpublished).

Strech, D., Mertz. M., Knupperl, H., Neitzke, G., & Schmidhuber, M. (2013). The full spectrum of ethical issues in dementia care: systematic qualitative reviews. *The British Journal of Psychiatry. 202*, 400-406.

Suicide and Assisted Suicide. (n.d.). Fact sheet. Ethical issues in Alzheimer's Disease. Alzheimer's Association.

Sulmasy, D.P. (2011). Speaking of the value of life. *Kennedy Institute of Ethics Journal, 21*(2), 181-199.

Summers, J. (2009). Principles of Health Care Ethics. In E.E. Morrison (Ed.), *Heatlh Care Ethics: Critical issues for the 21st Century.* USA: Jones & Bartlett.

Summersall, J. & Wight, S. (2006). When it's difficult to swallow: The role of the speech therapist. In J. C. Hughes (Ed.), *Palliative care in severe dementia in association with nursing and residential care* (pp. 105-113). Quay Books. London.

Superintendent's Office (2017, October, 3). *Total Population at St. Vincent de Paul LTCF*

SVP Dependency Evaluation Report. (2016). St Vincent de Paul Residence. Department of Health. Malta. (Unpublished).

Swedish National Council on Medical Ethics. (2008). *Patient's autonomy in EOL decisions*. Stockholm.

Ten Have, H. A. M. J. (2010). Expanding the scope of palliative care. In R. B. Purtilo & H. A. M. J. ten Have (Eds.), *Ethical foundations of palliative care for Alzheimer disease* (pp. 61-79). Baltimore: John Hopkins University Press.

Ten Have, H. (2016). *Vulnerability. Challenging Bioethics*. UK: Routledge.

Teno, J.M., Mitchell, S.L., Kuo, S.K., Gozalo, P.L., Rhodes, R.L., Lima, J.C. & Mor, V. (2011). Decision-making and outcomes of feeding tube insertion: a five-state study. *Journal of the American Geriatric Society, 59*(5), 881-886.

Ter Meulen, R. H. J. (2008). The lost voice: how libertarianism and consumerism obliterate the need for relational ethics in the national health care service. *Christian Bioethics*, *14*(1), 78-94.

The American Civil Liberties Union. (2008, April 6). *Should euthanasia or physician-assisted suicide be legal?*

The European Health Examination Survey – Pilot Study 2010. (2012). Ministry for Health, the Elderly and Community Care. Government Printing Press, Marsa.

The Gold Standards Framework- Proactive Identification Guidance. (2016). Quality Care Commission. UK.

The Gold Standards Framework. (2018, Autumn). Quality Care Commission. UK.

The President's Commission for the study of Ethical Problems in Medicine and Biomedical and Behavioural Research (1983). *Deciding to Forego Life-Sustaining Treatment.* Washington, DC.

The Stages of Alzheimer's disease (1984). *Ec-online.net.*

Thomas, K., et al., (2011, September*). The GSF Prognostic Framework*. Royal College of General Practitioners.

Thompson, C., & Dowding, D. (2012). *Clinician decision-making and judgement in nursing*. UK: Churchill Livingston.

Thompson Beckley, E. (2017). Patient wishes before risk.

Tilly, J., & Reed, P. (Eds.) (2006, September). *Dementia care practice recommendations for assisted living residences and nursing homes*. Alzheimer's Association.

Torke, A.M., Alexander, G. C., & Lantos, J. (2008). Substituted judgement: the limitations of autonomy in surrogate decision-making. *Journal of General Internal Medicine, 23*(9), 1514-1517.

Treloar, A. & Crugel, M., & Adamis, D. (2009). Palliative and EOL care of dementia at home is feasible and rewarding. Results from the 'Hope for Home' study. *Dementia 8*(3); 335-347.

Tuckett, A. G. (2006). On paternalism, autonomy, and best interests: telling the (competent) aged-care resident what they want to know. *International Journal of Nursing Practice*, *12,* 166-173.

University of New Mexico. (n.d.). *Values History Sheet*.

Unobtrusive Measures. (2006). Social Research Methods

Ursery, D. (2005, September). *Moral Reasoning Guidelines*. St. Edwards Faculty.edu

US Conference of Catholic Bishops (2009, November 17). *Ethical and Religious Directives for Catholic Health Care Services.*

US Supreme Court Majority Opinion. (1997, June 26). Washington v. Glucksberg

Van der Riet,P., Good, P., Higgins, I., & Sneesby, L. (2008). Palliative care professionals' perceptions of nutrition and hydration at the EOL. *International Journal of Palliative Nursing*, *14*(3), 145-151.

Van der Steen, J.T. (2010). Dying with dementia: what we know after more than a decade of research. *Journal Alzheimers Disease, 22*(1), 37-55.

Van der Steen, J.T., Radbruch, L., Hertogh, C.M.P.M., de Boer, M.E., Hughes, J.C., Larkin, P. et al. (2014). White Paper defining optimal palliative care in older people with dementia: A Delphi study and recommendations from the European Association for Palliative Care. *Palliative Medicine, 28*(3), 197-209.

Vassallo, M.A. (2014). *Artificial nutrition and hydration in EOL geriatric care: medical treatment or basic care?* (Unpublished master's thesis). University of Malta, Malta

Vaughn, L. (2011). *Doing Ethics.* Norton Incorporated

Velasquez, M., Andre, C., Shanks, S.J., & Meyer, M.J. (1990). Justice and Fairness. *Issues in Ethics, 3*, 2.

Verhofstadt, G. (November 9, 2012). *The European Union is in essence a Liberal Project*.

Vincenti, P. (2008, July 13). Rights for apes –Euthanasia for dementia. *The Malta Independent Online*.

Volicer, L., Rheaume, Y., Brown, J., Fabiszewski, K., & Brady, R. (1986). Hospice approach to the treatment of patients with advanced dementia of the Alzheimer type. *Journal of the American Medical Association, 256*(16), 2210-2213.

Volicer, L., Cantor, M. D., Derse, A. R., Murray Edwards, D., Prudhomme, A. M., Rasinski Gregory, D. C., Reagan, J. E., Tulsky, J. A., & Fox, E. (2002). Advance care planning by proxy for residents of LTC facilities who lack decision-making capacity. *Journal of the American Geriatric Society*, *50,* 761-767.

Volicer, L., & Ganzini, L. (2003). Health professionals' views on standards of decision-making capacity regarding refusal of medical treatment in mild Alzheimer's disease. *Journal of the American Geriatric Society*, 51, 1270-1274

Volicer, L. (2005). EOL care for people with dementia in residential care settings. *Alzheimer Association.*

Wackerbarth, S. (1999). Modelling a dynamic decision process: supporting the decisions of caregivers of family members in dementia. *Qualitative Health Research, 9*(3), 294-314.

Walshe, M., & Regan, T. (2017, Decemeber 15). Managing dysphagia in dementia- can we do better? *Irish Medical Times,* p. 34.

Walter, J.J. (2003). QOL in clinical decisions. In S.G., Post (Ed.), *Encyclopedia of Bioethics* (pp. 1388-1393). (3rd. Edition). USA: Gale.

Watson, J., Hockley, J., & Murray, S. (2010). Evaluating the effectiveness of the GSFCH and LCP in Care Homes. *EOL Care, 4*(3), 42-49.

Welie, J. V. M. (2010). The tendency of contemporary decision-making strategies to deny the condition of Alzheimer disease. In R. B. Purtilo & H. A. M. J. ten Have (Eds.), *Ethical foundations of palliative care for Alzheimer disease* (pp. 163-199). Baltimore: John Hopkins University Press.

Welie, J. V. M. & Gordijn, B. (2010). Commentary on the Declaration of Berg en Dal. In R. B. Purtilo & H. A. M. J. ten Have (Eds.), *Ethical foundations of palliative care for Alzheimer disease* (pp. 343-347). Baltimore: John Hopkins University Press.

Where is Euthanasia legal? (2016, January 5). *New Health Guide*.

Wilson, H.S. (1989). Family caregiving for a relative with Alzheimer's dementia: coping with negative choices. *Nursing Research 38,* 94-98.

Wirth, R., Bauer, J.M., Willschrei, H.P., Volkert, D., & Sieber, C.C. (2009). Prevalence of percutaneous endoscopic gastrostomy in nursing home residents – a national survey in Germany. *Gerontology, 56*, 371-377.

Wong, R.K., Brierley, J., & Brouwers, M. (2012). What is the best way to produce consensus and buy in to guidelines for rectal cancer. *Current Colorectal Cancer Report, 8*(2), 83-89.

Wood, A. W. (2002) (trans.). *Groundwork of the Metaphysics of Morals*. Yale University. Binghamton, New York. (trans. Kant, 1783, Grundlegung zur Metaphysik der Sitten).

Woolbridge, K., & Fulford, K.W.M (2004). *Whose values?* A workbook for values based practice in mental health care. London: Sainsbury Centre for Mental Health.

World Alzheimer Report 2011. (2011, September). M., Prince, R., Bryce, & C., Ferri (Eds), *The benefits of early diagnosis and intervention*. *Executive Summary*. USA: Alzheimer Disease International.

WHO. (2001). *The international classification of functioning, disability and health.* Geneva. WHO.

WHO. (2003). *Palliative Care for Older People; Better Practices.* S. Hall; H. Petkova; A. Tsouros; M. Costantini; & I.J. Higginson (Eds.). Denmark: WHO.

World Population Day (July, 11, 2016). National Statistics Office, Malta. European Statistic System.

Wortman, P.M., Vinokur, A., & Sechrest, L. (1988). Do consensus conferences work? A process evaluation of the NIH consensus development program. *Journal of Health Politics, Policy & Law, 13*, 469-498.

Xie, J., Bryne, C., & Matthews, F. E. (2008). Survival times in people with dementia analysis from population based cohort study with 14year follow up. *British Medical Journal,*

Yean, T.T., & Anantham, D. (2015). Commentary on EOL decision-making in Singapore. Best interests conflicting with surrogate decision-making. *Asian Bioethics Review, 7*(4), 394-401.

Yin, R. K. (1994). *Case study research. Design and methods.* (2nd. Edition). USA: SAGE Publications.

Yin, R. K. (2009). *Case study research: Design and methods* (4th Edition.). USA: SAGE Publications.

Yin, R. K. (2014). *Case study research. Design and methods.* (5th. Edition). USA: SAGE Publications.

Yrjönen, J. (2017, August). *The Forgotten Stakeholder.* Frantic Designers.

Zammit, A. R. (2015). Cogntive function and psychological wellbeing. In M. Formosa, & C. Scerri. (Eds.), *Population ageing in Malta: multidisciplinary perspectives* (pp. 217-237). Malta: Malta University Press.

Zsambok, C. E. (2014). Naturalistic decision-making research and improving team decision-making. In C. E. Zsambok & G. Klein (Eds.), *Naturalistic decision-making* (pp. 111-120). New York: Psychology Press.

Zucker, D. M. (2009). *How to do case study research*. School of nursing faculty publication series. Paper 2. University of Massachusetts.

Zutshi, B. (2012). *End-of-life Care* - The Amber Care Bundle for patients whose recovery is uncertain.

9. Appendix 1: Interview Schedules: English and Maltese Versions

1. Patient's Medical File Data

Date: ....

Ward Code: ....

Consultant's Code: ....

Patient Code: ....

1. Exclusion Criteria:

Age less than 65y:	Yes / No
Pre-study already had a feeding tube	Yes / No
Died by date of survey	Yes / No

2. Eligibility Criteria (A):

2.1. Date when decision re swallowing difficulties was taken (7 days time window):

....

2.2. Relatives / Legal authorised representative involved in care Yes / No

3. Eligibility Criteria (B): End-stage dementia criteria

Functional Assessment Staging of Alzheimer's Disease. (FAST)©

STAGE	SKILL LEVEL
1.	No difficulties, either subjectively or objectively
2.	Complains of forgetting location of objects. Subjective word finding difficulties.
3.	Decreased job function evident to co-workers; difficulty in travelling to new locations. Decreased organisational capacity
4.	Decreased ability to perform complex tasks (e.g., planning dinner for guests), handling personal finances (forgetting to pay bills), difficulty marketing etc.
5.	Requires assistance in choosing proper clothing to wear for day, season, occasion.
6a.	Difficulty putting clothing on properly without assistance.
b.	Unable to bathe properly; (e.g., difficulty adjusting bath water temperature) occasional or more frequently over the past weeks.
c.	Inability to handle mechanics of toileting (e.g., forgets to flush the toilet, does not wipe properly or properly dispose of toilet tissue) occasionally or more frequently over the past weeks.*
d.	Urinary incontinence, occasional or more frequent.
e.	Faecal incontinence, (occasional or more frequently over the past week).
7a.	Ability to speak limited to approximately a half dozen different words or fewer, in the course of an average day or in the course of an intensive interview
b.	Speech ability limited to the use of a single intelligible word in an average day or in the course of an interview (the person may repeat the word over and over)
c.	Ambulatory ability lost (cannot walk without personal assistance).
d.	Ability to sit up without assistance lost (e.g., the individual will fall over if there are no lateral rests [arms] on the chair).
e.	Loss of the ability to smile.

STAGE: ________________

Reproduced with permission from: Reisberg, (1988). All rights reserved.

3.1 FAST Stage : 7c or worse: Yes / No

3.2 In addition to <u>at least one of the following</u>

3.2.1 Pressure sores: Yes / No

Where ....

Grade: ....

3.2.2 Chest Infection in last 12 months: Yes / No

3.2.3 Severe Renal infection/Sepsis in last 12months: Yes / No

4. Eligibility Criteria (C): Severe / Life-threatening (which at the time seems to be a prolonged situation / permanent) leading to either <u>one of the following</u>:

4.1 Severe difficulty in swallowing Yes / No

Choking in food or normal liquid Yes / No

leading to risk of: *dehydration* Yes / No *or*

aspiration Yes / No

4.2 Severe eating/drinking problems secondary to swallowing difficulties

i.e. not enough food and drink to survive / life threatening Yes / No

5. Eligibility Criteria (D):

Swallowing difficulties not reversible in the near future: Yes / No

ADDITIONAL DATA

6.1 Food consistency pre decision ....

6.2 Liquids staging with thickener pre decision ....

DEMOGRAPHIC DATA (from the medical file)

7. Age:

8. Gender:

9. Marital status:

10. Relationship of the Next of kin:

11. Date of admission to SVP:

12. Cognitive Tool Score: ....

14. What is the patient's main diagnoses (one or more): (from the patient's med file)

Cerebrovascular disease	1
Cardiovascular disease	2
Cancer	3
Muscle/Tissue/Bone disease	4
Hip #	5

Recurrent falls	6
Amputee	7
Dementia	8
Depression	9
Psychiatric disease other than above	10
Parkinson’s disease	11
Neurological disease including eye/ear	12
Diabetes Mellitus including complications	13
Infectious disease e.g. Non-Aspiration Pneumonia / UTI	14
Aspiration Pneumonia	15
Other Respiratory disease excluding pneumonia	16
Other medical disease	17
Pressure Sores	18
Surgical disease	19
Deterioration of gen. cond. without further specification	20

15. WHAT INVESTIGATIONS / ACTION WERE TAKEN IN THE DECISION?

(from patient documentation)

15.1 Referral to a gastroenterologist (PEG)	Yes / No
15.2 Referral to hospice / palliative care	Yes / No
15.3 Referral to a radiologist (RIG)	Yes / No

15.4 What investigations were taken in (previous month) the decision-making

Video fluoroscopy	Yes / No
Barium swallow	Yes / No
Basic blood work-out	Yes / No
Chest X –Ray	Yes / No

Other:...

15.5 What vital parameters where being monitored in last month

Weight Yes / No

Feeding chart Yes / No

Fluid input chart Yes / No

15.6 Was the decision-process re swallowing difficulties documented? Yes / No

16. WHAT WAS THE DECISION TAKEN?

16.1 Normal food consistency Yes / No

16.2 Normal liquid consistency Yes / No

16.3 Adapted food consistency Yes / No

16.4 Adapted liquid consistency Yes / No

16.5 Forced oral feeding / hydration Yes / No

16.6 Comfort EOL feeding Yes / No

16.7 Nil orally Yes / No

16.8 Introduced an NG tube Yes / No

16.9 Booked for a PEG tube Yes / No

16.10 Booked for a RIG tube Yes / No

16.11 Parenteral Hydration Yes / No

16.12 Transfer to hospital Yes / No

16.13 Other ....

2. Medical Team's Interview Schedule

Dear Participant, (*Read INFORMATION LETTER to the Participant)*

Thank you for agreeing to take part in this study. Your participation will consist of an interview about one of your patients under your care. Do note that you will remain anonymous and total confidentiality will be safeguarded, still do please try not to mention your name or the patient's name or anything else which will identify you in this interview. Just in case you do so, these details will be erased and confidentiality will remain preserved. Remember you have the right to avoid answering any of the following questions or even stop this interview at any time, this will not adversely affect your rights and you will still continue to be treated as before. As agreed in the consent form, this interview will be audio recorded. This audio information will be eventually deleted once the study is ready. Thank you

---

Date: ....

Ward Code: ....

Consultant's Code: ....

Patient's Code: ....

Clinical Discipline type: ....

I have worked with institutionalised older people for the past 6 months: Yes / No

...

Please answer the following questions:

1. A few days ago a decision was taken in ward ....to manage the swallowing difficulties of your patient in care (*mentioned name*). We will go over the decision-making process so you can describe how and why you think this decision was taken.

1.1 How far were you aware that your patient in care was having serious problems with swallowing?

1.2 How were you involved in the decision process to treat this problem?

If the answer to **1.2 is Yes**, go to Form: A; If the answer to **1.2 is No**, go to Form: B

<u>FORM: A</u>

A1. Please describe in detail how you progressed towards a decision? / What decision was taken?

A2. Were any other alternative interventions considered for the patient to be provided with food and drink?

A3. What was your role in the decision taken?

A4. How was your decision influenced by other members of the team / the relatives / what the patient wished for himself in the past (if he were to come to be in this situation of care)? *Why?*

A5. How difficult was it for you to take this decision? *Why?*

A6. Looking back at the decision-process related to the management of swallowing difficulties in this patient, how satisfied are you with the process? *Why?*

A7. What do you think should professionals aim for when taking a decision in such situations?

A8. If you were to give advice to a colleague about the decision process to manage swallowing difficulties, what would you tell him to keep in mind and not forget in this decision?

A9. Is there anything else you want to tell me about how you think the decision process was appropriate or not appropriate, and how in situations like these, it can be improved?

A10. Knowing the present situation of your patient with dementia, if you were to be in his position, what would you want to be done for yourself regarding management of swallowing difficulties? *Why?*

FORM: B

B1. Would you have wanted to be involved in this decision? *Why?*

B2. Why do you think you weren't consulted in this decision?

B3. What do you think about the decision taken? Would you have wanted a different decision? *Why?*

B4. How would you proceed to come to a decision in this situation? *Why?*

B5. What alternative interventions would you have considered so that the patient is provided with food and drink? *Why?*

B6. How could your decision be influenced by other members of the team / the relatives / what the patient wished for himself in the past (if he were to come to be in this situation of care)? *Why?*

B7. Looking back at the decision process related to the management of swallowing difficulties in this patient, how satisfied are you with the decision process as carried out? *Why?*

B8. If you were to give advice to a colleague about the decision process to manage swallowing difficulties, what would you tell him to keep in mind and not forget in this decision? *Why?*

B9. Is there anything else you want to tell me about how you think the decision process was appropriate or not appropriate, and how in situations like these, it can be improved?

B10. Knowing the present situation of your patient with dementia, if you were to be in his position, what would you want to be done for yourself regarding management of swallowing difficulties? *Why?*

3. Relative's Interview Schedule

Dear Participant (*Read INFORMATION LETTER to the Participant*)

Thank you for agreeing to take part in this study. Your participation will consist of an interview about your family member in care. Do note that you will remain anonymous and total confidentiality will be safeguarded, still do please try not to mention your name or family member's name or anything else which will identify you in this interview. Just in case you do so, these details will be erased and confidentiality will remain preserved. Remember you have the right to avoid answering any of the following questions or even stop this interview at any time, this will not adversely affect your rights and you will still continue to be treated as before. As agreed in the consent form, this interview will be audio recorded. This audio information will be eventually deleted once the study is ready. Thank you

---

Date: .... Ward Code: ....

Consultant's Code: .... Patient's Code:......................

...

2. What is your relationship to the patient.................. / who is present for this interview?

Spouse	Yes / No	
Sibling	Yes / No	*number present...*
Son	Yes / No	*number present...*
Daughter	Yes / No	*number present...*
Grandson	Yes / No	*number present...*
Granddaughter	Yes / No	*number present...*
Niece / Nephew	Yes / No	*number present...*
Holder of General Power of Attorney	Yes / No	relation ....
Holder of Guardianship	Yes / No	relation ....
Holder of Legal Curator Position	Yes / No	relation ....

Please answer the following questions:

1. A few days ago a decision was taken in ward .... to manage the swallowing difficulties of your relative (*mentioned name*). What we will be doing now is go over the decision-making process so you can describe how and why you think this decision was taken.

1.1 How far were you aware that your relative .... was having serious problems with swallowing?

1.3 How were you involved in the decision process to treat this problem?

If the answer to **1.2 is Yes**, go to Form: A; If the answer to **1.2 is No**, go to Form: B

<u>FORM: A</u>

A1. Please describe in detail how you progressed towards a decision? / What decision was taken?

A2. Were any other alternative interventions considered so that........... would be provided with food and drink?

A3. What was your role in the decision taken?

A4. How was your decision influenced by other members of your relatives / members of the medical team / what your relative .... wished for himself in the past (if he were to come to be in this situation of care)? *Why?*

A5. How difficult was it for you to take this decision? *Why?*

A6. Looking back at the decision-process related to the management of swallowing difficulties in your relative ...., how satisfied are you with the process? *Why?*

A7. Were your values and beliefs and those of your relative ...., considered and respected in the decision-making process?

A8. How were you supported to come to this decision? Would you have wished to be given more support? *How? Why?*

A9. If you were to give advice to another person who has a relative in the same situation as............, what would you tell him to keep in mind and not forget in this decision? *Why?*

A10. Is there anything else you want to tell me about how you think the decisions process was appropriate or not appropriate, and how in situations like these, it can be improved?

A11. Knowing the present situation of your relative .... (with dementia), if you were to be in his condition, what would you want to be done for yourself regarding management of swallowing difficulties? *Why?*

FORM: B

B1. Would you have wanted to be involved in this decision? *Why?*

B2. Why do you think you weren't involved in this decision?

B3. What do you think about the decision taken? Would you have wanted a different decision? *Why?*

B4. How would you have proceeded to come to a decision in this situation? *Why?*

B5. What alternative interventions would you have considered so that .... is provided with food and drink? *Why?*

B6. How could your decision be influenced by other members of your relatives / members of the medical team / what your relative .... wished for himself in the past (if he were to come to be in this situation of care)? *Why?*

B7. Looking back at the decision-process related to the management of swallowing difficulties in your relative ...., how satisfied are you with the process as carried out? *Why?*

B8. Were your values and beliefs and those of your relative .... considered and respected in the decision-making process?

B9. If you were to give advice to another person who has a relative in the same situation as.........., what would you tell him to keep in mind and not forget in this decision? *Why?*

B10. Is there anything else you want to tell me about how you think the decision process was appropriate or not appropriate, and how in situations like these, it can be improved?

B11. Knowing the present situation of your relative .... (with dementia), if you were to be in his condition, what would you want to be done for yourself regarding management of swallowing difficulties? *Why?*

4. L-Intervista tat-Tim Mediku

Għażiż Parteċipant (*Aqra l-ITTRA TA' INFORMAZZJONI LILL-PARTEĊIPANT)*

Grazzi talli aċċettajt li tieħu sehem f'dan l-istudju. Il-parteċipazzjoni tiegħek se tikkonsisti f'intervista dwar il-pazjent/a tiegħek li j/tinsab għal kura f'din id-dar ta' l-anzjani. Ifhem illi l-parteċipazzjoni tiegħek sejra tibqa' anonima u l-kunfidenzjalita' se tiġi issalvagwardjata, xorta nagħtik parir li tipprova ma issemmix ismek u isem il-pazjent/a tiegħek jew kull ħaġa oħra li tista' tagħti ħjiel ta' min int f'din l-intervista. Jekk għal xi raġuni dan isir, dawn id-dettalji se jiġu mħassra u l-kunfidenzjalita' tibqa' mhix mittiefsa. Infakkrek li għandek id-dritt li tevita li tirrispondi kull mistoqsija li se nistaqsik jew anke twaqqaf din l-intervista meta trid, jekk tagħmel dan id-drittijiet tiegħek ma jiġux effetwati u inti se tibqa' tiġi stmat/a bħal qabel. Kif int qbilt fil-formola ta' kunsens, din l-intervista se tiġi irrekordjata. Din l-informazzjoni irrekordjata se tiġi ikkanċellata meta l-istudju jkun spiċċa. Grazzi

---

Data: .... Il-Kodiċi tas-Sala: ....

Il-Kodiċi tal-Konsulent: .... Il-Kodiċi tal-Pazjent: ....

It-tip ta' Dixxiplina Klinika: ....

Jiena ħdimt fid-djar tal-anzjani għal dawn l-aħħar 6 xhur: Iva / Le

...

Jekk jogħġbok irrispondi dawn il-mistoqsijiet:

1. Ftit jiem ilu ittieħdet deċiżjoni fis-sala ....sabiex il-pazjent tiegħek (*semmi l-isem*) jiġi ikkurat għall-problema ta' *swallowing difficulties* (tbagħtija biex jibla'). Li se nagħmlu issa huwa li nagħtu ħarsa lejn lid-*decision process* (proċess deċiżjonali) u b'hekk tispjegali kif u għalfejn taħseb li din id-deċiżjoni ittieħdet.

1.1 Kemm kont taf li l-pazjent/a tiegħek kien qed ikollu problema serja ta' ***swallowing difficulties (*****biex jibla)?**

1.2 Kif kont involut f'din id-***decision process (*****proċess deċiżjonali) sabiex tiġi ikkurata din il-problema?**

Jekk ir-risposta ta' **1.2 kienet Iva,** mur Formola: A; Jekk **Le**, mur Formola: B

FORMOLA: A

A1. Jekk jogħbok iddeskrivi fid-dettal kif wasaltu għal deċiżjoni? / X'deċiżjoni ħadtu?

A2. Kien hemm xi interventi alternattivi li kkonsidrajtu sabiex il-pazjent jingħata ikel u xorb?

A3. X'kien ir-rwol tiegħek fid-deċiżjoni li ittieħdet?

A4. Id-deċiżjoni tiegħek, kif kienet influwenzata minn membri oħra tat-tim / il-qraba / dak li l-pazjent xtaq li jsir għalih (fil-passat kieku kellu jasal f'dan l-istat)? *Għalfejn?*

A5. Kemm kienet difficli għalik id-deċiżjoni li ittieħdet? *Għalfejn?*

A6. Jekk tħares lura lejn id-*decision process* (proċess ta' deċiżjoni) dwar il-*management* ta' *swallowing difficulties* (diffikolta' biex jibla) f'dan il–pazjent, kemm inti sodisfatt bil-proċess kif sar? *Għalfejn?*

A7. X'taħseb li għandhom ikunu l-għanijiet tal-professjonisti meta jaslu biex jieħdu deċiżjoni f'ċirkostanzi bħal dawn?

A8. Kieku kellek tagħti parir lill-kollegi tiegħek dwar id-*decision process* (proċess ta' teħid ta' deċiżjoni) dwar il-*management* ta' *swallowing difficulties* (tbagħtija sabiex tibla'), x'kont tgħidlu biex iżomm f'moħħu u ma jinsiex f'din id-deċiżjoni?

A9. Hemm xi ħaġa oħra li xtaqt tgħidli dwar kif taħseb li d-*decision process* (proċess deċiżjonali) kienx xieraq jew le, u kif f'sitwazzjonijiet bħal dawn, dan jista' jitjieb??

A10. Fiċ-ċirkostanzi li jinsab fihom il-pazjent bid-dementia, kieku kellek tkun fl-istess kondizzjoni tiegħu, int x'kont tixtieq li jsir għalik innifsek fil-*management* (kura) ta' *swallowing difficulties* (diffikolta' biex tibla)? *Għalfejn?*

<u>FORMOLA: B</u>

B1. Xtaqt li tkun involut fid-deċiżjoni? *Għalfejn?*

B2. Għalfejn taħseb li ma kontx ikkonsultat fid-deċiżjoni?

B3. X'Taħseb dwar id-deċiżjoni li ittieħdet? Li kien għalik kont tixtieq deċiżjoni differenti? *Għalfejn?*

B4. Inti kif kont tipproċedi biex tasal għal deċizjoni f'din is-sitwazzjoni? *Għalfejn?*

B5. X'interventi alternattivi kont tikkonsidra sabiex il-pazjent jingħata ikel u xorb? *Għalfejn?*

B6. Id-deċiżjoni tiegħek, kif setgħet tiġi influwenzata minn membri oħra tat-tim / il-qraba / dak li l-pazjent xtaq li jsir għalih (fil-passat kieku kellu jasal f'dan l-istat)? *Għalfejn?*

B7. Jekk tħares lura lejn id-*decision process* (proċess ta' deċiżjoni) dwar il-*management* (il-kura) ta' *swallowing difficulties* (diffikolta' biex jibla) tal-pazjent, kemm inti sodisfatt bid-*decision process* (proċess) kif sar? *Għalfejn?*

B8. Kieku kellek tagħti parir lill-kollegi tiegħek dwar id-*decision process* (proċess ta' teħid ta' deċiżjoni) dwar il-*management* ta' *swallowing difficulties* (tbagħtija sabiex tibla'), x'kont tgħidlu biex iżomm f'moħħu u ma jinsiex f'din id-deċiżjoni? *Għalfejn?*

B9. Hemm xi ħaġa oħra li xtaqt tgħidli dwar kif taħseb li d-*decision process* (proċess deċiżjonali) kienx xieraq jew le, u kif f'sitwazzjonijiet bħal dawn, dan jista' jitjieb?

B10. Fiċ-ċirkostanzi li jinsab fihom il-pazjent bid-dementia, kieku kellek tkun fl-istess kondizzjoni tiegħu, int x'kont tixtieq li jsir għalik innifsek fil-*management* (kura) ta' *swallowing difficulties* (diffikolta' biex tibla)? *Għalfejn?*

5. L-Intervista tal-Qraba

Għażiż Parteċipant (*Aqra l-ITTRA TA' INFORMAZZJONI LILL-PARTEĊIPANT*)

Grazzi talli aċċettajt li tieħu sehem f'dan l-istudju. Il-parteċipazzjoni tiegħek se tikkonsisti f'intervista dwar il-qarib/a tiegħek li j/tgħix f'din id-dar ta' l-anzjani. Ifhem illi l-parteċipazzjoni tiegħek sejra tibqa' anonima u l-kunfidenzjalita' se tiġi issalvagwardjata, xorta nagħtik parir li tipprova ma issemmix ismek u isem il-qarib/a tiegħek jew kull ħaġa oħra li tista' tagħti ħjiel ta' min int f'din l-intervista. Jekk għal xi raġuni dan isir, dawn id-dettalji se jiġu mħassra u l-kunfidenzjalita' tibqa' mhix mittiefsa. Infakkrek li għandek id-dritt li tevita li tirrispondi kull mistoqsija li se nistaqsik jew anke twaqqaf din l-intervista meta trid, jekk tagħmel dan id-drittijiet tiegħek ma jiġux effetwati u inti se tibqa' tiġi stmat/a bħal qabel. Kif int qbilt fil-formola ta' kunsens, din l-intervista se tiġi irrekordjata. Din l-informazzjoni irrekordjata se tiġi ikkanċellata meta l-istudju jkun spiċċa. Grazzi

---

Data: .... Il-Kodiċi tas-Sala: ....

Il-Kodiċi tal-Konsulent: .... Il-Kodiċi tal-Pazjent:................

..

2. X'tiġi mill-pazjent .... / min huwa preżenti f'din l-intervista ?

Il-Mara / Raġel	Iva / Le	
Aħwa tal-pazjent	Iva / Le	*numru presenti...*
Iben	Iva / Le	*numru presenti...*
Bint	Iva / Le	*numru presenti...*
Neputi (Grandson)	Iva / Le	*numru presenti...*
Neputija (Granddaughter)	Iva / Le	*numru presenti...*
Neputi/Neputija	Iva / Le	*numru presenti...*
Min għandu l-Prokura Ġenerali	Iva / Le	relazzjoni ....
Min huwa l-Gwardjan Legali	Iva / Le	relazzjoni ....
Min huwa l-Kuratur Legali	Iva / Le	relazzjoni ....

Jekk jogħġbok irrispondi dawn il-mistoqsijiet:

1. Ftit jiem ilu ittieħdet deċiżjoni fis-sala ....biex il-qarib tiegħek (*semmi l-isem*) jiġi ikkurat għall-problema ta' *swallowing difficulties* (tbagħtija biex jibla'). Li se nagħmlu issa huwa li nagħtu ħarsa lejn id-*decision process* (proċess deċiżjonali) u b'hekk tispjegali kif u għalfejn taħseb li din id-deċiżjoni ittieħdet.

1.1 Kemm kont taf li l qarib/a tiegħek ....kien qed ikollu problema serja ta' *swallowing difficulties* (biex jibla)?

1.2 Kif kont involut f'din id-*decision process* (proċess deċiżjonali) sabiex tiġi ikkurata din il-problema?

Jekk ir-risposta ta' **1.2 kienet Iva,** mur Formola: A;

Jekk ir-risposta ta' **1.2 kienet Le**, mur Formola: B

<u>FORMOLA: A</u>

A1. Jekk jogħbok iddeskrivi fid-dettal kif wasaltu għal deċiżjoni? / X'deċiżjoni ħadtu?

A2. Kien hemm xi interventi oħra (alternattivi) li ikkonsidrajtu sabiex .... jingħata ikel u xorb?

A3. X'kien ir-rwol tiegħek fid-deċiżjoni li ittieħdet?

A4. Id-deċiżjoni tiegħek kif kienet influwenzata minn membri oħra tal-familja / membri tat-tim mediku / dak li l-qarib tiegħek .... xtaq li jsir għalih fil-passat (kieku kellu jasal f'dan l-istat)? *Għalfejn?*

A5. Kemm kienet difficli għalik id-deċiżjoni li ħadt? *Għalfejn?)*

A6. Jekk tħares lura lejn id-*decision process* (proċess ta' deċiżjoni) dwar il-*management* ta' *swallowing difficulties* (diffikolta' biex jibla) fil-qarib tiegħek ...., kemm inti sodisfatt bil-proċess kif sar? *Għalfejn?*

A7. Il-valuri ta' dak li temmen fih inti, u sew dak li jemmen fih il-qarib tiegħek ...., kienu ikkunsidrati w irrispettati fil-proċess ta' *decision-making* (teħid ta' deċiżjoni)?

A8. Kif kont mgħejjuna sabiex tasal għal deċiżjoni? Kont tixtieq li tiġi mogħti/ija aktar għajnuna? *Kif? Għalfejn?*

A9. Kieku kellek tagħti parir lill-persuna oħra li għandu membru tal-familja fl-istess sitwazzjoni bħal ...., x'kont tgħidlu biex iżomm f'moħħu u ma jinsiex f'din id-deċiżjoni? *Għalfejn?*

A10. Hemm xi ħaġa oħra li xtaqt tgħidli dwar kif taħseb li d-*decision process* (proċess deċiżjonali) kienx xieraq jew le, u kif f'sitwazzjonijiet bħal dawn, dan jista' jitjieb?

A11. Fiċ-ċirkostanzi li jinsab fihom il-qarib tiegħek....... (bid-demensja), kieku kellek tkun fl-istess kondizzjoni tiegħu, int x'kont tixtieq li jsir għalik innifsek fil-*management* (kura) ta' *swallowing difficulties* (diffikolta' biex tibla)? *Għalfejn?*

FORMOLA: B

B1. Xtaqt li tkun involut/a fid-deċiżjoni? *Għalfejn?*

B2. Għalfejn taħseb li ma kontx involuta fid-deċiżjoni?

B3. X'Taħseb dwar id-deċiżjoni li ittieħdet? Li kien għalik kont tixtieq deċiżjoni differenti? *Għalfejn?*

B4. Inti kif kont tipproċedi biex tasal għal deċizjoni f'din is-sitwazzjoni? Għalfejn?

B5. X'interventi oħra (alternattivi) kont tikkonsidra sabiex .... jingħata ikel u xorb? *Għalfejn?*

B6. Id-deċiżjoni tiegħek, kif setgħet tiġi influwenzata bl-involviment ta' membri oħra tal-familja / membri tat-tim mediku / dak li l-qarib tiegħek .... xtaq li jsir għalih (fil-passat kieku kellu jasal f'dan l-istat)? *Għalfejn?*

B7. Jekk tħares lura lejn id-*decision process* (proċess ta' deċiżjoni) dwar il-*management* ta' *swallowing difficulties* (diffikolta' biex jibla) fil-qarib tiegħek ...., kemm inti sodisfatt bil-proċess kif sar? *Għalfejn?*

B8. Il-valuri ta' dak li temmen fih inti, u sew dak li jemmen fih il-qarib tiegħek ...., kienu ikkunsidrati w irrispettati fil-proċess ta' *decision-making* (teħid ta' deċiżjoni)?

B9. Kieku kellek tagħti parir lill-persuna oħra li għandu membru tal-familja fl-istess sitwazzjoni bħal ...., x'kont tgħidlu biex iżomm f'moħħu u ma jinsiex f'din id-deċiżjoni? *Għalfejn?*

B10. Hemm xi ħaġa oħra li xtaqt tgħidli dwar kif taħseb li d-*decision process* (proċess deċiżjonali) kienx xieraq jew le, u kif f'sitwazzjonijiet bħal dawn, dan jista' jitjieb?

B11. Fiċ-ċirkostanzi li jinsab fihom il-qarib tiegħek....... (bid-demensja), kieku kellek tkun fl-istess kondizzjoni tiegħu, int x'kont tixtieq li jsir għalik innifsek fil-*management* (kura) ta' *swallowing difficulties* (diffikolta' biex tibla)? *Għalfejn?*

10. Appendix 2: Tables

Table 1

The step-wise process involved in decision-making

1. “Identify the key factors.
2. Identify and analyse the major stakeholders.
3. Identify the underlying driving forces.
4. Identify/prioritise operating values and ethical principles.
5. Decide who should be involved in making the decision.
6. Determine and evaluate all viable alternatives.
7. Test preferred alternative with a worst-case scenario.
8. Add a preventive component.
9. Decide and build a short and long-term action plan.
10. Use a decision-making checklist.”

From Pekel and Wallace, (2006, p. 2)

Table 2

Naturalistic decision-making approach in teams

- “Monitors personal performance and self-control.
- Gives feedback.
- Is aware of functions and roles.
- Adaptive to changes in their task.
- Easy communication.
- Shared understanding of current status and actions.
- Receptive of all team members’ needs and actions.
- Co-ordination of inputs and deeds” (Zsambok, 2014).
- “Integrate their knowledge, opinions and preferences” into a common decision (Kolbe & Boos, 2009, p. 2)

Table 3
Styles of practice in team decision-making

1. “Decision-making by authority without group discussion.
2. Decision by an expert.
3. Decision by averaging individuals’ opinions.
4. Decision made by authority after group discussion.
5. Decision by minority.
6. Decision by majority vote.
7. Decision by consensus”

From *Effective Decision-making* (n.d., pp. 3, 4) (see also Johnson & Johnson, 2000)

Table 4
Benefits coming from an early diagnosis of dementia

- "Optimising current medical management - attention to treatable causes.
- Relief gained from better understanding.
- Maximising decision-making autonomy about the future while still retaining mental capacity.
- Access to medical care, advice and support.
- Risk reduction - safety at home, driving assessment.
- Planning for the future - early retirement, financial planning, and safety issues.
- Improving clinical outcomes - slowing or stabilising cognitive and functional decline.
- Avoiding or reducing future costs - chiefly through delaying or avoiding transition into a care home.
- Diagnosis as a human right - both to have access to an accurate diagnosis, and to be informed of it, or not, according to preference" (pp. 15-16)

From *World Alzheimer Report* (2011)

Table 5
List of barriers to advance care planning

1. Patients are oblivious that advance directives exist.
2. Conscientious objective in clinicians to satisfy the wishes of patients as expressed in their living wills.
3. Filling out advance directives requires preserved capacity, which state may already be lost at the diagnostic point of dementia.
4. Patients or clinicians may be wary of discussing and taking up decisions about future care (Bowker, 2006).
5. Socio-cultural issues may hinder patients and their families from pursuing EOL discussion and decision-making.
6. Lack of knowledge and engagement of clinicians to deal proactively on EOL issues (Hertogh, 2006).
7. Lack of opportunities for communication on ACP between the patient/family and clinicians.
8. Patients are often worried that their views might change with time as they believe ACP would restrict their options if they wish it to be changed. This is a real problem as such decisions cannot be changed by the patient when mental incapacity sets in.
9. It is not an easy task to enable a patient with early dementia to give an adequate informed consent; many persons end up understanding very little about what they are signing in advance directives (Welie, 2010).
10. The drawing up of an ACP depends on the patient’s willingness, physical, emotional, cognitive readiness and abilities to comply (Stewart, Goddard, Schiff, & Hall, 2011).
11. No one can for-tell or control all the clinical situations that may arise in end-stage dementia (Gastmans, 2016).
12. Service factors, including lack of funding or time constraints (Hertogh, p. 553).
13. The efficiency in the transfer of papers related to advance directives from one care setting to another may be poor.
14. Poor storage procedures of advance directives and living wills at home, in hospital and long-term-care.
15. The advance directive documentation may be inaccurate, ambiguous or too vague to be used and applied to an exact clinical situation by physicians in care (Bowker).
16. Conflicting views between clinicians and the family of what constitutes the patient’s best interests.
17. The family might disagree on management based on an advanced directive as they do not see advanced dementia as an EOL clinical situation (Kissell, 2010).
18. Other considerations eventually end up overruling stated patient wishes, (e.g. the family having divergent views or interests, or clinician paternalism) (Welie).
19. Nobody considers the effect of advance directives on the family.
20. Lack of trust between the patient/family and their physician thus hindering the drawing up advance care plans (*RCP,* 2010).
21. Many advance directives are drawn up by attorneys who have little experience in clinical care (Hanson et al., 2008).
22. One problem that occurs is when a patient draws up an advance directive deciding a preference to avoid aggressive care in the EOL. However, at an advanced stage of dementia, such decision would later seem to be at discord with what happens to be in the best interests of the patient’s at that point in time (*RCP*).
23. Despite the legal force behind advance care directives, they may end up not being respected in clinical practice (Stewart et al.)
24. Lack of legislative backing as is the case in Malta (Cassar, 2010).

25. The fact that ACP is a clinical intervention that is not legally binding may lead to situations where they end up being ignored (Stewart et al.).
26. In reality the benefit of advance directives “has not substantially reduced the difficulties faced by families and health professionals” (Gordon, 2002, p. 324) in ethically charged clinical decisions.

Table 6
“Functional Assessment Staging of Alzheimer’s disease. (FAST)©

STAGE	SKILL LEVEL
1.	“No difficulties, either subjectively or objectively.
2.	Complains of forgetting the location of objects. Subjective word finding difficulties.
3.	Decreased job function evident to co-workers; difficulty in travelling to new locations. Decreased organisational capacity.
4.	Decreased ability to perform complex tasks (e.g., planning dinner for guests), handling personal finances (forgetting to pay bills), difficulty marketing etc.
5.	Requires assistance in choosing proper clothing to wear for day, season, and occasion.
6a	Difficulty putting clothing on properly without assistance.
b.	Unable to bathe properly; (e.g., difficulty adjusting bath water temperature) occasional or more frequently over the past weeks.
c.	Inability to handle mechanics of toileting (e.g., forgets to flush the toilet, does not wipe properly or properly dispose of toilet tissue) occasionally or more frequently over the past weeks.
d.	Urinary incontinence, occasional or more frequent.
e.	Faecal incontinence, (occasional or more frequently over the past week).
7a.	Ability to speak limited to approximately a half dozen different words or fewer, in the course of an average day or the course of an intensive interview
b.	Speech ability limited to the use of a single intelligible word in an average day or in the course of an interview (the person may repeat the word over and over)
c.	Ambulatory ability lost (cannot walk without personal assistance).
d.	Ability to sit up without assistance lost (e.g., the individual will fall over if there are no lateral rests [arms] on the chair).
e.	Loss of the ability to smile.”

STAGE: ________________

Reproduced with permission from: Reisberg, (1988).

Table 7

The signs and symptoms of end-stage dementia

1. Loss of ability to move about purposefully.
2. Loss of regular verbal communication.
3. Dependence in all activities of daily living.
4. Needs to be fed and tends to choke.
5. Loss of recognition of family members except during moments of clarity.
6. Spontaneous behaviours, such as yelling, tapping or banging.
7. Contractures – where the joints are "frozen" in a flexed position.
8. Pathological (spontaneous) fractures.
9. Severe weight loss.
10. Strong potential for skin breakdown and / or skin tears.
11. Repeated infections – especially pneumonia and urinary tract infections.
12. Aspiration – breathing in food, fluid, or saliva, causing pneumonia.
13. Falls from bed (roll-outs or climb-outs).
14. Return of primitive reflexes (reflexes seen in infancy that disappear after the first three months of life).
15. Seizures, additional neurological problems ("Stages of Alzheimer-type Dementia" (2011)
16. Muscle atrophy, contractures, increased susceptibility to delirium and peripheral shutdown (Abbey et al., 2007)
17. Oppositional paratonia, hypertonia, myoclonus and epileptic seizures (Hertogh, 2010)
18. Prone to suffer pain which is frequently inadequately treated (Hughes et al., 2007)
19. Persons with end-stage dementia where more prone to be older; of female gender; being fed via feeding tubes; had a lower admission haemoglobin, total cholesterol and albumin; and had a higher level of suffering on the MSSE scale Aminoff and Adunsky (2006), and dying within 6 months of assessment in a geriatric hospital.
20. Persons in end-stage dementia lose their cognitive function (NICE, 2006, November) and their ability to respond to the environment and the ability to control movement (*Alzheimer's Association*, 2003).
21. Persons in end-stage dementia lose interest in food, are dually incontinent and are more prone to develop pressure sores (Birch and Stokoe, 2010).
22. The implied feeding problems in end-stage dementia strongly contribute to the development of malnutrition as the disease progresses (Pace et al., 2011).
23. Persons in end-stage dementia lose the ability for autonomy and control on self (Dekkers, W. J. M., 2010).

Table 8

Staging tools that quantify the severe phase of dementia

1. Functional Assessment Staging Test [FAST] (Reisberg, 1988).
2. Bedford Alzheimer Nursing Severity Scale [BANS-S]
3. Global Deterioration Scale [GDS]
4. Clinical Dementia Rating [CDR]
5. Mattis Rating Scale (Abbey et al., 2007)
6. The Mini Suffering State Examination [MSSE] scale (Aminoff & Adunsky, 2006).
7. The Advanced Dementia Prognostic Tool [ADEPT]
8. Cognitive Performance Score (Mitchell et al., 2010).
9. Functional Status Questionnaire (Raymond et al., 2003).

Table 9

“Needs-based criteria for an improved palliative approach in EOL care

1. “Does the patient have moderately severe or severe dementia?
2. Does the patient also have severe distress (mental or physical) which is not easily amenable to treatment?
    - OR severe physical frailty which is not easily amenable to treatment?
    - OR another condition (e.g. comorbid cancer) which merits palliative care services in its own right?

If criteria 1 and 2 co-exist, then the patient ought to have a full assessment of need and a focused analysis of why they are in distress and how best their symptoms can be improved and distress reduced" (p. 64).

From: Gibson et al. (2009); see also Pace et al. (2011)

Table 10

Content of care planning meetings

1. ”Determine the goals of the resident and relatives for EOL care provides a framework for the care team and enables it to tailor care to the resident’s needs and preferences.
2. When meeting the resident, proxy decision maker or relatives, the broader care team can discuss potential medical crises and treatment alternatives, and make decisions about the best course of action based on the resident’s condition.
3. It is important that residents and families consider the following care decisions and the relationship of each of them to the resident’s care goals during planning for the EOL: CPR; invasive medical procedures and tests (e.g. surgery, blood tests, dialysis); hospitalisation; use of intensive care units; artificial nutrition / hydration; antibiotics; use of preventive health screening, medications and dietary restrictions.
4. The resident’s desires regarding EOL care, cultural and religious traditions, functional capabilities and health status care decisions. This information includes potential benefits and burdens of each intervention.
5. Decisions about the intervention options need to be part of the care plan and be translated into medical orders.
6. As the resident’s condition declines with the progression of dementia, care goals may change form: curing coexisting conditions, or preserving function, to palliative care. It is important to re-evaluate, revise the care goals, and decisions in regularly scheduled care planning meetings.
7. If a thoroughly informed resident, proxy decision maker or relatives decide on an aggressive or alternative medical intervention, or refuse treatment or care, the broader care team needs to make all feasible efforts to honour such a decision. However, the care team is not required to deliver treatment or care that is determined to be medically inappropriate” (p. 12)

From: *Alzhiemer's Association* (2007)

Table 11

Management protocol based on dysphagia severity in advanced dementia

Level 1: Dysphagia that is manageable by routine treatment protocols. In such cases the SLP's management plan should be handed over to nursing staff and management instructions and inputed in the nursing documentation; such information may include "diet modification, correcting position or feeding strategies" (p. 109).

Level 2: Dysphagia is where the patient is at high risk of aspiration, even though corrective dysphagia management measures are taken. Risks include continued vocalisation during feeding and a level of alertness that fluctuates during feeding. In such cases, SLP assessment should be done with nursing staff and management instructions inputted in the nursing documentation; the situation should be brought forward for the attention of the family.

Level 3: Dysphagia is where the patient is aspirating, even though corrective dysphagia management measures are in place. Signs include "recurrent chest infection, cough or choking, 'wet' or 'gurgly' voice or respiratory distress when being fed" (pp. 109-110). In such cases, SLP assessment should be done with the nursing staff. The consultant and the rest of the team (namely nurses) should be informed and team management options explored (maximal oral precautions in adapted feeding and drinking thickened fluids). One of the options to be considered is nil by mouth. The situation should be brought forward for the attention of the family who should be provided with written information (e.g. leaflets) on the problem and informed on what options are pertinent about advanced dementia management.

Adapted from Summersall and Wight (2006)

Table 12

Clinical indications for enteral tube feeding: A Cochrane Review

- Neurological deficiency.
- Refusal to eat.
- Diminished consciousness.
- Inadequate oral feeding and hydration because of cognitive impairment.
- Loss of weight.
- Dysphagia.
- Stroke.

Adapted from Sampson et al. (2009, pp. 8-9)

Table 13

Potential benefit of CANH in advanced dementia

- To provide nutrition and hydration (Birch & Stokoe, 2010).
- Avoiding hunger and thirst (*Potack & Chokhavatia, 2008*).
- Decreasing aspiration risk and associated pneumonia.
- Improving ulcers/pressure sores.
- Improving survival (*RCP,* 2010).
- "Greater sense of accomplishment, and a lesser sense of failure" (Finucane et al., 1999, p. 30) in relatives.
- The following are claimed benefits of CANH as expressed by relatives of hospitalised older patients, many of whom suffer from dementia:
    - Improved comfort.
    - Better pain control.
    - Better QOL.
    - More freedom.
    - Fewer feeding difficulties.
    - Fewer coughing episodes.
    - Greater enjoyment of food (Carey et al., 2006).

Table 14

Disadvantages of enteral tube feeding in advanced dementia

- Studies on enteral tube feeding showed no beneficial effect to improve malnutrition, weight loss and serum albumen levels (Sampson et al. 2009; *RCP*, 2010).
- Concerning hunger and thirst in patients with dementia, no associated discomfort was observed if insufficient oral intake were pursued (Shah, 2006).
- Enteral feeding did not show any significant benefit on pressure sores, where on the contrary, the actual risk of ulcers was increased.
- Tube-fed patients were more prone to be restrained than those that were hand-fed (Sampson et al., 2009; *Howland, 2009*).
- PEG placement is associated with increased social loneliness and denial of the pleasures of oral feeding (*Potack & Chokhavatia, 2008*).
- PEG placement didn't end up reducing the risk of aspiration pneumonia and other infections and it didn't lead to an improvement in self-care nor improved survival (*Morris & Volicer, 2001*; Shah, 2006).

Table 15
Risks of enteral tube feeding

1. Risks related to PEG feeding
    - An associated risk of significant morbidity and mortality. PEG placement has a 30 day 6% mortality and 10% morbidity (Chalmers-Watson, et al., 2002).
    - PEG placement is an invasive procedure and includes the passage of an endoscope after sedation (*RCP*, 2010).
    - Post-op complications are: perforation of the peritoneal cavity and stomach wall; intra-abdominal haemorrhage; stomal sepsis; peritonitis; colonic perforation and transfixion; gastrocolocutaneous fistula; tube migration and buried bumper syndrome; wound infection and necrotizing fasciitis.
    - Inadvertent pulling out of the PEG tube.
    - Tube leakage or blocking.
    - Risks of placement, reflux and aspiration pneumonia (Potack & Chokhavatia, 2008).
    - Deprivation of the normal pleasures of oral feeding
    - Restriction to movement, as the individual has to remain attached to a feeding machine (*RCP*)
    - Legal issues were given insufficient consideration for the patients' / relatives' wishes (Potack & Chokhavatia)
2. Risks related to NG tube feeding,
    - Notable discomfort created by a foreign tube through the nostrils.
    - Increased propensity for restraining cognitively impaired patients as they may attempt to stop them from pulling out the tubing.
    - Epistaxis.
    - Inappropriate bronchial placement (*RCP,* 2010; Rimon, Kagansky & Levy, 2005).
3. Risks common to both NG and PEG enteral feeding:
    - Aspiration pneumonia due to food reflux.
    - Re-feeding syndrome can happen if the patient is malnourished for a lengthy period. This leads to hypophosphataemia, hypomagnesemia, hypokalemia, heart failure, respiratory failure, cardiac arrhythmias, seizures and coma.
    - "Fluid overload and heart failure" (Bowker et al., 2006, p. 381).
    - Increased abdominal discomfort, nausea, vomiting and diarrhoea (Bowker et al.), leading to increased risk of skin breakdown or pressure sores (Dunlop, 2006).
    - Increased restraint leading to increased immobility and increased restlessness in the patient which may necessitate sedation (Potack & Chokhavatia).

Table 16
The aims to administer CANH to be discussed between all decisional stakeholders

1. "Decrease in discomfort / symptoms as medication can be given.
2. Increase in the weight if the patient is underweight.
3. Improvement of healing of pressure sores.
4. Increased capacity for rehabilitation.
5. Reversal of confusion" (*RCP,* 2010, pp. 69-70).

From: *RCP* (2010)

Table 17

Standard 19: Dying and death (for care homes for older people)

Standard:

- "Care and comfort are given to service users who are dying, their death is handled with dignity and propriety, and their spiritual needs, rites and functions observed.
- Care staff make every effort to ensure that the service user receives appropriate attention and pain relief.
- The service user's wishes concerning terminal care and arrangements after death are discussed with them, recorded in the care plan and are respected, wherever possible.
- The service user's relatives and friends are involved, if that is what the service user wants, in planning for and dealing with increasing infirmity, terminal illness and death.
- The privacy and dignity of the service user who is dying are maintained at all times.
- Service users can spend their final days in their rooms, surrounded by their personal belongings, unless there are compelling medical reasons to prevent this.
- The registered person ensures that staff and service users who wish to offer comfort to a service user who is dying are enabled and supported to do so.
- The registered person ensures that expert advice is available to staff in order to provide effective palliative care. Bereavement counselling, provided by trained professionals or specialist agencies, should also be available to the service user if they request it.
- The changing needs of service users with deteriorating conditions or dementia, for personal support or technical aids, are reviewed and met swiftly to ensure the individual retains maximal control.
- Relatives and friends of a service user who is dying can stay with her/him unless the service user makes it clear that she does not want them to for as long as they wish
- The body of a service user who has died is handled with dignity. The time allowed for relatives and friends to pay their respects.
- Policies and procedures for handling dying and death are in place and observed by staff who have been trained in their implementation" (pp. 18-19).

From: *Dying and Death* National Minimum Standards (2004)

Table 18

Inductive categories explaining the context of withdrawal and withholding CANH

1. The nature of the illness and goals and trajectory of treatment.
2. Personhood and individual rights and autonomy.
3. Family involvement and symbolism of food and emotional issue of starvation.
4. The rights of providers.
5. Costs.
6. Religion.
7. Legal issues.
8. Ethical principles and lack of consensus on withdrawal and withholding artificial feeding.

Adapted from Monturo (2009)

Table 19

Quality markers on EOL care in care homes.

- "Setting up an action plan within the home that is in line with local palliative policies.
- The promotion of a system to record and implement advance care planning and involve residents and carers in their end of care to the extent that they wish.
- An ongoing assessment to revise the clinical plan through time as the resident's EOL needs to develop.
- Nomination of a key EOL co-ordinator of care for individual residents in their EOL.
- Provision of support to other residents who are prone also to bereave the loss of a resident living in the same closed environment.
- All systems should be regularly audited.
- Training of staff to help residents make decisions about their care.
- Implementation of care staff training on EOL clinical care pathways as practised in the home.
- Processes are in place to ensure that patients who are relocated in their EOL are reviewed appropriately by the caring team" (p. 1).

From: *Quality Markers Care* (2010)

Table 20

Barriers to Palliation in End-stage dementia

1. Funding issues.
2. Lack of appropriate staffing levels.
3. Socio-cultural, namely, legal factors that effect clinical decision-making.
4. As compared to cancer patients, persons with dementia are less often recognised by physicians and families as suffering from a terminal condition leading to fewer referrals to hospice care in the last year of life (Hertogh, 2006).
5. Persons with "dementia have difficulty with recall, interpretation of sensations and verbal expression" (Sachs et al., 2004, p. 1059) thus it is quite difficult to manage palliative related symptoms (e.g. pain, discomfort with tube feeding).
6. Lack of mental capacity adversely affects the patient to the point that they are unable to engage in informed consent to treatment and hinders their involvement in forwarding care planning for the EOL (Bayer, 2006).
7. There is limited use of advance directives by nursing home residents with dementia. Thus the will and wishes of the patient are unknown (Mitchell et al., 2004).
8. Physicians in LTC, have limited experience and training with advanced dementia leading to a problematic assessment and management of symptoms and an imperfect EOL care strategy.
9. Barriers to communication between family and health professionals.
10. The family/health care proxies have limited knowledge of dementia and EOL care decision-making, leading to requests for futile EOL treatment and demand for transfer to hospital (Hertogh).
11. Treatment decisions on nutrition and hydration are highly emotive issues for the family (Bowker et al., 2006).
12. Health system issues (Seymour et al., 2005).
13. Current criteria for grading dementia give most importance to cognitive and functional disability and not to prognosis and needs (Pace et al., 2011).
14. Current dementia-staging measures, on their own, cannot give sufficient data to guide the management of EOL decision-making (Hertogh).
15. Evidence of burdens/risks and benefits of treatment regimens (e.g. for CANH) in the EOL are not fully clear (Volicer, 2005).
16. Decisions on whether or not to institute artificial feeding are compounded by problems related to the assessment of QOL about survival.
17. Measurement of both QOL and quality of care in the EOL in dementia are lacking (Goodman et al., 2010).
18. Limited scientific research is available on the therapeutic interventions in advanced dementia. (Hertogh).
19. The clinical difficulty that does dispute palliation in end-stage of dementia when the patient becomes acutely ill from associated co-morbidity. This tends to create uncertainty in many physicians who in such cases, would find it easier to treat aggressively (Birch & Stokoe, 2010).

Table 21

Hospice model of care

"LEVEL 1: includes an aggressive diagnosis workup, treatment of co-morbid conditions, cardiopulmonary resuscitation CPR, tube feedings, and transfer to an acute medical unit if needed
LEVEL 2: includes the same level of care as in Level 1, but excluded CPR
LEVEL 3: care also excluded CPR. In addition it excluded a transfer to an acure care unit, thereby eliminating the use of respirators, cardiovascular support, and so forth.
LEVEL 4: care excluded CPR and mandated no transfer to an acute care unit, no aggressive diagnostic workup, and no antibiotic treatment of life-threatening infections (pneumonia, urinary tract infection etc). Patient comfort needs were met with analgesics and antipyretics
LEVEL 5: care, strategies such as cardiopulmonary resuscitation, transfers to acute medical facilities, diagnositic workups, antibiotics, and tube feeding were not done. Patient comfort care and supportive care were continued."

From: Furlong, 2010, p. 244; see also Volicer, Rheaume, Brown, Fabinszewski and Brady (1986)

Table 22

Reasons why curative approaches supercede palliation in end-stage dementia

1. In situations of acute on chronic clinical situations, doctors find it difficult to delineate a difference between aggressive care and palliation (Birch & Stokoe, 2010).
2. Clinical options in the EOL are limited, and doctors do find difficulty to delineated a practical balance of "too much aggressive care akin to overtreatment versus not to give too little care akin to undertreatment" (Hertogh, 2010, p. 272).
3. Many grey areas of uncertainty do exist in the absence of a clear cut-off point between curative and palliative care (Hertogh, 2006).
4. In many situations, doctors have limited feedback from significant others (patient and family) to guide their care in the absence of advance directives, (Bowker et al., 2006).
5. The approach to EOL management in long-term-care settings does lag behind in the provision of palliative approaches as criteria for the exposure to hospice lack clear definitions (Seymour et al., 2005).
6. Nursing home physicians lack the necessary expertise to identify the limits of the benefits and burdens of a curative approach in the advanced stages of dementia, which renders the conversion to palliative management problematic (Froggatt & Parker, 2010).
7. Doctors might take the easy way out, that of continuing aggressive care, this being a no fail strategy as nobody can say you wouldn't have done your best to save the patient (*RCP* (2010).

Table 23

Arguments in favour of euthanasia and assisted suicide

1. Euthanasia “is the ultimate civil right” of the terminally ill cognitively preserved person. Thus the terminally ill person has a “protected liberty” (“Euthanasia Assisted Suicide”, 2013, p. 1) to bring about his/her termination of life (American Civil Liberties, 2008).
2. It grants respect to personal autonomy (“Euthanasia Assisted Suicide”, 2013).
3. It grants a dignified, peaceful death to the terminally ill (“Euthanasia Assisted Suicide”).
4. It leads to avoidance of EOL suffering and painful agony (“Euthanasia Assisted Suicide”).
5. Medical advances in the quest to prolong life have managed to “prolong the dying rather than the living” (“Should Euthanasia Physician-Assisted”, 2013, p. 1), thus euthanasia allows the patient to retake back control on their EOL.
6. Acceptance of euthanasia is just another occasion where the Hippocratic Oath had been amended over the years (e.g. no female doctors; the patient’s skin should not be broken are Hippocratic views that have been withdrawn in the past) (Nitschke, 2001).
7. The administration of euthanasia does not differ a lot from the administration of strong drugs given for pain relief in the terminally ill, that unintentionally hasten the advent of death (“Euthanasia Assisted Suicide”).
8. Legalising euthanasia helps to regulate its practice and thus neutralises euthanasia when it is performed by physicians surreptitiously. This ends up leading to the protection of vulnerable persons from abusive practices and “from wrongful death” (“Euthanasia Assisted Suicide”, p. 1).
9. The slippery slope argument is just a “doomsday cult” that is used by the anti-euthanasia group, which never materialises (Frey, 2014, p. 76).
10. Euthanasia is complementary to palliative care and not a substitute (Kimsma & van Leeuwen, 2004).
11. As opposition to euthanasia is strongly related to religion, this signifies that laws to legislate against euthanasia are unconstitutional given the division between state and church (“Euthanasia Assisted Suicide”).
12. In situations of cognitive decline, living wills do allow persons to plan and retain control on their own death in future situations of suffering in their EOL, for when they lose mental capacity (Pozzuolo, Lassoff, & Valentine, 2005).
13. If one accepts that argument that preserving life is preserving autonomy, therefore there is no argument to keep alive persons in coma as their autonomy is absent (“Australian Association Professional”, 2005).

Table 24

Arguments against euthanasia and assisted suicide

1. “The history of the law’s treatment of assisted suicide in this country has been and continues to be one of rejection” (“Should Euthanasia Physician-Assisted”, 2013, p. 1; see also US Supreme Court, 1997, June 26) thus assisted suicide “is not a fundamental liberty” (p. 1).
2. Laws against euthanasia have the intention to prevent abuse and protection of people “from unscrupulous doctors” (Marker & Hamlon, 2010, p. 1) and thus do not have the intention to make persons suffer.
3. Human life should be protected as an ethical-legal principle that is not dependent on sickness and health and ultimately is more fundamental than autonomy on its own; this applies especially to the vulnerable and sick. A reversal of the above principles would make medical practitioners operate a “mere technical function whereby the doctor performs whatever the patient wishes” (Safeguard Dignity Human, 2016, p. 2).
4. Arguments that sanction the rational management of euthanasia as a dignity-preserving act in the face of intractable suffering are based on the assumption that killing is a value, yet it is known that “human dignity is not a value that can be rendered nugatory in some overall calculation of the worth of a life to yield a judgement which justifies killing” (Gormally, 1994, pp. 771-772), and would rob many people’s lives of their dignity in the face of suffering.
5. The axiom to respect for autonomy goes against another axiom that of sanctity-of-life, which situation is a contradiction as axioms cannot be tagged against each other. Furthermore, by allowing termination of life, one would be terminating autonomous choice (“Australian Association Professional”, 2005).
6. In a society geared only to pursue cost containment in health care, the introduction of euthanasia would lead our society “down a dangerous slippery slope” (“Euthanasia Assisted Suicide”, n.d., p. 1). By slippery-slop, it is meant that legalisation of euthanasia could lead to new uncharted situations which are morally undesirable (Gordijin, 2010).
7. The Hippocratic Oath poses on the medical profession self-restraint and not to harm your patients. For the physician, “human life in living bodies commands respect and reverence by its own nature. An important ethical issue is the “dignity and mysterious power of human life itself” (“Should Euthanasia Physician-Assisted” p. 2). Thus the sanctity-of-life makes it never justified to lead to interventions to hasten death (*RCP*, 2010).
8. Legislation against euthanasia is a clear regulation on the medical community to apply restrictions on how far to intervene in the face of vulnerable disabled persons (Drake, 2001).
9. Utilitarianism and health care cost control may expose minority groups and other persons prone to be victims of social inequality and discrimination (who are most vulnerable to mistakes and apathy), thus more exposed to abuse of euthanasia as it is much cheaper to terminate the life of a disabled person through euthanasia than to provide proper palliative care (Marker & Hamlon).
10. Wherever euthanasia is legalised, hospice as a palliative intervention was found to be poor or non-existent. Thus one cannot corraborate claims by the pro-euthanasia campaign that euthanasia and palliative care do exist together (Smith, 1997, p. 3).
11. It is denied that in clinical practice there is widespread surreptitious euthanasia (“Euthanasia Assisted Suicide”).
12. Moral teachings through Catholicism rest on the belief that life is a gift of God (US Conference Catholic Bishops, 2009). At the same time, Catholic teachings do recognise that

"every person reserves the legal and moral right to refuse medical treatment that does not offer any hope, which involves exorbitant costs or inconvenience, or incurs severe pain and suffering" ("Cherishing Life", 2016, August 6, p. 2).

13. The goals of living wills as an expression of the patient's past wishes for their EOL are frequently unachievable for the following reasons. Persons who fill out living wills are not fully aware of all the consequences in life and death situations. At the same time living wills draft formats are not sensitive enough to allow persons to fully express their wishes accurately. Furthermore, "living wills seem not to increase the accuracy with which surrogates identify patient's preferences" (Fagerlin & Schneider, 2004, p. 31).

14. Timely and effective hospice and palliative care is the proper morally acceptable treatment strategy to manage EOL care ("Euthanasia Assisted Suicide"). Gordijin (2010) remarked that the best management to deal with suffering is to take measures to reduce the amount of distress and agony. However in the case of suffering where active, direct euthanasia [ADE] is utilised, this literally leads to annihilation and irreversible elimination of the subject of all conscious experience.

Table 25

Dignity concerns for EOL patients in institutional care

1) "Illness-related concerns;
    a) Level of independence (particularly loss of control on their financial affairs, personal care and their social lives)
        i) Cognitive acuity
        ii) Functional capacity
    b) Symptom distress
        i) Physical distress
        ii) Psychological distress
            (1) Medical uncertainty (lack of knowledge about their current health status or treatment)
            (2) Feeling of loss (of home, relatives, friends, important roles, function and independence, freedom and future)
2) Dignity conserving repertoire
    a) Dignity conserving perspectives (maintenance of pride particular with respect to control on their cognitive abilities, independence and valued roles)
        i) Continuity of self
        ii) Role preservation
        iii) Generativity/legacy
        iv) Maintenance of pride
        v) Hopefulness
        vi) Autonomy/control
        vii) Resilience/fighting spirit
        viii) Living in the moment
        ix) Maintaining normalcy
        x) Seeking spiritual comfort
3) Social aspects of the illness experience
    a) Privacy boundaries
    b) Social support
    c) Care tenor
    d) Burden to others" (p. 412)

Chochinov et al. (2002)

Table 26

An ethical framework to resolve decisional dilemmas in dementia

1. A case-based approach giving importance to ethical values based on casuistry.
2. Identifying a conviction or belief of the effects of dementia on the person involved.
3. Exploring a belief of the effects of dementia on the QOL of the individual.
4. Acknowledging that in the management of a situation of care involving dementia, there is not only the person with dementia involved but also his immediate family carers.
5. The awareness to safeguard solidarity, where the person with dementia should continue to be held as a valued citizen in a situation of care.
6. Recognition of "personhood, identity and value" (p. xviii) of the person.

From: *Nuffield Council Bioethics*, 2009

Table 27

Berg en Dal Declaration on palliative care in persons with Alzheimer's disease

1. "Principle of respect for dignity.
2. Principle of well being (to be considered when planning and providing care).
3. Principle of participation (irrespective of their capabilities, should be enabled to participate as much as possible in their own care).
4. Principle of equal consideration (care and dignity to both patients in care and their caregivers).
5. Principle of non-abandonment.
6. Principle of moderation (care for persons with Alzheimer's disease should be provided in the least intrusive and least restrictive yet adequate manner).
7. Principle of proportionality (care for persons with Alzheimer's disease should be offered at the level of organisational complexity that is proportionate to the needs and concerns of the persons with Alzheimer's disease and their caregivers"

From: Purtilo & ten Have, 2010b, p. 343

Table 28
Patients with dementia and caregivers at risk of injustice

1. In situations of scarce resources, the issue of justice and fairness are highly debated and it is difficult to find consensus to what constitutes fairness in distribution of resources (Velasquez et al., 1990).
2. Participation of persons with dementia in the setting up of the social contract for the allocation of resources is absent as such decisions are taken by persons who retain autonomy (Purtilo, 2010), it is known that persons with dementia are unable to enable a direct personal intervention to ensure that their needs are respected (*Alzheimer Europe*, 2009, October).
3. Mental incapacity, increased vulnerability, and failure of stakeholders in care to acknowledge the patient's personhood. These all may pave the way to distributive injustice (*Alzheimer Europe*).
4. A society that gives more meaning to worth rather than dignity does end up degrading persons with dementia to a situation where they are deprived of their respect (Purtilo, 2010).
5. Persons with dementia are often stigmatised and devalued, as mental incapacity and physical deterioration are attributes that lead to devaluation of the person (*Alzheimer Europe*).
6. The network of care services offered to persons with dementia is fragmented, thus leading to increased risk to situations where needs are forgotten (Purtilo).
7. The fact that persons with dementia in LTC, particularly those in their EOL are perceived as being solely a burden given their grave mental disabilities, this renders them at risk of being marginalised and stigmatised (Purtilo).
8. In a society where autonomy reigns supreme, the physical and mental degradation and increased dependency that is experienced in persons with dementia, does lead to a situation where persons with dementia themselves do actually lose personal worth, and experience a degeneration of their self-regard and personal respect, to the point that they feel morally ashamed, lose confidence and personal identity. One consequence is that persons with dementia do renounce from forwarding their legitimate claims and rights for human resources, which are daily necessities for them to thrive in fulfilment of their capabilities (Purtilo).
9. The shortcoming in moral shame experienced by persons with dementia and society's detachment from prioritisation of care in favour of the disabled non-productive cohort in care leads decision makers to marginalise the allocation of resources away from meeting the needs of persons with dementia (Purtilo).
10. Such negative judgement and an ever-increasing dependency are devastating problems for persons with dementia particularly as we live in a society reigned by utilitarian ideals where the contribution to society gives value. Such augmented devaluation and suspicion targeted towards persons with dementia in society render them more vulnerable to challenges that adversely affect their value in the community they live in and degrades their QOL (Purtilo).
11. As society gives value to the level of contribution that is rendered, the institutions do end up expecting a lessened contribution by persons with disability, including dementia. In so doing society ends up doing a disservice to such vulnerable persons as it ”robs disabled persons of their ability to participate meaningfully in the various communities to which they belong” (Purtilo, p. 297).

Table 29

European Charter of Patients' Rights

1. "Right to preventive measures.
2. Right to access to health services.
3. Right to information.
4. Right to consent.
5. Right to free choices.
6. Right to privacy and confidentiality.
7. Right to respect patients' time.
8. Right to the observance of quality standards.
9. Right to safety.
10. Right to innovation.
11. Right to avoid unnecessary suffering and pain.
12. Right to personalised treatment.
13. Right to complain.
14. Right to compensation."

From: *European Charter of Patients Rights*, 2002

Table 30

The values that characterise a consensus-building approach in EOL decision-making

1. It is an agreement seeking and participatory process with the promotion of communication and resolution of objections on EOL decisions that concerns all stakeholders (Chun-yan & Tao, 2004). Consensus-building works in a decisional environment where consultation, collaboration, and empowerment are given meaning *(*Hoy, Rickart, & Durham, 2010) with accepted ground rules by the group and shared control ("American Heart Association", 2010).
2. "Consensus is a team approach where after identifying and addressing concerns, the group constructs an agreed proposal for consensus with input from all interested group members"((Hartnett, 2011, p. 1), which proposal is henceforth committed for implementation ("American Heart Association").
3. Development of a trusting care relationship, where the physician and family discuss their views without the moral abdication of either party (Chun-yan & Tao). Where all relevant information regarding diagnosis, prognosis and risks/benefits of treatment options (*GMC*, 2010), particularly in decisions to either tube feed or not tube feed (*RCP*, 2010) are shared between all stakeholders, in the quest to reach consensus that respects the person in care's values and past wishes (*GMC*).
4. The involvement of a facilitator, who in palliative care practice is usually the physician (Karlawish et al., 1999). The facilitator guides a consensus-seeking process to concentrate on the more relevant problems that need group deliberation which merit agreement. At the same time, the facilitator also ensures that ground rules are followed throughout the process ("American Heart Association").
5. Medical input and information sharing with the family should be based on a thorough initial assessment of the patient's condition, leading to a diagnosis and probable prognosis, where treatment options should be based on relevant clinical guidelines (*GMC*) in line with palliative care.
6. Promotion of shared decisions that respect family values in the best interests of kin with dementia (Chun-yan & Tao).
7. Minimising "misunderstanding, misinformation or false expectation" (Chun-yan & Tao, p. 216) through discussion with the family.
8. Respect patient's values and beliefs even where their past wishes have not been reported (Chun-yan & Tao; *Swedish National Council*, 2008).
9. "Accountability to stakeholders" ("American Heart Association", p. 1), which in end-stage dementia decision-making, stakeholders must seek to attain the best interests of the person in care (Chun-yan & Tao).

Table 31

Checklist of Research Inclusion Criteria

Name of resident:____
ID of resident:____
SVP Ward:____
Consultant:____

1. END-STAGE DEMENTIA: (FAST Score 7c + Associated co-morbidity)

☐ ADL – TOTALLY DEPENDENT
☐ DUALLY INCONTINENT
☐ CHAIR/BED BOUND
☐ COGNITION TOTALLY LOST
☐ NO COMMUNICATION / SPEAKS ONLY 1 WORD (not due to acute confusion state)
☐ HAS HAD GRADE 3 PRESSURE SORES or CHEST INFECTION or UTI in past year

☐ 2. SEVERE LIFE-THREATENING SWALLOWING DIFFICULTY resulting in:

CHOKING IN FOOD or LIQUID &/or RISK OF ASPIRATION &/or DEHYDRATION RISK &/or LACK OF APPROPRIATE FEEDING

☐ 3. DECISION TO MANAGE SWALLOWING DIFFICULTIES IN PAST 7 DAYS *

*Decisional options: pursue ORAL food & water / IV or SC drip / NG/RIG/PEG / nil orally / same as before / other

☐ 4. REGULAR VISITS BY RELATIVE / LEGAL REPRESENTATIVE AT LEAST ONCE A MONTH IN THE PAST 3 MONTHS

☐ 5. PATIENT’S AGE is 65 years and over

* If <u>all above boxes</u> are ticked up as present, do kindly contact Dr. Joseph Dimech

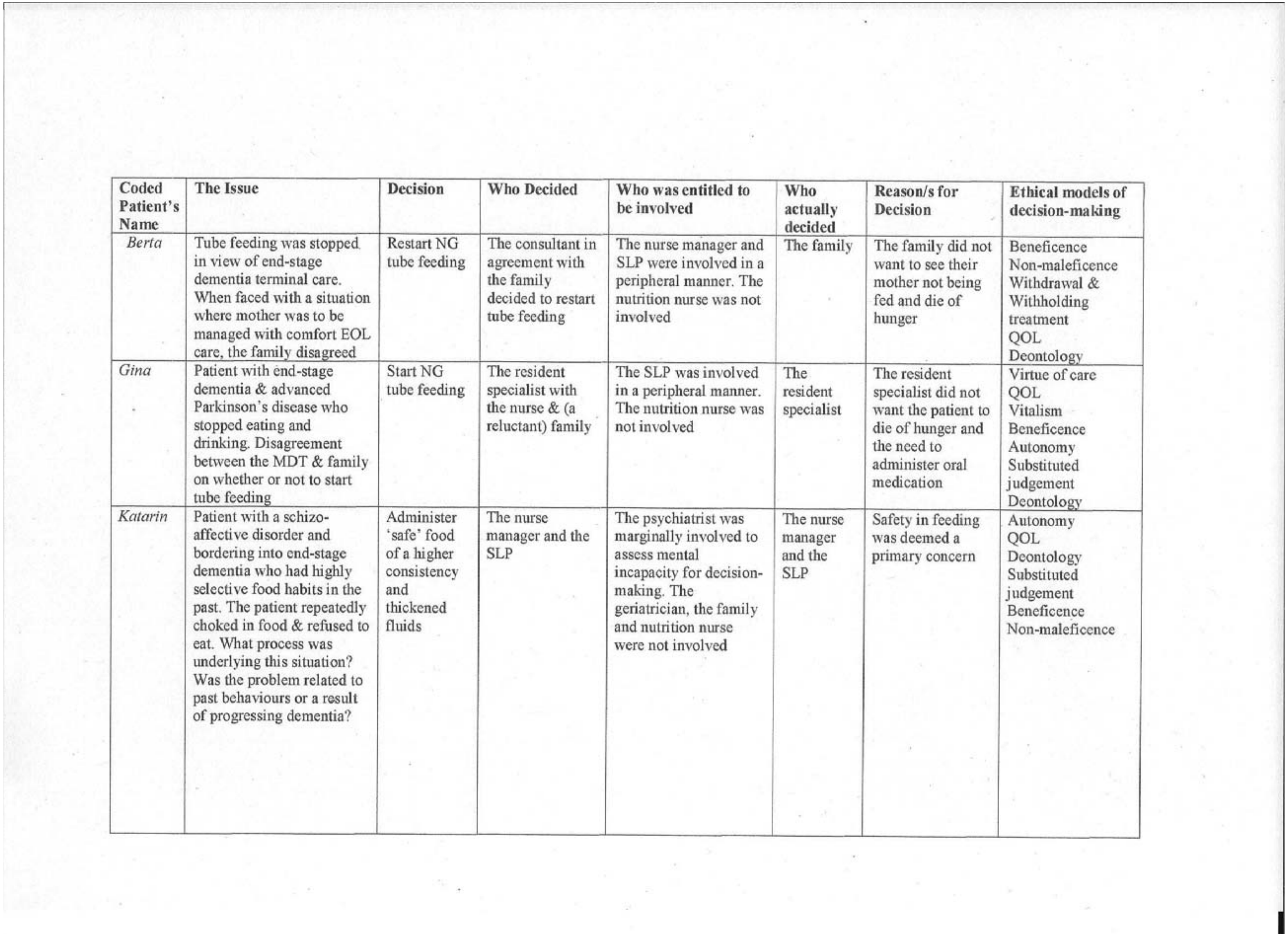
Table 32

List of questions in the interview schedules as they related to the eight themes

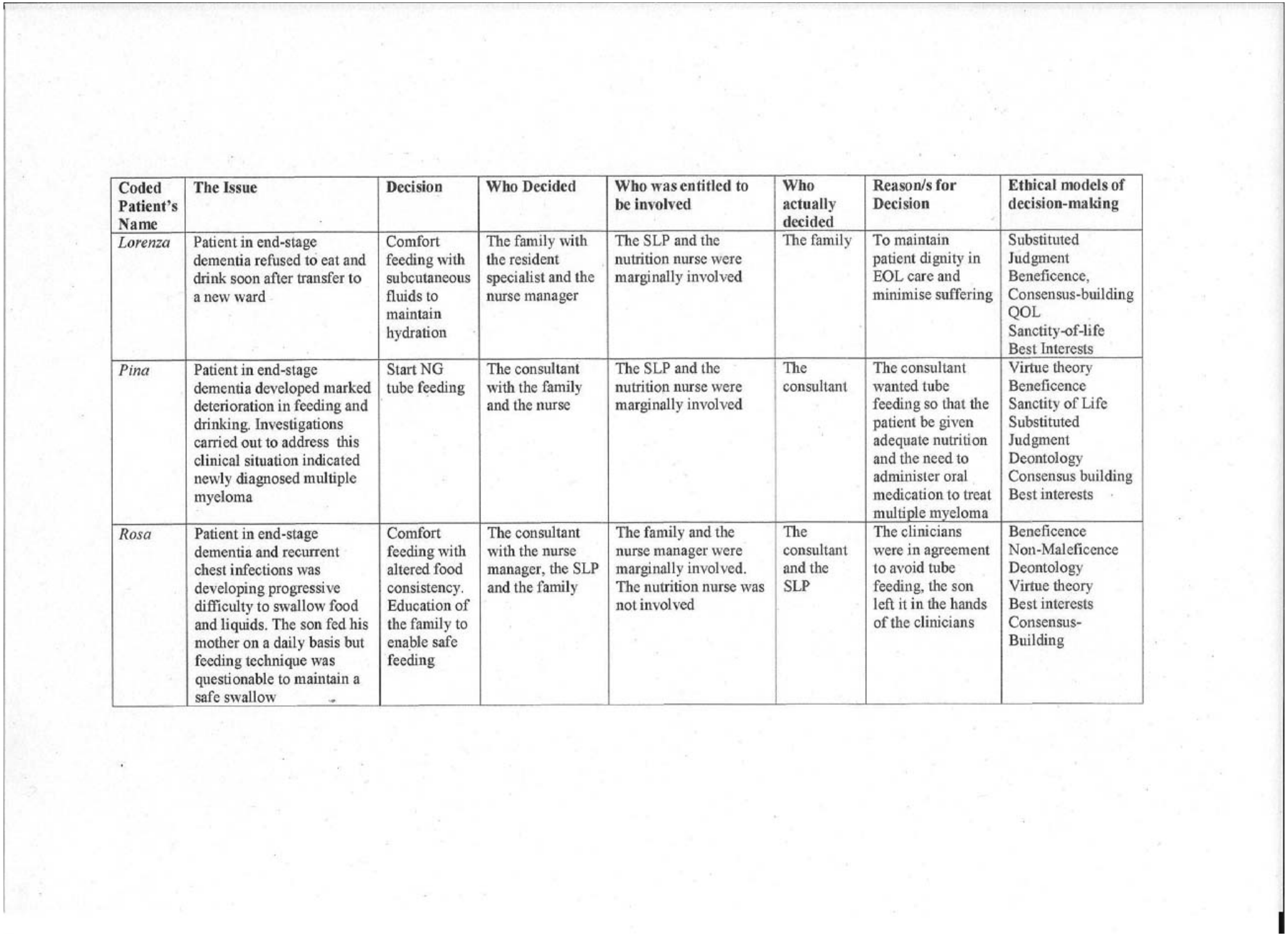
Theme:	**Questions in the Interview Schedules relating to the said theme**
1. The challenge of safeguarding human dignity in end-stage dementia	A4 & B6 (clinicians & relatives) A7, A8, A10, B8 & B10 (clinicians) A7, A11, B8 & B11 (relatives)
2. Substituted judgement	A1 to A4, B1 to B6 (clinicians & relatives) A7, A8, A10, B8 & B10 (clinicians) A5 to A8, A11, B7, B8 & B11 (relatives)
3. Principlism	A1 to A4, A6, B1 to B 7 (clinicians & relatives) A7, A8, A10, B8 & B10 (clinicians) A7, A9, A11, B8 & B10 (relatives)
4. The debate between sanctity-of-life and quality-of-life	A1, A2, A6, B3, B5 & B4 (clinicians & relatives) A7, & B8 (clinicians) A7, A8 & B8 (relatives)
5. Virtue ethics as an ethical framework to promote optimal care	A1, A3, A4 & B6 (clinicians & relatives) A7, A8, A10, B8 & B10 (clinicians) A7, A8, A9, A11, B8, B9 & B11 (relatives)
6. Paternalism and Deontology	A1 to A4, B1 to B4 (clinicians & relatives) A7, A8, B6, B7 & B8 (clinicians) A7, A8, B5, B6, B7 & B8 (relatives)
7. Patient's best interests judgement	A1, A3, A4, A6, B1 to B7 (clinicians & relatives) A7, A8, A10, B8 & B10 (clinicians) A11, A9, B9 & B11 (relatives)
8.Consensus-building approach	A1 to A4, A6; B1, B3 to B7 (clinicians & relatives) A7, A8 & B8 (clinicians) A7, A8, A9, B8 & B9 (relatives)

Table 33

Tabular diagram giving an overview of the six cases studies



Coded Patient's Name	The Issue	Decision	Who Decided	Who was entitled to be involved	Who actually decided	Reason/s for Decision	Ethical models of decision-making
Berta	Tube feeding was stopped in view of end-stage dementia terminal care. When faced with a situation where mother was to be managed with comfort EOL care, the family disagreed	Restart NG tube feeding	The consultant in agreement with the family decided to restart tube feeding	The nurse manager and SLP were involved in a peripheral manner. The nutrition nurse was not involved	The family	The family did not want to see their mother not being fed and die of hunger	Beneficence Non-maleficence Withdrawal & Withholding treatment QOL Deontology
Gina	Patient with end-stage dementia & advanced Parkinson's disease who stopped eating and drinking. Disagreement between the MDT & family on whether or not to start tube feeding	Start NG tube feeding	The resident specialist with the nurse & (a reluctant) family	The SLP was involved in a peripheral manner. The nutrition nurse was not involved	The resident specialist	The resident specialist did not want the patient to die of hunger and the need to administer oral medication	Virtue of care QOL Vitalism Beneficence Autonomy Substituted judgement Deontology
Katarin	Patient with a schizo-affective disorder and bordering into end-stage dementia who had highly selective food habits in the past. The patient repeatedly choked in food & refused to eat. What process was underlying this situation? Was the problem related to past behaviours or a result of progressing dementia?	Administer 'safe' food of a higher consistency and thickened fluids	The nurse manager and the SLP	The psychiatrist was marginally involved to assess mental incapacity for decision-making. The geriatrician, the family and nutrition nurse were not involved	The nurse manager and the SLP	Safety in feeding was deemed a primary concern	Autonomy QOL Deontology Substituted judgement Beneficence Non-maleficence



Coded Patient's Name	The Issue	Decision	Who Decided	Who was entitled to be involved	Who actually decided	Reason/s for Decision	Ethical models of decision-making
Lorenza	Patient in end-stage dementia refused to eat and drink soon after transfer to a new ward	Comfort feeding with subcutaneous fluids to maintain hydration	The family with the resident specialist and the nurse manager	The SLP and the nutrition nurse were marginally involved	The family	To maintain patient dignity in EOL care and minimise suffering	Substituted Judgment Beneficence, Consensus-building QOL Sanctity-of-life Best Interests
Pina	Patient in end-stage dementia developed marked deterioration in feeding and drinking. Investigations carried out to address this clinical situation indicated newly diagnosed multiple myeloma	Start NG tube feeding	The consultant with the family and the nurse	The SLP and the nutrition nurse were marginally involved	The consultant	The consultant wanted tube feeding so that the patient be given adequate nutrition and the need to administer oral medication to treat multiple myeloma	Virtue theory Beneficence Sanctity of Life Substituted Judgment Deontology Consensus building Best interests
Rosa	Patient in end-stage dementia and recurrent chest infections was developing progressive difficulty to swallow food and liquids. The son fed his mother on a daily basis but feeding technique was questionable to maintain a safe swallow	Comfort feeding with altered food consistency. Education of the family to enable safe feeding	The consultant with the nurse manager, the SLP and the family	The family and the nurse manager were marginally involved. The nutrition nurse was not involved	The consultant and the SLP	The clinicians were in agreement to avoid tube feeding, the son left it in the hands of the clinicians	Beneficence Non-Maleficence Deontology Virtue theory Best interests Consensus-Building

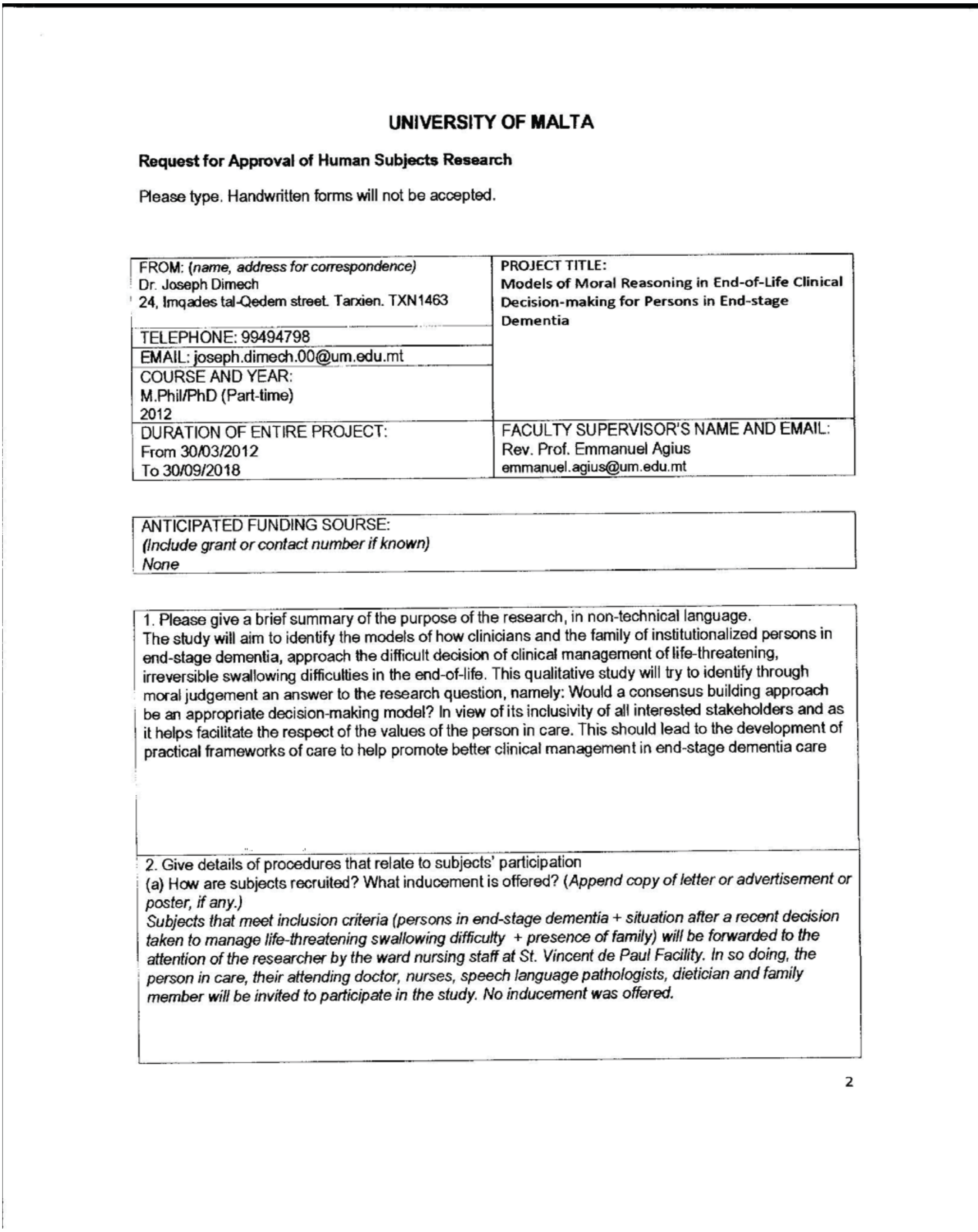
Table 34

The convergence of initial codes/ sub-themes into main themes

INITIAL CODES and SUB-THEMES	THEMES
a. Narrative of the problem/ decision point/ how she is now *b. Difficulty/complexity of decision* *c. Influence on decision-making of unstable prognosis / co-morbidities effect / dementia* *d. Patient reaction to treatment* *e. Maltese culture / Giving a diagnosis ideas* *f. Safeguarding patient dignity* *g. Values-based medicine* *h. Patient's Rights*	1. The challenge of safeguarding human dignity in end-stage dementia
a. Relatives an asset in decision-making *b. Early relatives intervention in care* *c. Relatives burn-out / afraid to decide/need support/knowledge of what is happening* *d. When relatives do not agree between themselves* *e. Relatives in patient's shoes (substituted judgment)* *f. Substituted judgement*	2. Substituted judgement
a. Beneficence in care (good care) *b. Need for the administration of food/medications p.o.* *c. Variance on ideas regarding Safety / Hunger / Starvation / Food is Life / Proper Nutrition / Comfort care / By mouth is by mouth!* *d. Non-Maleficence in care* *e. End-stage dementia care guidelines / Foreign care guidelines* *f. Respect of patient's past wishes / informed decision-making* *g. Autonomy /Advance Care Planning / Advance Directives* *h. Institution's rules / influence* *i. Conscientious objection* *j. Issues re medico-legal framework* *k. Relatives Legality (POA / Guardianship)* *l. Training of all involved* *m. Justice* *n. Health Policy Utilitarianism*	3. Principlism
a. Sanctity-of-life *b. Vitalism* *c. QOL / EOL* *d. Ideas about Euthanasia*	4. The debate between sanctity-of-life and QOL
a. Virtuous ethics as framework *b. Virtuous care approach* *c. Extremes in care Aggressive management vs. Let go / c. Variance on ideas regarding* *d. To tube feed or not to tube feed* *e. What life or death do we want for our patients?* *f. Feeding/care options taken (NBM; Comfort feeding; Tube Feed options; drip)*	5. Virtue ethics as an ethical framework to promote optimal care
a. Paternalism / leadership / who decides *b. Deontological care approach / duty* *c. Problems to work together* *d. Forgotten stakeholder*	6. Paternalism and deontology
a. Preserving patient's best interests *b. Relatives' interests* *c. Clinicians' interests* *d. Keep alive/ Enjoy more!* *e. Disclaimer of responsibilities* *f. Safety to swallow concerns*	7. Best interests judgement
a. When stakeholders do not agree (reasons) *b. Team approach / Shared decision-making in team approach* *c. Importance / Problems of communication* *d. Consensus-building pros and cons.* *d. Stakeholder involvement in decision* *e. Recommendations re Ethical committee / Peer review*	8. Consensus-building approach

11. Appendix 3: Permission Letters*

* To ensure anonymity, the permission letters signed by family members and clinicians giving their consent for participation in the study, have been excluded from inclusion in this appendix.



UNIVERSITY OF MALTA

Request for Approval of Human Subjects Research

Please type. Handwritten forms will not be accepted.

FROM: (*name, address for correspondence*) Dr. Joseph Dimech 24, Imqades tal-Qedem street. Tarxien. TXN1463	PROJECT TITLE: **Models of Moral Reasoning in End-of-Life Clinical Decision-making for Persons in End-stage Dementia**
TELEPHONE: 99494798	
EMAIL: joseph.dimech.00@um.edu.mt	
COURSE AND YEAR: M.Phil/PhD (Part-time) 2012	
DURATION OF ENTIRE PROJECT: From 30/03/2012 To 30/09/2018	FACULTY SUPERVISOR'S NAME AND EMAIL: Rev. Prof. Emmanuel Agius emmanuel.agius@um.edu.mt

ANTICIPATED FUNDING SOURSE:
(Include grant or contact number if known)
None

1. Please give a brief summary of the purpose of the research, in non-technical language.

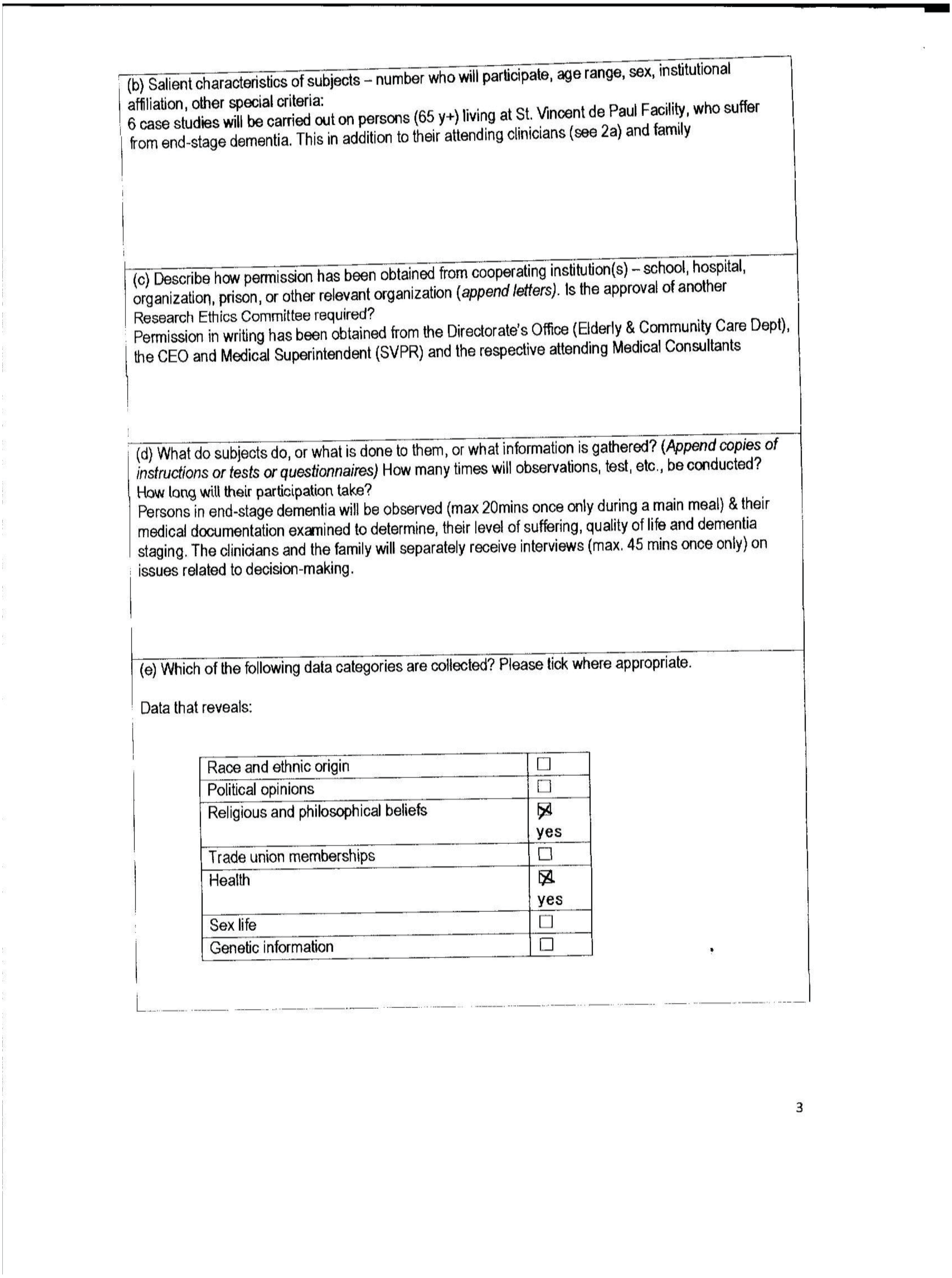
The study will aim to identify the models of how clinicians and the family of institutionalized persons in end-stage dementia, approach the difficult decision of clinical management of life-threatening, irreversible swallowing difficulties in the end-of-life. This qualitative study will try to identify through moral judgement an answer to the research question, namely: Would a consensus building approach be an appropriate decision-making model? In view of its inclusivity of all interested stakeholders and as it helps facilitate the respect of the values of the person in care. This should lead to the development of practical frameworks of care to help promote better clinical management in end-stage dementia care

2. Give details of procedures that relate to subjects' participation

(a) How are subjects recruited? What inducement is offered? (*Append copy of letter or advertisement or poster, if any.)*

Subjects that meet inclusion criteria (persons in end-stage dementia + situation after a recent decision taken to manage life-threatening swallowing difficulty + presence of family) will be forwarded to the attention of the researcher by the ward nursing staff at St. Vincent de Paul Facility. In so doing, the person in care, their attending doctor, nurses, speech language pathologists, dietician and family member will be invited to participate in the study. No inducement was offered.

2



(b) Salient characteristics of subjects – number who will participate, age range, sex, institutional affiliation, other special criteria:
6 case studies will be carried out on persons (65 y+) living at St. Vincent de Paul Facility, who suffer from end-stage dementia. This in addition to their attending clinicians (see 2a) and family

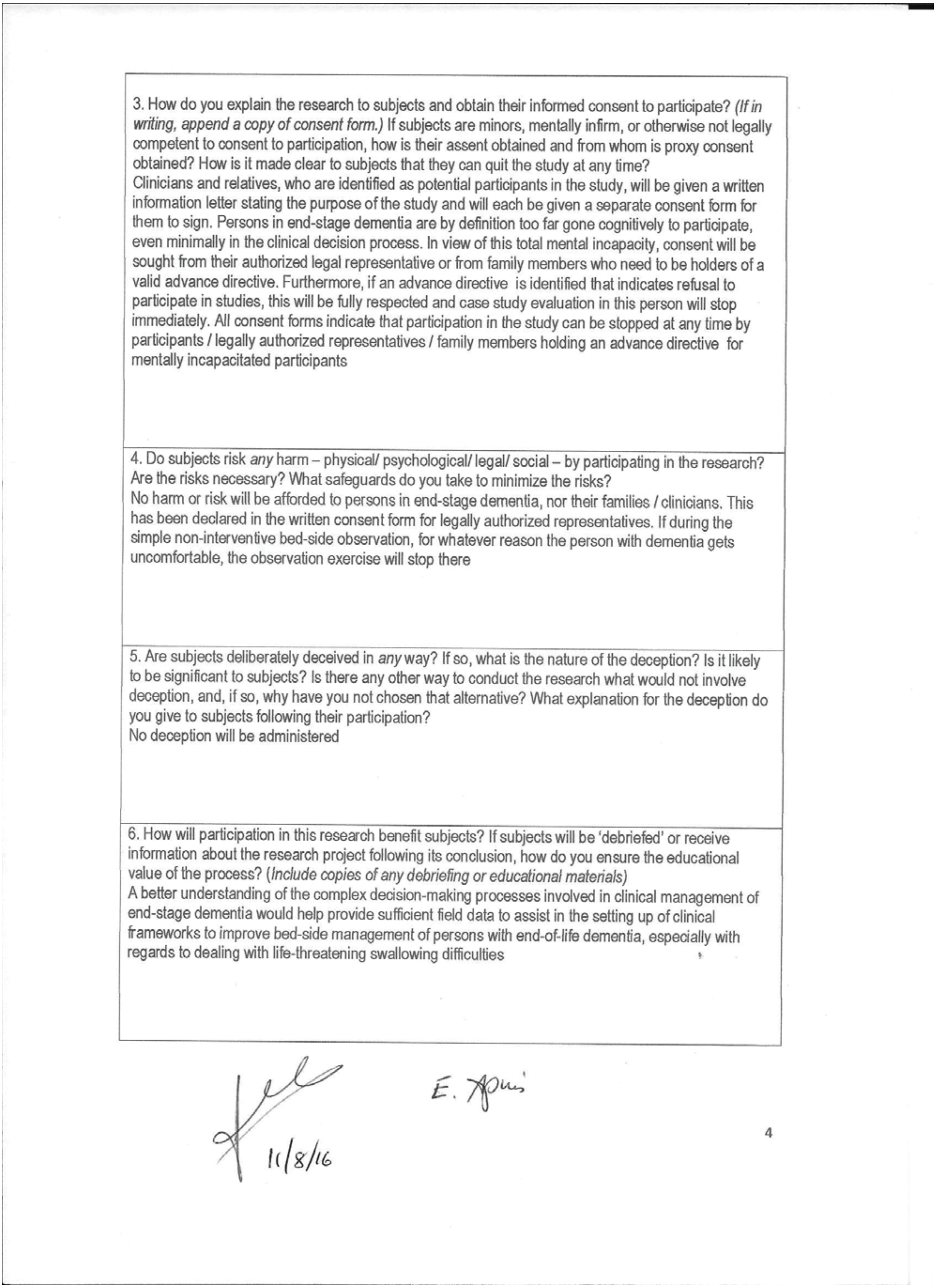
(c) Describe how permission has been obtained from cooperating institution(s) – school, hospital, organization, prison, or other relevant organization (*append letters*). Is the approval of another Research Ethics Committee required?
Permission in writing has been obtained from the Directorate's Office (Elderly & Community Care Dept), the CEO and Medical Superintendent (SVPR) and the respective attending Medical Consultants

(d) What do subjects do, or what is done to them, or what information is gathered? (*Append copies of instructions or tests or questionnaires)* How many times will observations, test, etc., be conducted? How long will their participation take?
Persons in end-stage dementia will be observed (max 20mins once only during a main meal) & their medical documentation examined to determine, their level of suffering, quality of life and dementia staging. The clinicians and the family will separately receive interviews (max. 45 mins once only) on issues related to decision-making.

(e) Which of the following data categories are collected? Please tick where appropriate.

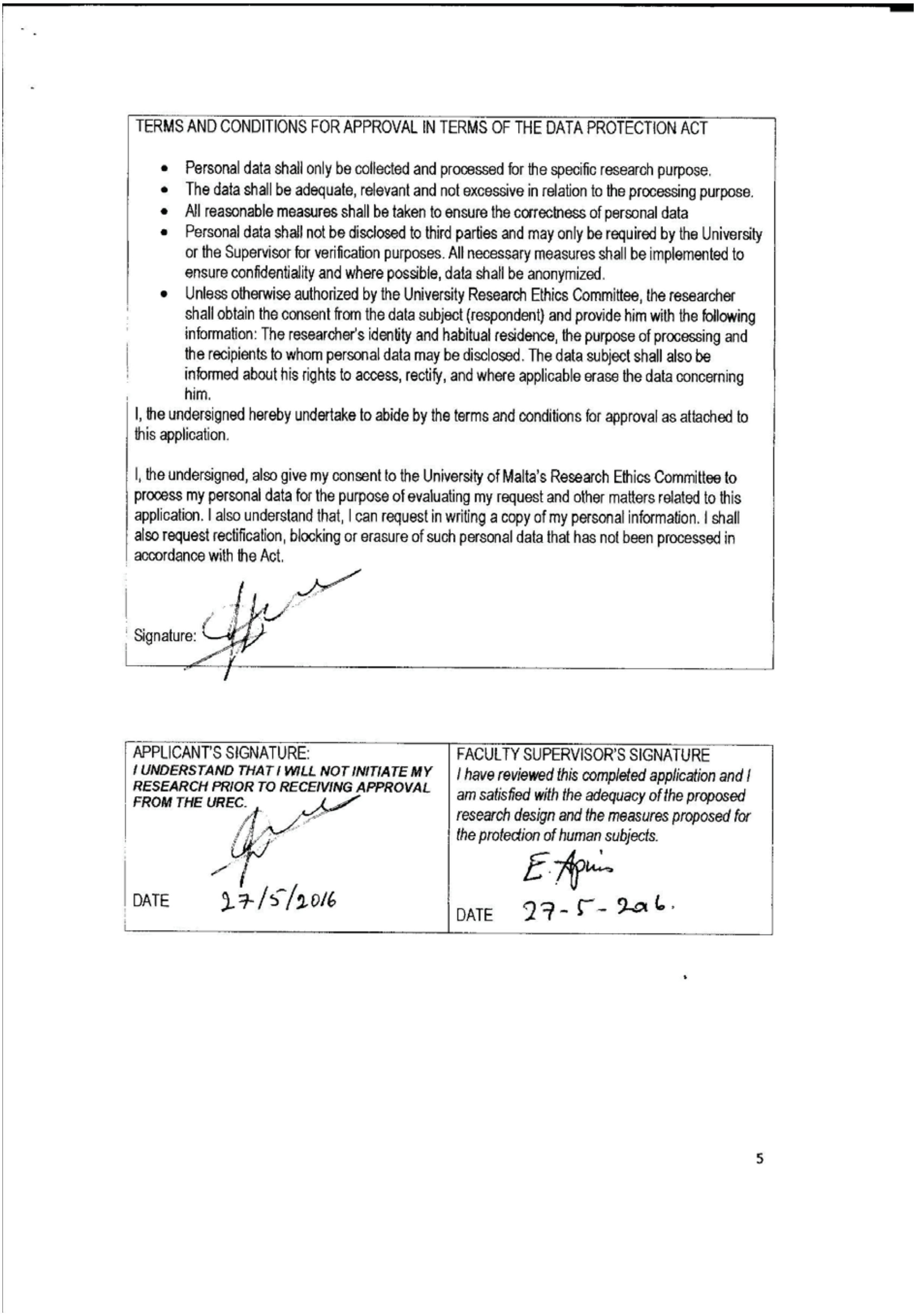
Data that reveals:

Race and ethnic origin	☐
Political opinions	☐
Religious and philosophical beliefs	☒ yes
Trade union memberships	☐
Health	☒ yes
Sex life	☐
Genetic information	☐



3. How do you explain the research to subjects and obtain their informed consent to participate? *(If in writing, append a copy of consent form.)* If subjects are minors, mentally infirm, or otherwise not legally competent to consent to participation, how is their assent obtained and from whom is proxy consent obtained? How is it made clear to subjects that they can quit the study at any time? Clinicians and relatives, who are identified as potential participants in the study, will be given a written information letter stating the purpose of the study and will each be given a separate consent form for them to sign. Persons in end-stage dementia are by definition too far gone cognitively to participate, even minimally in the clinical decision process. In view of this total mental incapacity, consent will be sought from their authorized legal representative or from family members who need to be holders of a valid advance directive. Furthermore, if an advance directive is identified that indicates refusal to participate in studies, this will be fully respected and case study evaluation in this person will stop immediately. All consent forms indicate that participation in the study can be stopped at any time by participants / legally authorized representatives / family members holding an advance directive for mentally incapacitated participants
4. Do subjects risk *any* harm – physical/ psychological/ legal/ social – by participating in the research? Are the risks necessary? What safeguards do you take to minimize the risks? No harm or risk will be afforded to persons in end-stage dementia, nor their families / clinicians. This has been declared in the written consent form for legally authorized representatives. If during the simple non-interventive bed-side observation, for whatever reason the person with dementia gets uncomfortable, the observation exercise will stop there
5. Are subjects deliberately deceived in *any* way? If so, what is the nature of the deception? Is it likely to be significant to subjects? Is there any other way to conduct the research what would not involve deception, and, if so, why have you not chosen that alternative? What explanation for the deception do you give to subjects following their participation? No deception will be administered
6. How will participation in this research benefit subjects? If subjects will be 'debriefed' or receive information about the research project following its conclusion, how do you ensure the educational value of the process? (*Include copies of any debriefing or educational materials)* A better understanding of the complex decision-making processes involved in clinical management of end-stage dementia would help provide sufficient field data to assist in the setting up of clinical frameworks to improve bed-side management of persons with end-of-life dementia, especially with regards to dealing with life-threatening swallowing difficulties

11/8/16



TERMS AND CONDITIONS FOR APPROVAL IN TERMS OF THE DATA PROTECTION ACT

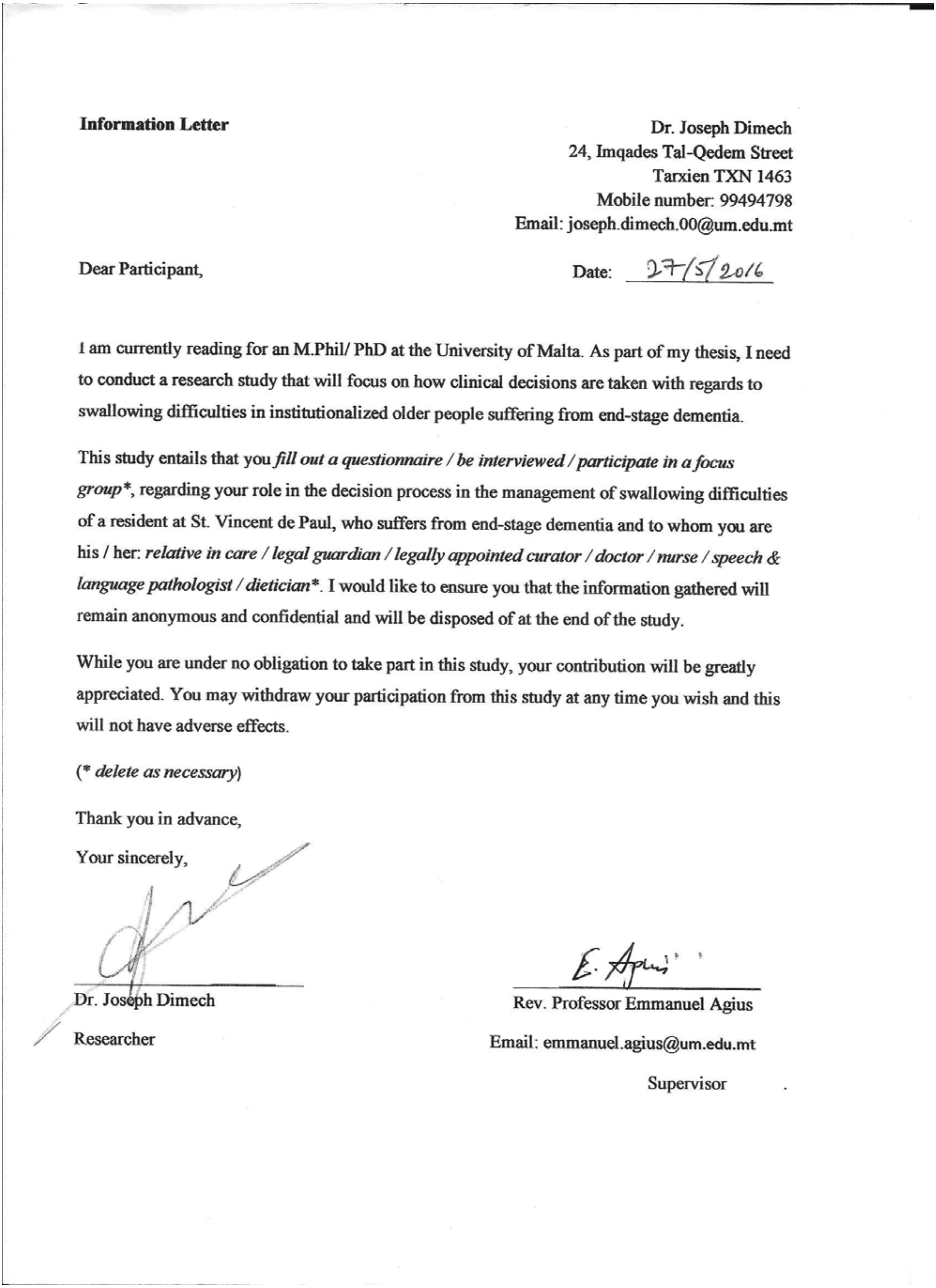
- Personal data shall only be collected and processed for the specific research purpose.
- The data shall be adequate, relevant and not excessive in relation to the processing purpose.
- All reasonable measures shall be taken to ensure the correctness of personal data
- Personal data shall not be disclosed to third parties and may only be required by the University or the Supervisor for verification purposes. All necessary measures shall be implemented to ensure confidentiality and where possible, data shall be anonymized.
- Unless otherwise authorized by the University Research Ethics Committee, the researcher shall obtain the consent from the data subject (respondent) and provide him with the following information: The researcher's identity and habitual residence, the purpose of processing and the recipients to whom personal data may be disclosed. The data subject shall also be informed about his rights to access, rectify, and where applicable erase the data concerning him.

I, the undersigned hereby undertake to abide by the terms and conditions for approval as attached to this application.

I, the undersigned, also give my consent to the University of Malta's Research Ethics Committee to process my personal data for the purpose of evaluating my request and other matters related to this application. I also understand that, I can request in writing a copy of my personal information. I shall also request rectification, blocking or erasure of such personal data that has not been processed in accordance with the Act.

Signature:

APPLICANT'S SIGNATURE: ***I UNDERSTAND THAT I WILL NOT INITIATE MY RESEARCH PRIOR TO RECEIVING APPROVAL FROM THE UREC.***	FACULTY SUPERVISOR'S SIGNATURE *I have reviewed this completed application and I am satisfied with the adequacy of the proposed research design and the measures proposed for the protection of human subjects.* E. Agius
DATE 27/5/2016	DATE 27-5-2016.



Information Letter

Dr. Joseph Dimech
24, Imqades Tal-Qedem Street
Tarxien TXN 1463
Mobile number: 99494798
Email: joseph.dimech.00@um.edu.mt

Dear Participant,

Date: 27/5/2016

I am currently reading for an M.Phil/ PhD at the University of Malta. As part of my thesis, I need to conduct a research study that will focus on how clinical decisions are taken with regards to swallowing difficulties in institutionalized older people suffering from end-stage dementia.

This study entails that you *fill out a questionnaire / be interviewed / participate in a focus group**, regarding your role in the decision process in the management of swallowing difficulties of a resident at St. Vincent de Paul, who suffers from end-stage dementia and to whom you are his / her: *relative in care / legal guardian / legally appointed curator / doctor / nurse / speech & language pathologist / dietician**. I would like to ensure you that the information gathered will remain anonymous and confidential and will be disposed of at the end of the study.

While you are under no obligation to take part in this study, your contribution will be greatly appreciated. You may withdraw your participation from this study at any time you wish and this will not have adverse effects.

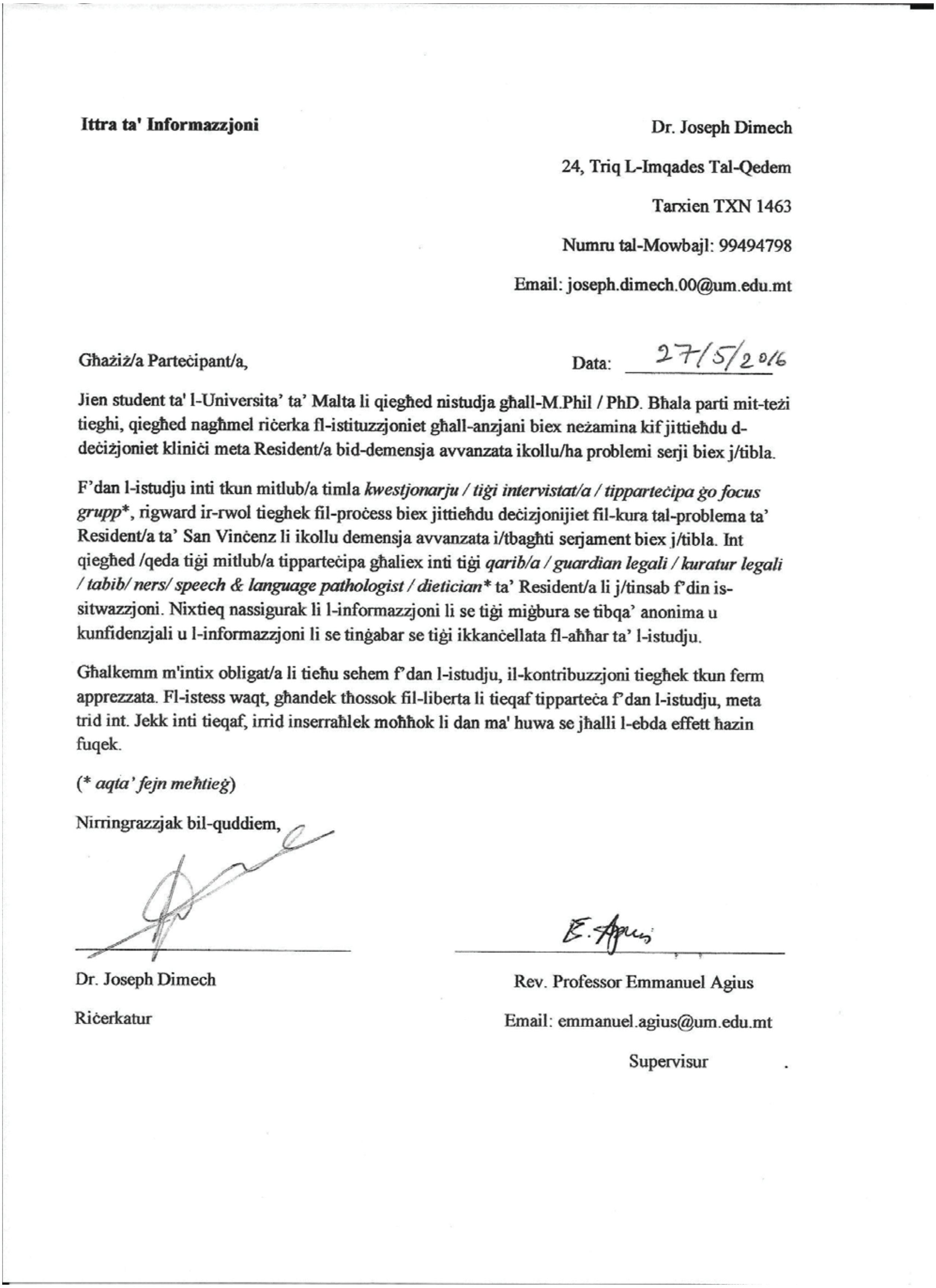
(* *delete as necessary*)

Thank you in advance,

Your sincerely,

Dr. Joseph Dimech
Researcher

E. Agius
Rev. Professor Emmanuel Agius
Email: emmanuel.agius@um.edu.mt
Supervisor



Ittra ta' Informazzjoni

Dr. Joseph Dimech
24, Triq L-Imqades Tal-Qedem
Tarxien TXN 1463
Numru tal-Mowbajl: 99494798
Email: joseph.dimech.00@um.edu.mt

Għażiż/a Parteċipant/a,

Data: 27/5/2016

Jien student ta' l-Universita' ta' Malta li qiegħed nistudja għall-M.Phil / PhD. Bħala parti mit-teżi tiegħi, qiegħed nagħmel riċerka fl-istituzzjoniet għall-anzjani biex neżamina kif jittieħdu d-deċiżjoniet kliniċi meta Resident/a bid-demensja avvanzata ikollu/ha problemi serji biex j/tibla.

F'dan l-istudju inti tkun mitlub/a timla *kwestjonarju / tiġi intervistat/a / tippartecipa ġo focus grupp**, rigward ir-rwol tiegħek fil-proċess biex jittieħdu deċizjonijiet fil-kura tal-problema ta' Resident/a ta' San Vinċenz li ikollu demensja avvanzata i/tbagħti serjament biex j/tibla. Int qiegħed /qeda tiġi mitlub/a tippartecipa għaliex inti tiġi *qarib/a / guardian legali / kuratur legali / tabib/ ners/ speech & language pathologist / dietician** ta' Resident/a li j/tinsab f'din is-sitwazzjoni. Nixtieq nassigurak li l-informazzjoni li se tiġi miġbura se tibqa' anonima u kunfidenzjali u l-informazzjoni li se tinġabar se tiġi ikkanċellata fl-aħħar ta' l-istudju.

Għalkemm m'intix obligat/a li tieħu sehem f'dan l-istudju, il-kontribuzzjoni tiegħek tkun ferm apprezzata. Fl-istess waqt, għandek tħossok fil-liberta li tieqaf tipparteċa f'dan l-istudju, meta trid int. Jekk inti tieqaf, irrid inserraħlek moħħok li dan ma' huwa se jħalli l-ebda effett ħazin fuqek.

(* *aqta' fejn meħtieġ*)

Nirringrazzjak bil-quddiem,

E. Agius

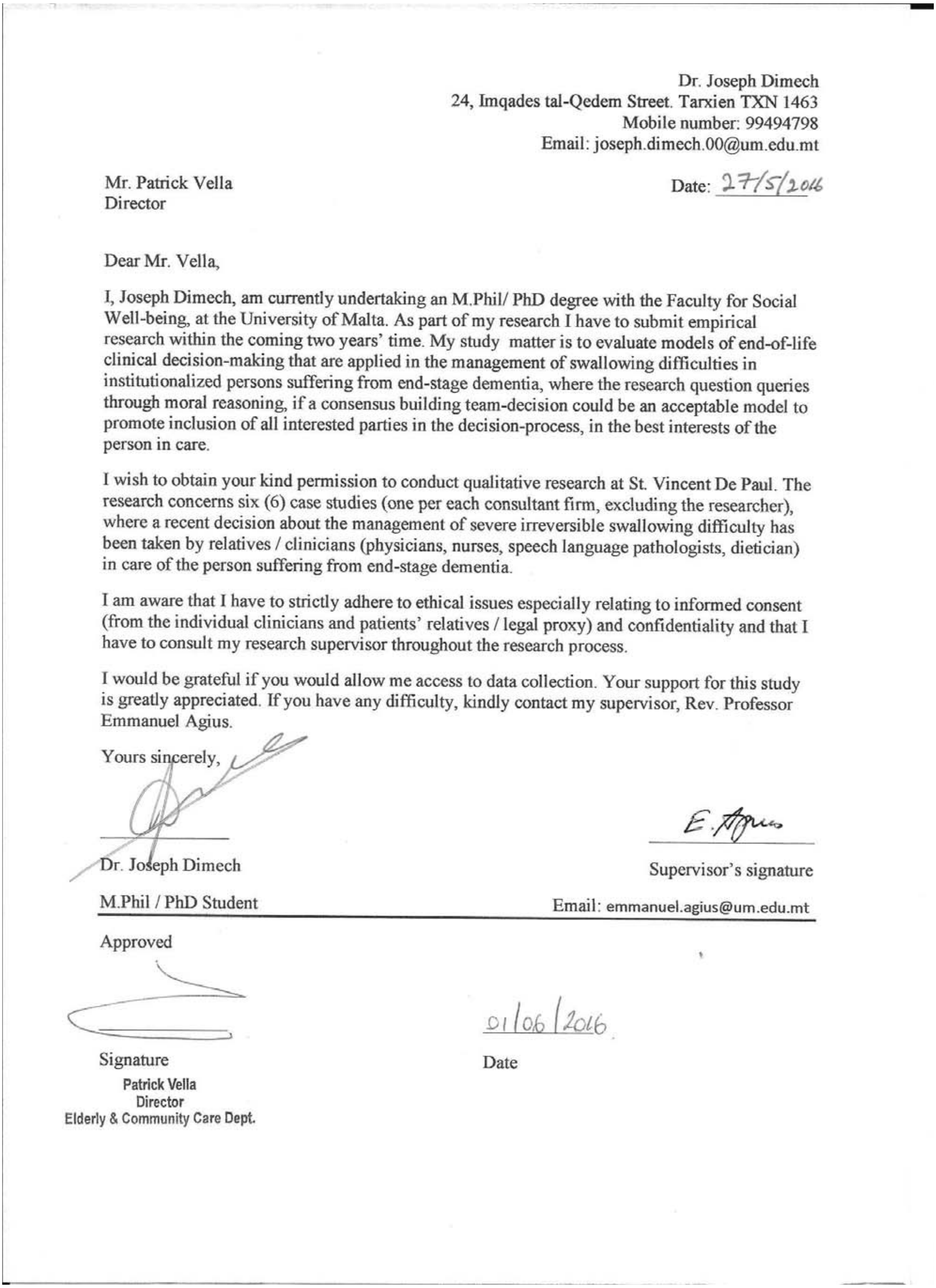
Dr. Joseph Dimech

Riċerkatur

Rev. Professor Emmanuel Agius

Email: emmanuel.agius@um.edu.mt

Supervisur



Dr. Joseph Dimech
24, Imqades tal-Qedem Street. Tarxien TXN 1463
Mobile number: 99494798
Email: joseph.dimech.00@um.edu.mt

Date: 27/5/2016

Mr. Patrick Vella
Director

Dear Mr. Vella,

I, Joseph Dimech, am currently undertaking an M.Phil/ PhD degree with the Faculty for Social Well-being, at the University of Malta. As part of my research I have to submit empirical research within the coming two years' time. My study matter is to evaluate models of end-of-life clinical decision-making that are applied in the management of swallowing difficulties in institutionalized persons suffering from end-stage dementia, where the research question queries through moral reasoning, if a consensus building team-decision could be an acceptable model to promote inclusion of all interested parties in the decision-process, in the best interests of the person in care.

I wish to obtain your kind permission to conduct qualitative research at St. Vincent De Paul. The research concerns six (6) case studies (one per each consultant firm, excluding the researcher), where a recent decision about the management of severe irreversible swallowing difficulty has been taken by relatives / clinicians (physicians, nurses, speech language pathologists, dietician) in care of the person suffering from end-stage dementia.

I am aware that I have to strictly adhere to ethical issues especially relating to informed consent (from the individual clinicians and patients' relatives / legal proxy) and confidentiality and that I have to consult my research supervisor throughout the research process.

I would be grateful if you would allow me access to data collection. Your support for this study is greatly appreciated. If you have any difficulty, kindly contact my supervisor, Rev. Professor Emmanuel Agius.

Yours sincerely,

E. Agius

Dr. Joseph Dimech
M.Phil / PhD Student

Supervisor's signature
Email: emmanuel.agius@um.edu.mt

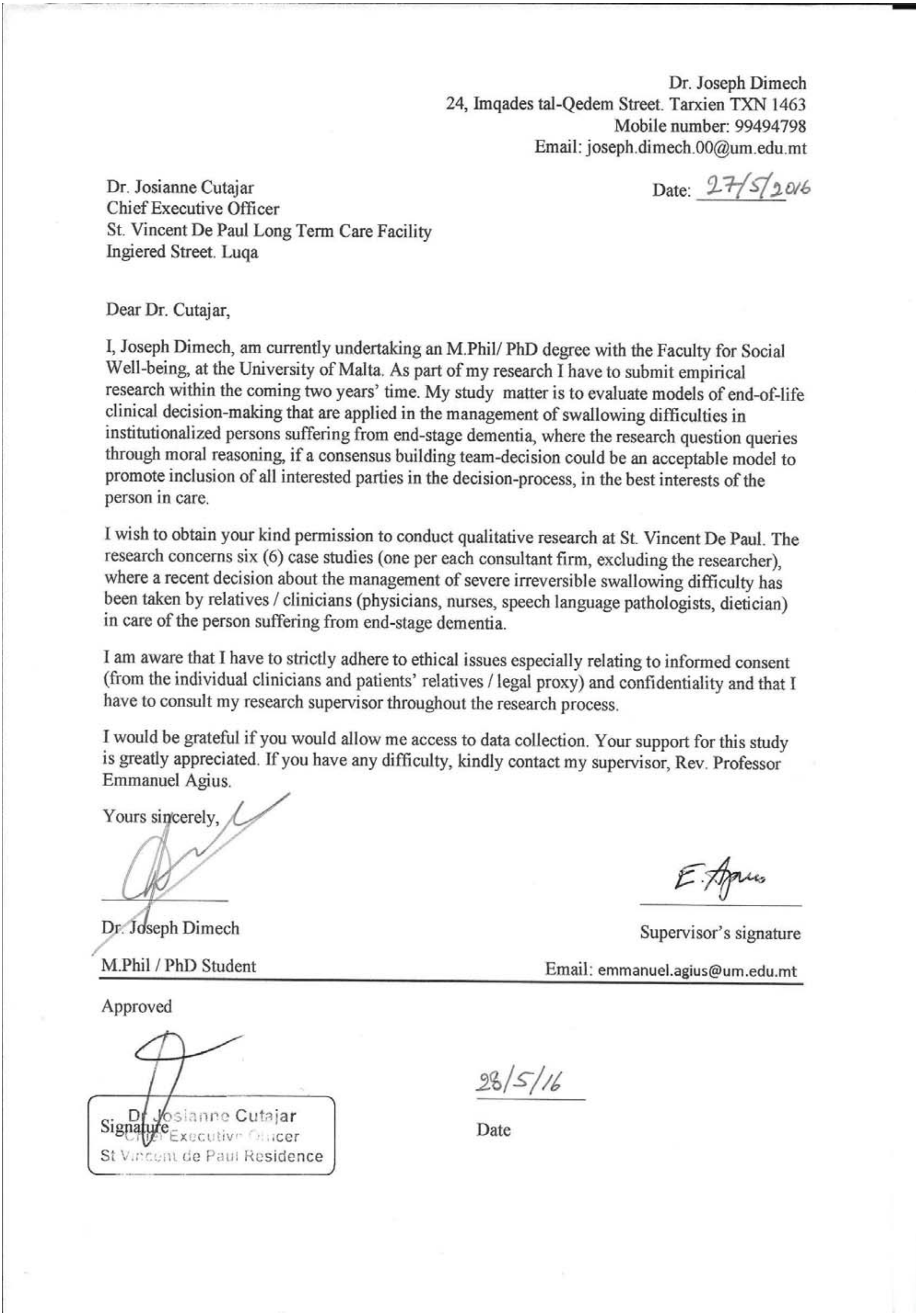
Approved

01/06/2016

Signature

Date

Patrick Vella
Director
Elderly & Community Care Dept.



Dr. Joseph Dimech
24, Imqades tal-Qedem Street. Tarxien TXN 1463
Mobile number: 99494798
Email: joseph.dimech.00@um.edu.mt

Date: 27/5/2016

Dr. Josianne Cutajar
Chief Executive Officer
St. Vincent De Paul Long Term Care Facility
Ingiered Street. Luqa

Dear Dr. Cutajar,

I, Joseph Dimech, am currently undertaking an M.Phil/ PhD degree with the Faculty for Social Well-being, at the University of Malta. As part of my research I have to submit empirical research within the coming two years' time. My study matter is to evaluate models of end-of-life clinical decision-making that are applied in the management of swallowing difficulties in institutionalized persons suffering from end-stage dementia, where the research question queries through moral reasoning, if a consensus building team-decision could be an acceptable model to promote inclusion of all interested parties in the decision-process, in the best interests of the person in care.

I wish to obtain your kind permission to conduct qualitative research at St. Vincent De Paul. The research concerns six (6) case studies (one per each consultant firm, excluding the researcher), where a recent decision about the management of severe irreversible swallowing difficulty has been taken by relatives / clinicians (physicians, nurses, speech language pathologists, dietician) in care of the person suffering from end-stage dementia.

I am aware that I have to strictly adhere to ethical issues especially relating to informed consent (from the individual clinicians and patients' relatives / legal proxy) and confidentiality and that I have to consult my research supervisor throughout the research process.

I would be grateful if you would allow me access to data collection. Your support for this study is greatly appreciated. If you have any difficulty, kindly contact my supervisor, Rev. Professor Emmanuel Agius.

Yours sincerely,

Dr. Joseph Dimech
M.Phil / PhD Student

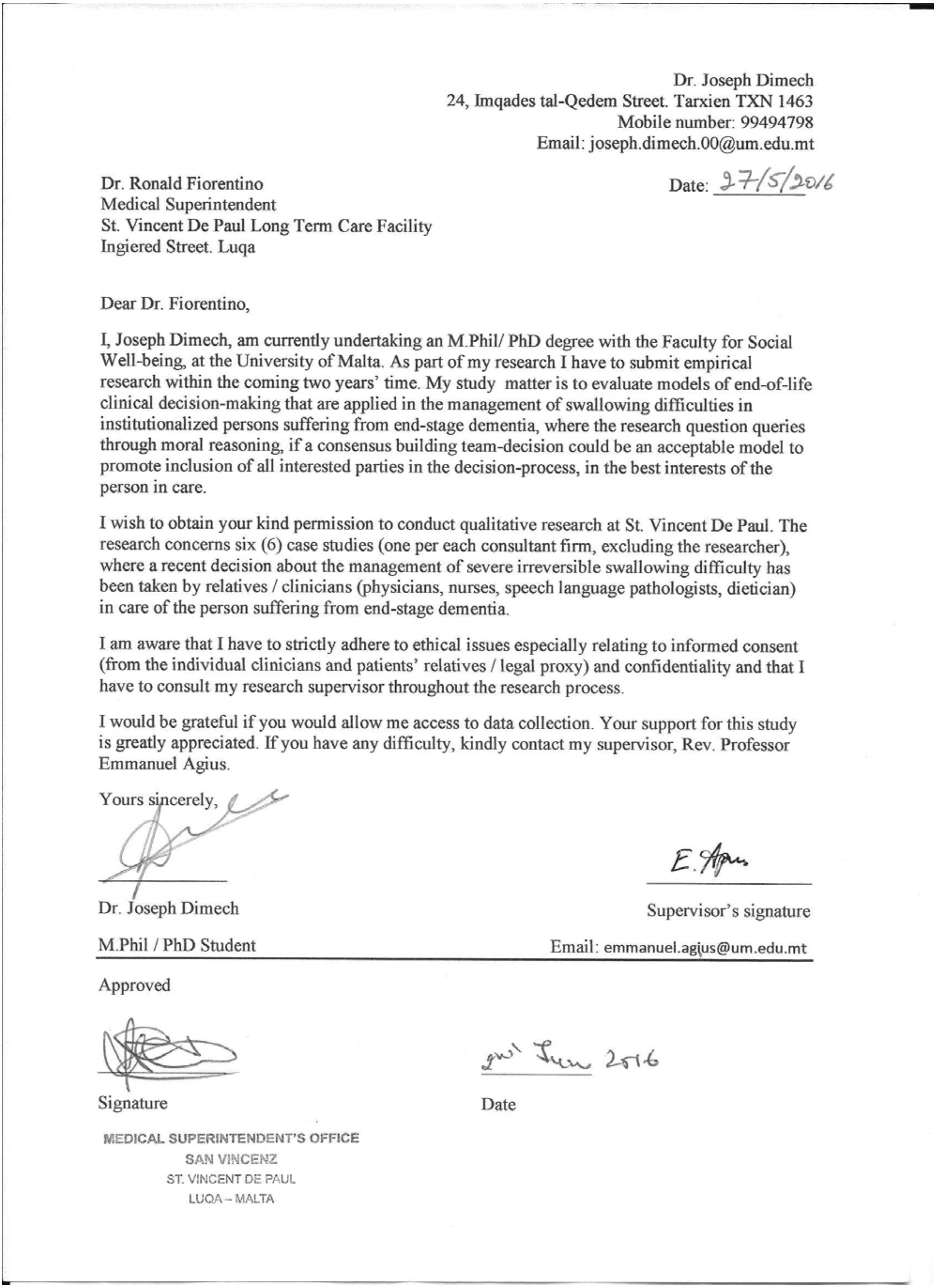
E. Agius
Supervisor's signature
Email: emmanuel.agius@um.edu.mt

Approved

Dr Josianne Cutajar
Chief Executive Officer
St Vincent de Paul Residence

Signature

28/5/16
Date



Dr. Joseph Dimech
24, Imqades tal-Qedem Street. Tarxien TXN 1463
Mobile number: 99494798
Email: joseph.dimech.00@um.edu.mt

Date: 27/5/2016

Dr. Ronald Fiorentino
Medical Superintendent
St. Vincent De Paul Long Term Care Facility
Ingiered Street. Luqa

Dear Dr. Fiorentino,

I, Joseph Dimech, am currently undertaking an M.Phil/ PhD degree with the Faculty for Social Well-being, at the University of Malta. As part of my research I have to submit empirical research within the coming two years' time. My study matter is to evaluate models of end-of-life clinical decision-making that are applied in the management of swallowing difficulties in institutionalized persons suffering from end-stage dementia, where the research question queries through moral reasoning, if a consensus building team-decision could be an acceptable model to promote inclusion of all interested parties in the decision-process, in the best interests of the person in care.

I wish to obtain your kind permission to conduct qualitative research at St. Vincent De Paul. The research concerns six (6) case studies (one per each consultant firm, excluding the researcher), where a recent decision about the management of severe irreversible swallowing difficulty has been taken by relatives / clinicians (physicians, nurses, speech language pathologists, dietician) in care of the person suffering from end-stage dementia.

I am aware that I have to strictly adhere to ethical issues especially relating to informed consent (from the individual clinicians and patients' relatives / legal proxy) and confidentiality and that I have to consult my research supervisor throughout the research process.

I would be grateful if you would allow me access to data collection. Your support for this study is greatly appreciated. If you have any difficulty, kindly contact my supervisor, Rev. Professor Emmanuel Agius.

Yours sincerely,

E. Agius

Dr. Joseph Dimech
M.Phil / PhD Student

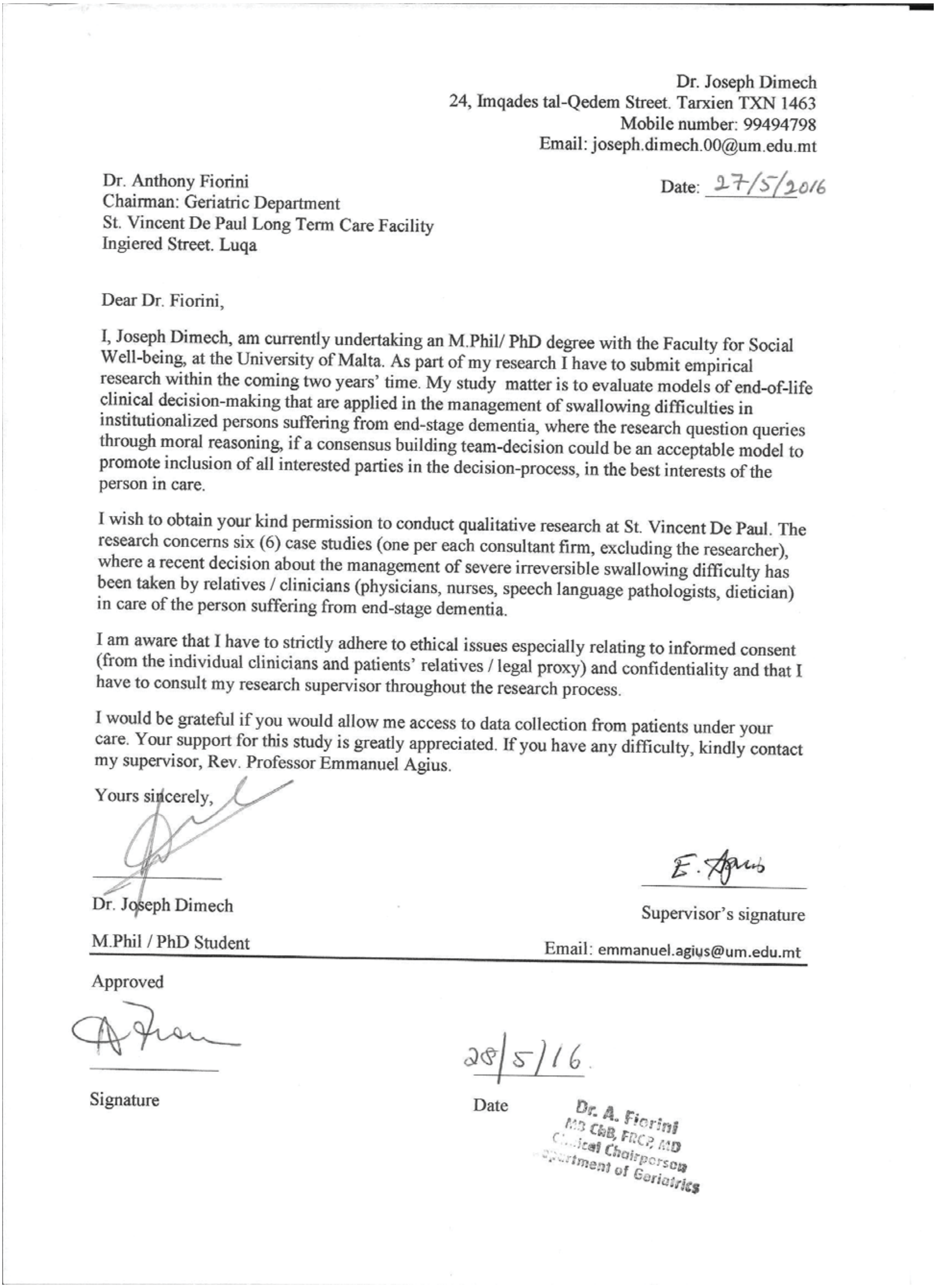
Supervisor's signature
Email: emmanuel.agius@um.edu.mt

Approved

9th Jun 2016

Signature
Date

MEDICAL SUPERINTENDENT'S OFFICE
SAN VINCENZ
ST. VINCENT DE PAUL
LUQA – MALTA



Dr. Joseph Dimech
24, Imqades tal-Qedem Street. Tarxien TXN 1463
Mobile number: 99494798
Email: joseph.dimech.00@um.edu.mt

Date: 27/5/2016

Dr. Anthony Fiorini
Chairman: Geriatric Department
St. Vincent De Paul Long Term Care Facility
Ingiered Street. Luqa

Dear Dr. Fiorini,

I, Joseph Dimech, am currently undertaking an M.Phil/ PhD degree with the Faculty for Social Well-being, at the University of Malta. As part of my research I have to submit empirical research within the coming two years' time. My study matter is to evaluate models of end-of-life clinical decision-making that are applied in the management of swallowing difficulties in institutionalized persons suffering from end-stage dementia, where the research question queries through moral reasoning, if a consensus building team-decision could be an acceptable model to promote inclusion of all interested parties in the decision-process, in the best interests of the person in care.

I wish to obtain your kind permission to conduct qualitative research at St. Vincent De Paul. The research concerns six (6) case studies (one per each consultant firm, excluding the researcher), where a recent decision about the management of severe irreversible swallowing difficulty has been taken by relatives / clinicians (physicians, nurses, speech language pathologists, dietician) in care of the person suffering from end-stage dementia.

I am aware that I have to strictly adhere to ethical issues especially relating to informed consent (from the individual clinicians and patients' relatives / legal proxy) and confidentiality and that I have to consult my research supervisor throughout the research process.

I would be grateful if you would allow me access to data collection from patients under your care. Your support for this study is greatly appreciated. If you have any difficulty, kindly contact my supervisor, Rev. Professor Emmanuel Agius.

Yours sincerely,

E. Agius

Dr. Joseph Dimech
M.Phil / PhD Student

Supervisor's signature
Email: emmanuel.agius@um.edu.mt

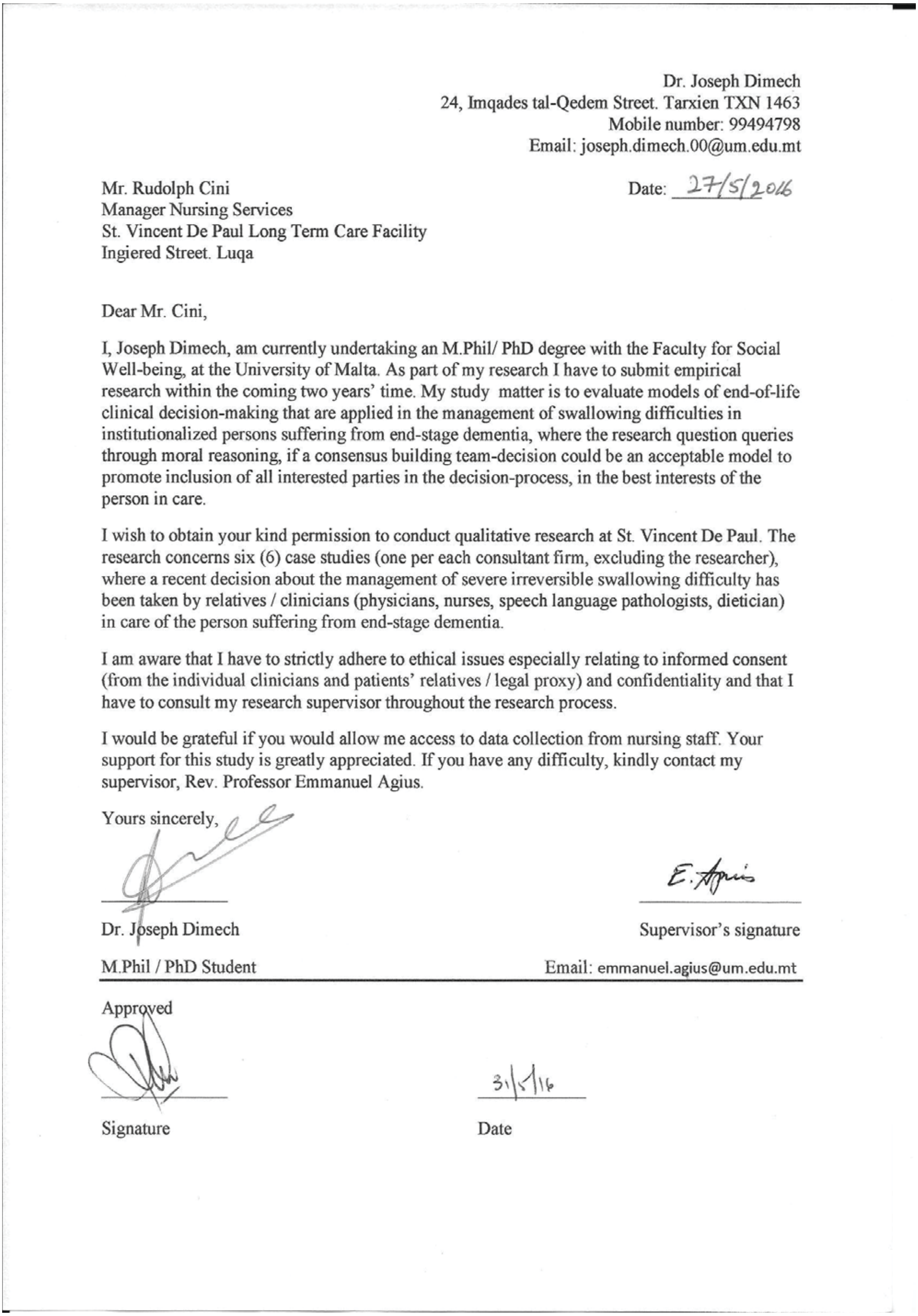
Approved

Signature

28/5/16.

Date

Dr. A. Fiorini
MB ChB, FRCP, MD
Clinical Chairperson
Department of Geriatrics



Dr. Joseph Dimech
24, Imqades tal-Qedem Street. Tarxien TXN 1463
Mobile number: 99494798
Email: joseph.dimech.00@um.edu.mt

Date: 27/5/2016

Mr. Rudolph Cini
Manager Nursing Services
St. Vincent De Paul Long Term Care Facility
Ingiered Street. Luqa

Dear Mr. Cini,

I, Joseph Dimech, am currently undertaking an M.Phil/ PhD degree with the Faculty for Social Well-being, at the University of Malta. As part of my research I have to submit empirical research within the coming two years' time. My study matter is to evaluate models of end-of-life clinical decision-making that are applied in the management of swallowing difficulties in institutionalized persons suffering from end-stage dementia, where the research question queries through moral reasoning, if a consensus building team-decision could be an acceptable model to promote inclusion of all interested parties in the decision-process, in the best interests of the person in care.

I wish to obtain your kind permission to conduct qualitative research at St. Vincent De Paul. The research concerns six (6) case studies (one per each consultant firm, excluding the researcher), where a recent decision about the management of severe irreversible swallowing difficulty has been taken by relatives / clinicians (physicians, nurses, speech language pathologists, dietician) in care of the person suffering from end-stage dementia.

I am aware that I have to strictly adhere to ethical issues especially relating to informed consent (from the individual clinicians and patients' relatives / legal proxy) and confidentiality and that I have to consult my research supervisor throughout the research process.

I would be grateful if you would allow me access to data collection from nursing staff. Your support for this study is greatly appreciated. If you have any difficulty, kindly contact my supervisor, Rev. Professor Emmanuel Agius.

Yours sincerely,

E. Agius

Dr. Joseph Dimech
M.Phil / PhD Student

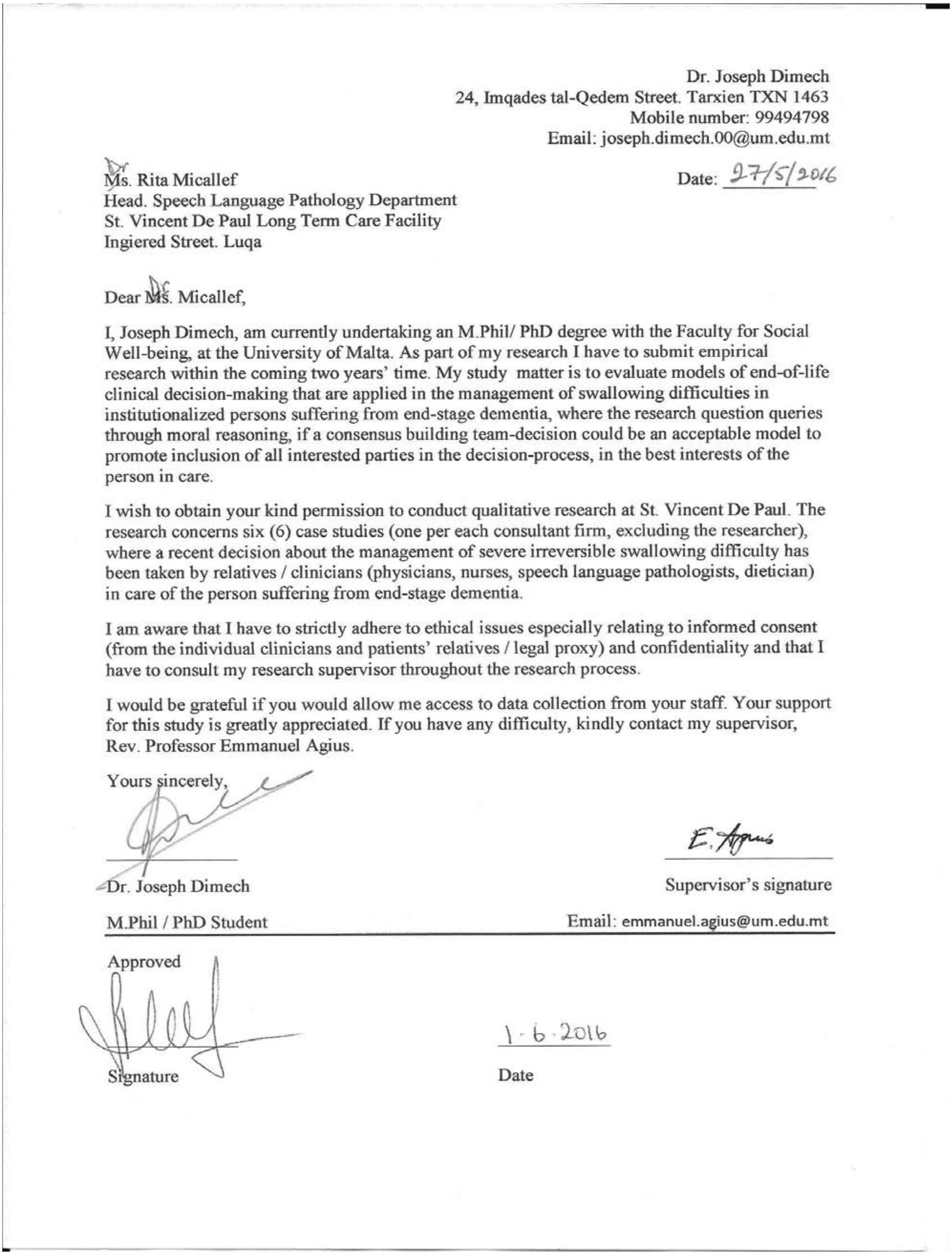
Supervisor's signature
Email: emmanuel.agius@um.edu.mt

Approved

31/5/16

Signature

Date



Dr. Joseph Dimech
24, Imqades tal-Qedem Street. Tarxien TXN 1463
Mobile number: 99494798
Email: joseph.dimech.00@um.edu.mt

Date: 27/5/2016

~~Ms.~~ Dr Rita Micallef
Head. Speech Language Pathology Department
St. Vincent De Paul Long Term Care Facility
Ingiered Street. Luqa

Dear ~~Ms.~~ Dr Micallef,

I, Joseph Dimech, am currently undertaking an M.Phil/ PhD degree with the Faculty for Social Well-being, at the University of Malta. As part of my research I have to submit empirical research within the coming two years' time. My study matter is to evaluate models of end-of-life clinical decision-making that are applied in the management of swallowing difficulties in institutionalized persons suffering from end-stage dementia, where the research question queries through moral reasoning, if a consensus building team-decision could be an acceptable model to promote inclusion of all interested parties in the decision-process, in the best interests of the person in care.

I wish to obtain your kind permission to conduct qualitative research at St. Vincent De Paul. The research concerns six (6) case studies (one per each consultant firm, excluding the researcher), where a recent decision about the management of severe irreversible swallowing difficulty has been taken by relatives / clinicians (physicians, nurses, speech language pathologists, dietician) in care of the person suffering from end-stage dementia.

I am aware that I have to strictly adhere to ethical issues especially relating to informed consent (from the individual clinicians and patients' relatives / legal proxy) and confidentiality and that I have to consult my research supervisor throughout the research process.

I would be grateful if you would allow me access to data collection from your staff. Your support for this study is greatly appreciated. If you have any difficulty, kindly contact my supervisor, Rev. Professor Emmanuel Agius.

Yours sincerely,

E. Agius

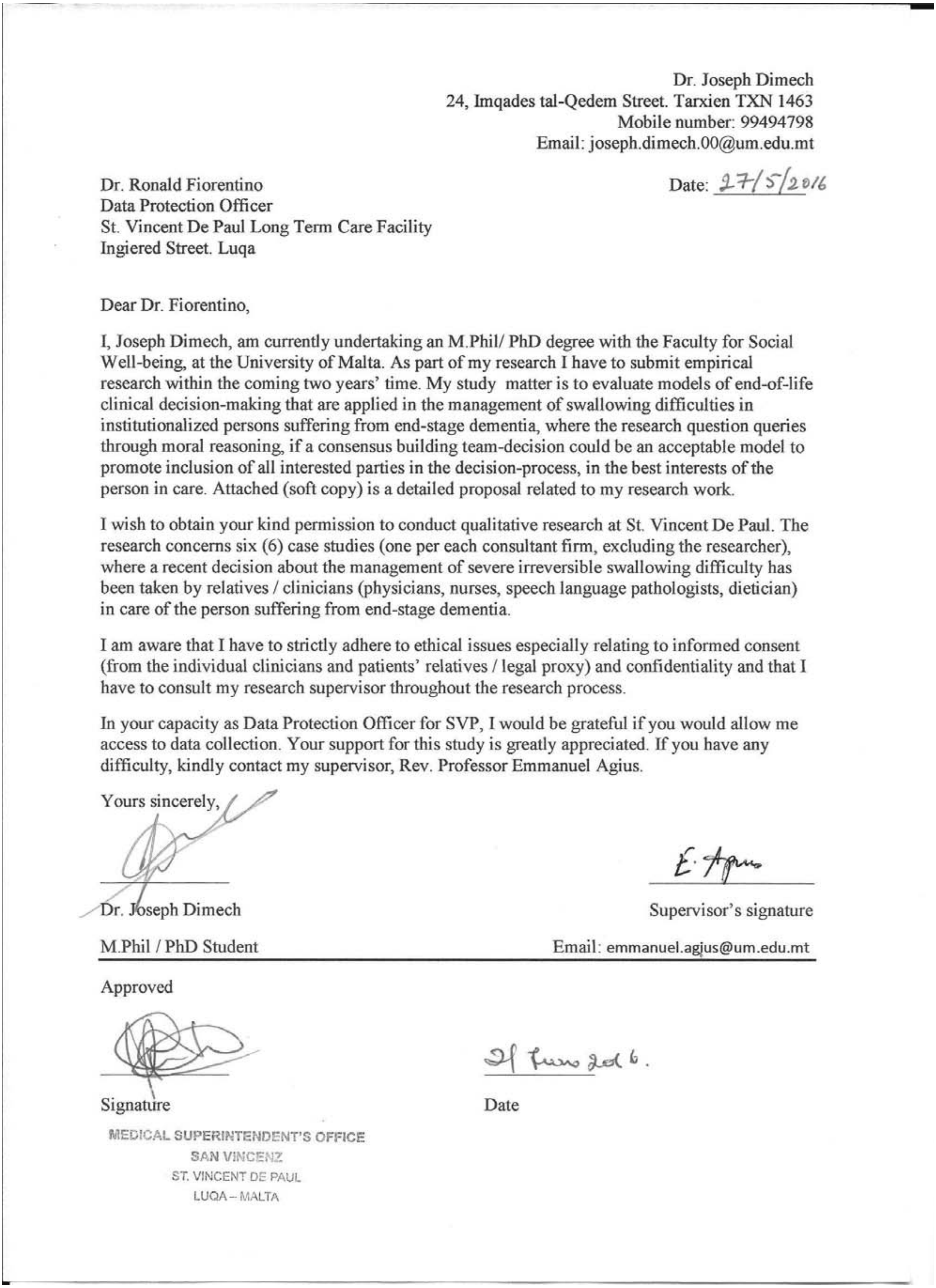
Dr. Joseph Dimech
M.Phil / PhD Student

Supervisor's signature
Email: emmanuel.agius@um.edu.mt

Approved

Signature

1.6.2016
Date



Dr. Joseph Dimech
24, Imqades tal-Qedem Street. Tarxien TXN 1463
Mobile number: 99494798
Email: joseph.dimech.00@um.edu.mt

Date: 27/5/2016

Dr. Ronald Fiorentino
Data Protection Officer
St. Vincent De Paul Long Term Care Facility
Ingiered Street. Luqa

Dear Dr. Fiorentino,

I, Joseph Dimech, am currently undertaking an M.Phil/ PhD degree with the Faculty for Social Well-being, at the University of Malta. As part of my research I have to submit empirical research within the coming two years' time. My study matter is to evaluate models of end-of-life clinical decision-making that are applied in the management of swallowing difficulties in institutionalized persons suffering from end-stage dementia, where the research question queries through moral reasoning, if a consensus building team-decision could be an acceptable model to promote inclusion of all interested parties in the decision-process, in the best interests of the person in care. Attached (soft copy) is a detailed proposal related to my research work.

I wish to obtain your kind permission to conduct qualitative research at St. Vincent De Paul. The research concerns six (6) case studies (one per each consultant firm, excluding the researcher), where a recent decision about the management of severe irreversible swallowing difficulty has been taken by relatives / clinicians (physicians, nurses, speech language pathologists, dietician) in care of the person suffering from end-stage dementia.

I am aware that I have to strictly adhere to ethical issues especially relating to informed consent (from the individual clinicians and patients' relatives / legal proxy) and confidentiality and that I have to consult my research supervisor throughout the research process.

In your capacity as Data Protection Officer for SVP, I would be grateful if you would allow me access to data collection. Your support for this study is greatly appreciated. If you have any difficulty, kindly contact my supervisor, Rev. Professor Emmanuel Agius.

Yours sincerely,

E. Agius

Dr. Joseph Dimech
M.Phil / PhD Student

Supervisor's signature
Email: emmanuel.agius@um.edu.mt

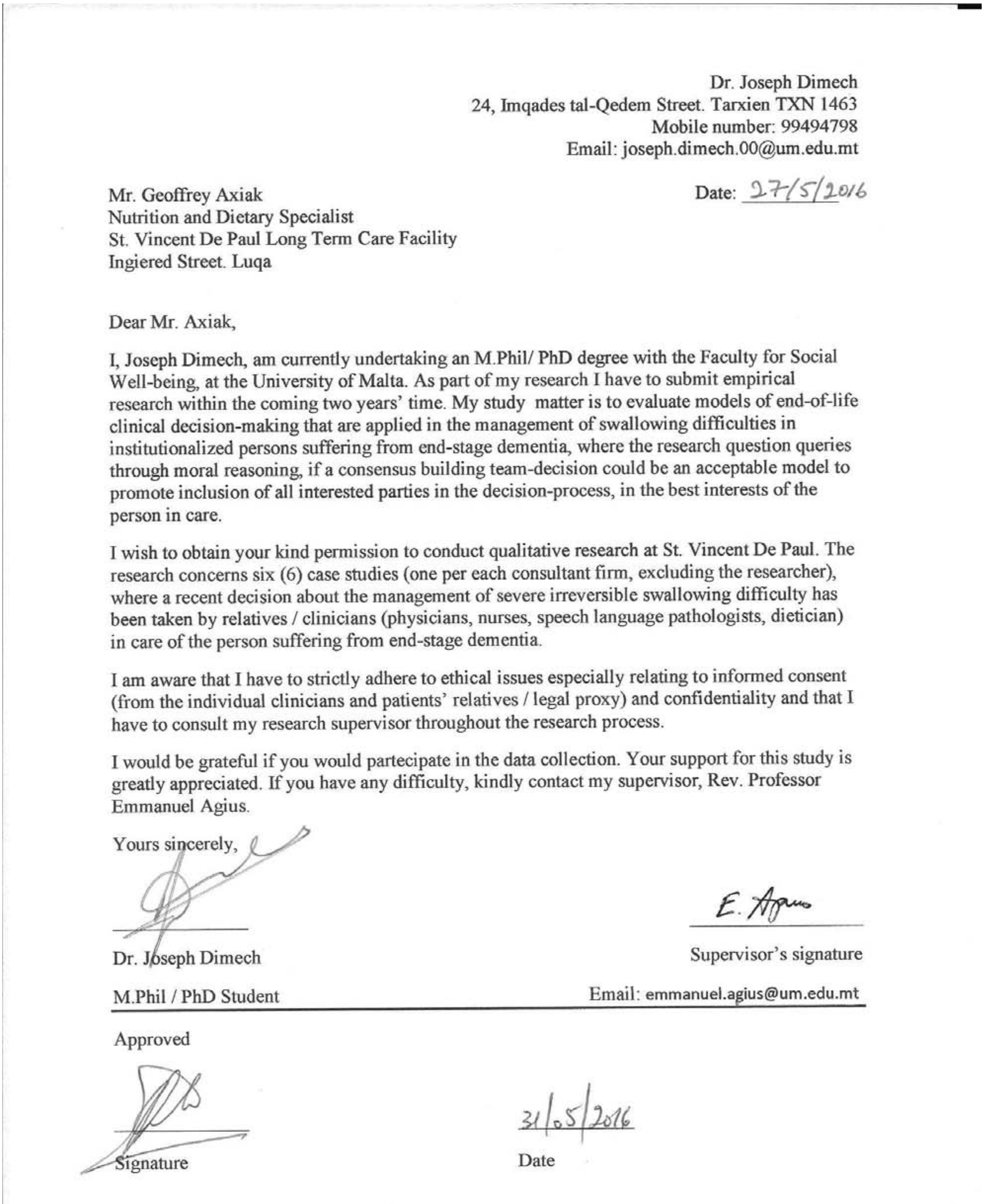
Approved

27 June 2016.

Signature

Date

MEDICAL SUPERINTENDENT'S OFFICE
SAN VINCENZ
ST. VINCENT DE PAUL
LUQA – MALTA



Dr. Joseph Dimech
24, Imqades tal-Qedem Street. Tarxien TXN 1463
Mobile number: 99494798
Email: joseph.dimech.00@um.edu.mt

Date: 27/5/2016

Mr. Geoffrey Axiak
Nutrition and Dietary Specialist
St. Vincent De Paul Long Term Care Facility
Ingiered Street. Luqa

Dear Mr. Axiak,

I, Joseph Dimech, am currently undertaking an M.Phil/ PhD degree with the Faculty for Social Well-being, at the University of Malta. As part of my research I have to submit empirical research within the coming two years' time. My study matter is to evaluate models of end-of-life clinical decision-making that are applied in the management of swallowing difficulties in institutionalized persons suffering from end-stage dementia, where the research question queries through moral reasoning, if a consensus building team-decision could be an acceptable model to promote inclusion of all interested parties in the decision-process, in the best interests of the person in care.

I wish to obtain your kind permission to conduct qualitative research at St. Vincent De Paul. The research concerns six (6) case studies (one per each consultant firm, excluding the researcher), where a recent decision about the management of severe irreversible swallowing difficulty has been taken by relatives / clinicians (physicians, nurses, speech language pathologists, dietician) in care of the person suffering from end-stage dementia.

I am aware that I have to strictly adhere to ethical issues especially relating to informed consent (from the individual clinicians and patients' relatives / legal proxy) and confidentiality and that I have to consult my research supervisor throughout the research process.

I would be grateful if you would partecipate in the data collection. Your support for this study is greatly appreciated. If you have any difficulty, kindly contact my supervisor, Rev. Professor Emmanuel Agius.

Yours sincerely,

E. Agius

Dr. Joseph Dimech
M.Phil / PhD Student

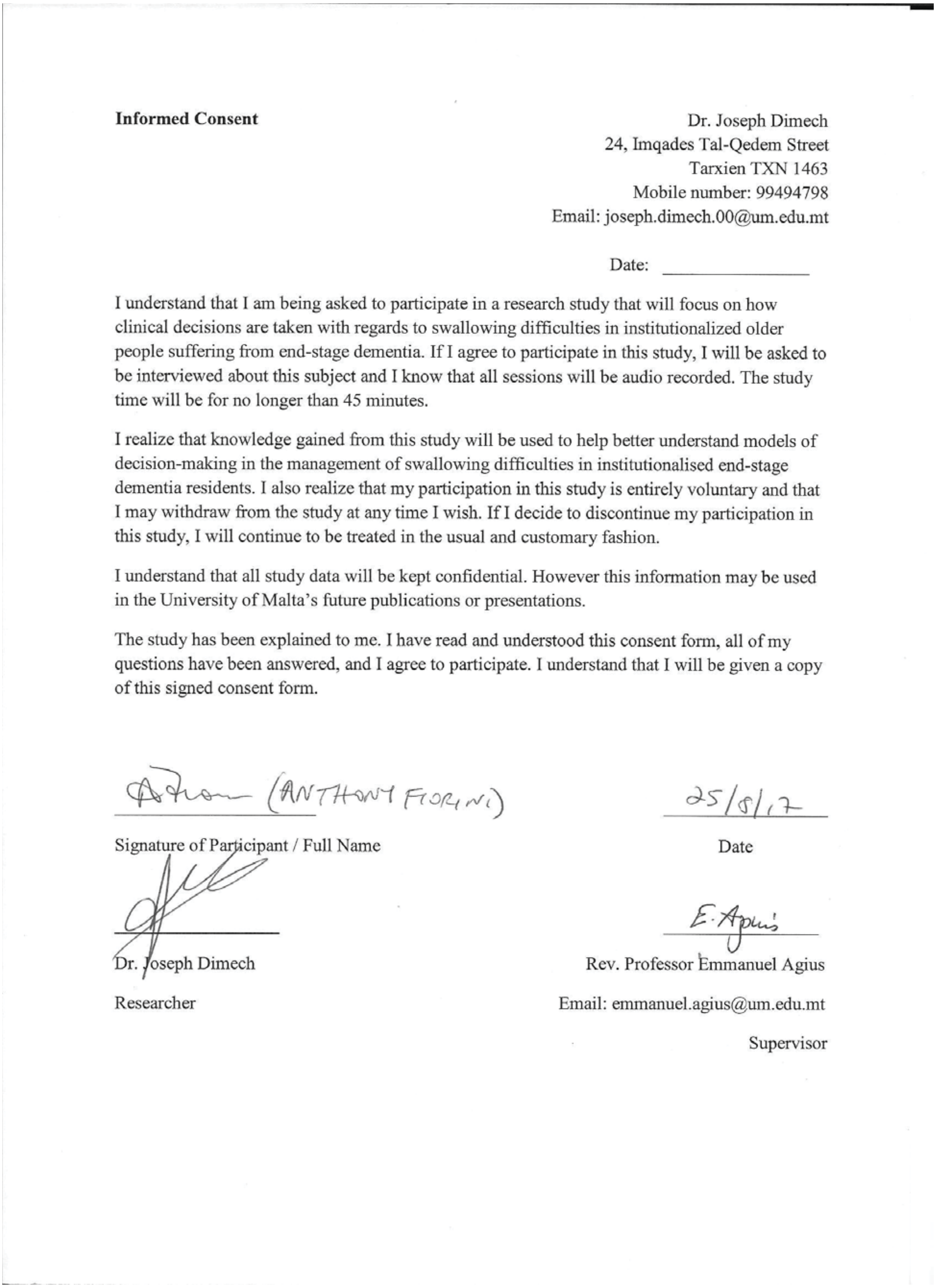
Supervisor's signature
Email: emmanuel.agius@um.edu.mt

Approved

31/05/2016

Signature

Date



Informed Consent

Dr. Joseph Dimech
24, Imqades Tal-Qedem Street
Tarxien TXN 1463
Mobile number: 99494798
Email: joseph.dimech.00@um.edu.mt

Date: ________________

I understand that I am being asked to participate in a research study that will focus on how clinical decisions are taken with regards to swallowing difficulties in institutionalized older people suffering from end-stage dementia. If I agree to participate in this study, I will be asked to be interviewed about this subject and I know that all sessions will be audio recorded. The study time will be for no longer than 45 minutes.

I realize that knowledge gained from this study will be used to help better understand models of decision-making in the management of swallowing difficulties in institutionalised end-stage dementia residents. I also realize that my participation in this study is entirely voluntary and that I may withdraw from the study at any time I wish. If I decide to discontinue my participation in this study, I will continue to be treated in the usual and customary fashion.

I understand that all study data will be kept confidential. However this information may be used in the University of Malta's future publications or presentations.

The study has been explained to me. I have read and understood this consent form, all of my questions have been answered, and I agree to participate. I understand that I will be given a copy of this signed consent form.

(ANTHONY FIORINI)

Signature of Participant / Full Name

25/8/17

Date

E. Agius

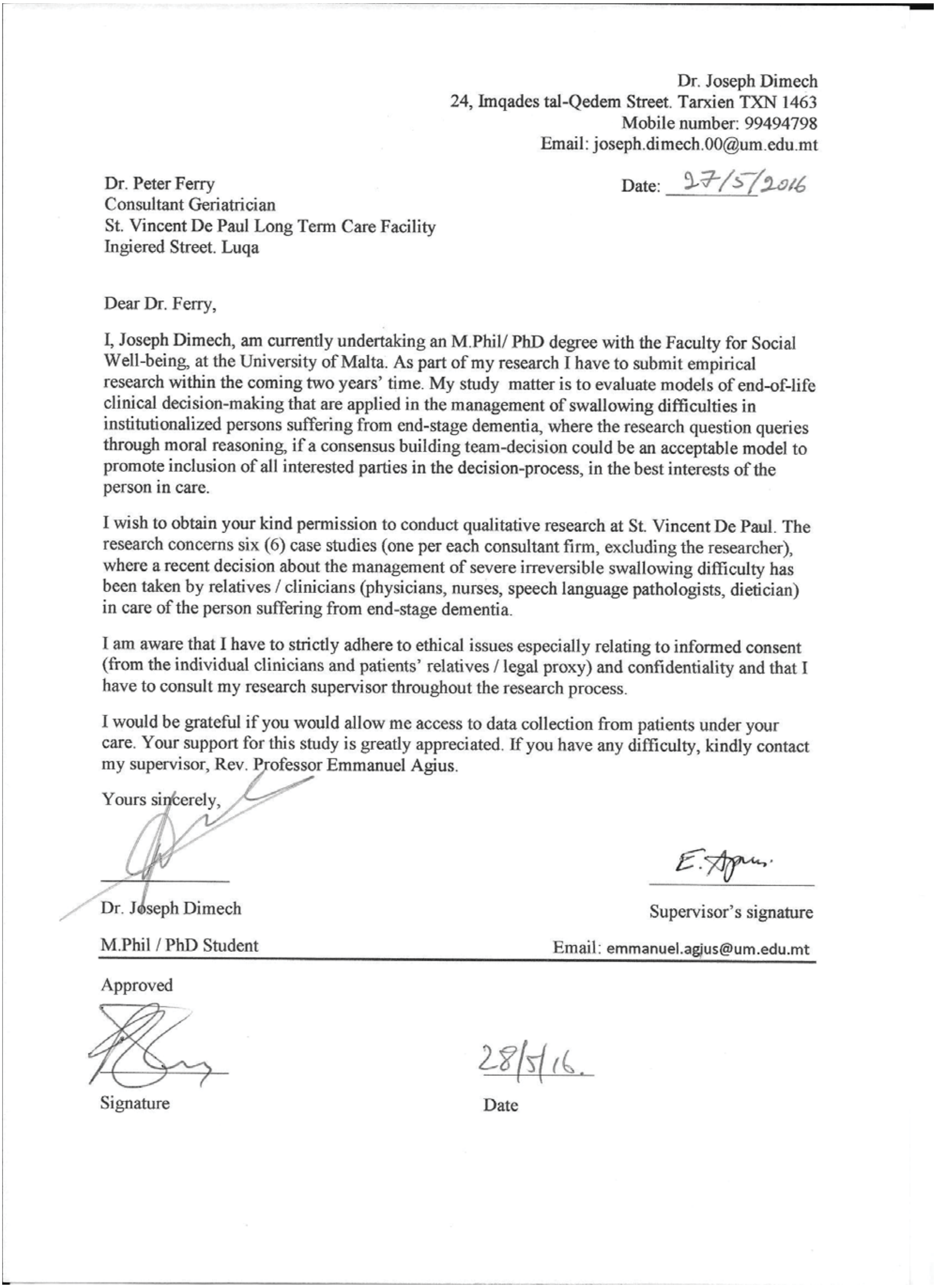
Dr. Joseph Dimech

Researcher

Rev. Professor Emmanuel Agius

Email: emmanuel.agius@um.edu.mt

Supervisor



Dr. Joseph Dimech
24, Imqades tal-Qedem Street. Tarxien TXN 1463
Mobile number: 99494798
Email: joseph.dimech.00@um.edu.mt

Date: 27/5/2016

Dr. Peter Ferry
Consultant Geriatrician
St. Vincent De Paul Long Term Care Facility
Ingiered Street. Luqa

Dear Dr. Ferry,

I, Joseph Dimech, am currently undertaking an M.Phil/ PhD degree with the Faculty for Social Well-being, at the University of Malta. As part of my research I have to submit empirical research within the coming two years' time. My study matter is to evaluate models of end-of-life clinical decision-making that are applied in the management of swallowing difficulties in institutionalized persons suffering from end-stage dementia, where the research question queries through moral reasoning, if a consensus building team-decision could be an acceptable model to promote inclusion of all interested parties in the decision-process, in the best interests of the person in care.

I wish to obtain your kind permission to conduct qualitative research at St. Vincent De Paul. The research concerns six (6) case studies (one per each consultant firm, excluding the researcher), where a recent decision about the management of severe irreversible swallowing difficulty has been taken by relatives / clinicians (physicians, nurses, speech language pathologists, dietician) in care of the person suffering from end-stage dementia.

I am aware that I have to strictly adhere to ethical issues especially relating to informed consent (from the individual clinicians and patients' relatives / legal proxy) and confidentiality and that I have to consult my research supervisor throughout the research process.

I would be grateful if you would allow me access to data collection from patients under your care. Your support for this study is greatly appreciated. If you have any difficulty, kindly contact my supervisor, Rev. Professor Emmanuel Agius.

Yours sincerely,

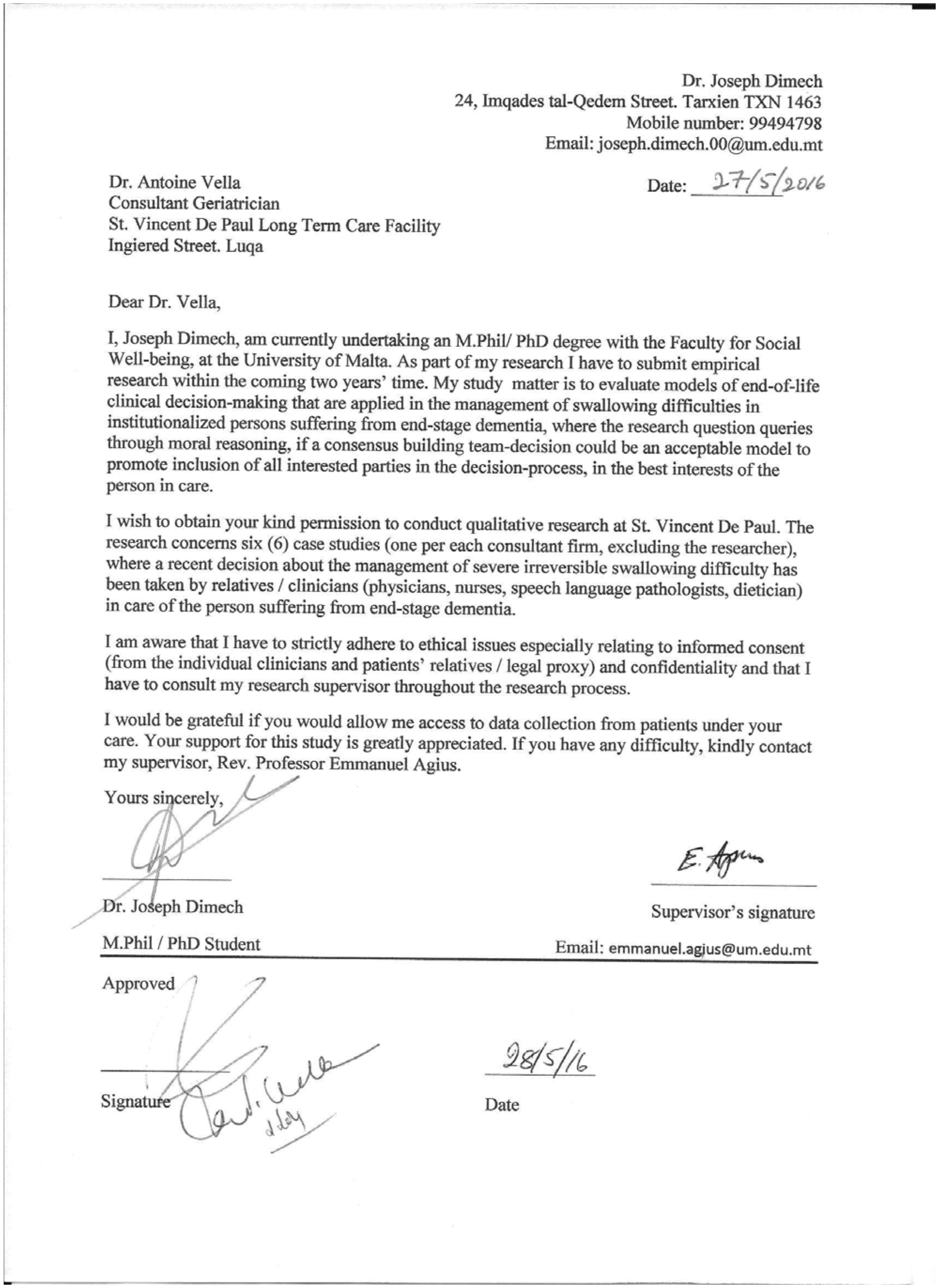
Dr. Joseph Dimech
M.Phil / PhD Student

Supervisor's signature
Email: emmanuel.agius@um.edu.mt

Approved

Signature

28/5/16.
Date



Dr. Joseph Dimech
24, Imqades tal-Qedem Street. Tarxien TXN 1463
Mobile number: 99494798
Email: joseph.dimech.00@um.edu.mt

Date: 27/5/2016

Dr. Antoine Vella
Consultant Geriatrician
St. Vincent De Paul Long Term Care Facility
Ingiered Street. Luqa

Dear Dr. Vella,

I, Joseph Dimech, am currently undertaking an M.Phil/ PhD degree with the Faculty for Social Well-being, at the University of Malta. As part of my research I have to submit empirical research within the coming two years' time. My study matter is to evaluate models of end-of-life clinical decision-making that are applied in the management of swallowing difficulties in institutionalized persons suffering from end-stage dementia, where the research question queries through moral reasoning, if a consensus building team-decision could be an acceptable model to promote inclusion of all interested parties in the decision-process, in the best interests of the person in care.

I wish to obtain your kind permission to conduct qualitative research at St. Vincent De Paul. The research concerns six (6) case studies (one per each consultant firm, excluding the researcher), where a recent decision about the management of severe irreversible swallowing difficulty has been taken by relatives / clinicians (physicians, nurses, speech language pathologists, dietician) in care of the person suffering from end-stage dementia.

I am aware that I have to strictly adhere to ethical issues especially relating to informed consent (from the individual clinicians and patients' relatives / legal proxy) and confidentiality and that I have to consult my research supervisor throughout the research process.

I would be grateful if you would allow me access to data collection from patients under your care. Your support for this study is greatly appreciated. If you have any difficulty, kindly contact my supervisor, Rev. Professor Emmanuel Agius.

Yours sincerely,

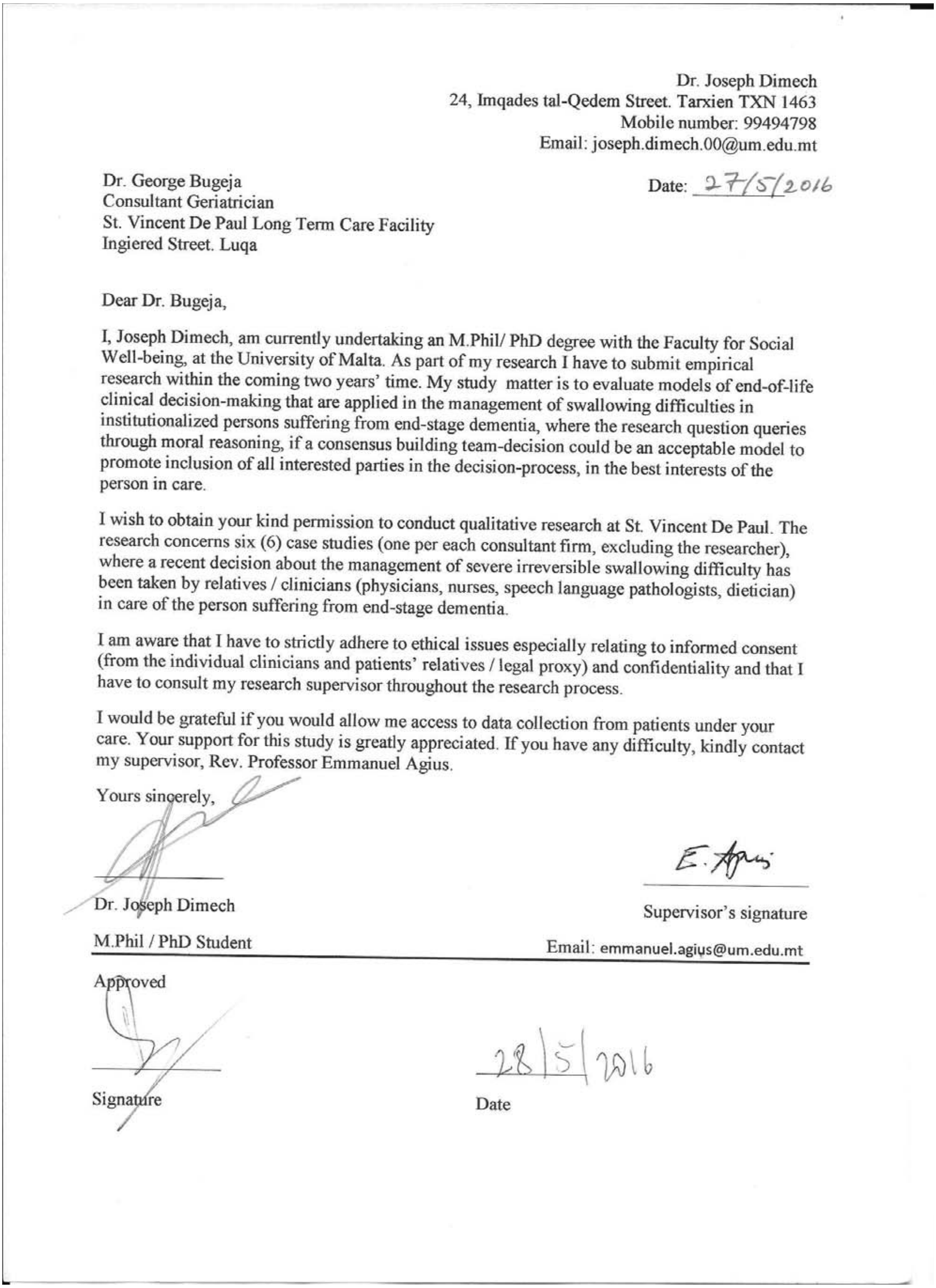
Dr. Joseph Dimech
M.Phil / PhD Student

E. Agius
Supervisor's signature
Email: emmanuel.agius@um.edu.mt

Approved

Signature

28/5/16
Date



Dr. Joseph Dimech
24, Imqades tal-Qedem Street. Tarxien TXN 1463
Mobile number: 99494798
Email: joseph.dimech.00@um.edu.mt

Date: 27/5/2016

Dr. George Bugeja
Consultant Geriatrician
St. Vincent De Paul Long Term Care Facility
Ingiered Street. Luqa

Dear Dr. Bugeja,

I, Joseph Dimech, am currently undertaking an M.Phil/ PhD degree with the Faculty for Social Well-being, at the University of Malta. As part of my research I have to submit empirical research within the coming two years' time. My study matter is to evaluate models of end-of-life clinical decision-making that are applied in the management of swallowing difficulties in institutionalized persons suffering from end-stage dementia, where the research question queries through moral reasoning, if a consensus building team-decision could be an acceptable model to promote inclusion of all interested parties in the decision-process, in the best interests of the person in care.

I wish to obtain your kind permission to conduct qualitative research at St. Vincent De Paul. The research concerns six (6) case studies (one per each consultant firm, excluding the researcher), where a recent decision about the management of severe irreversible swallowing difficulty has been taken by relatives / clinicians (physicians, nurses, speech language pathologists, dietician) in care of the person suffering from end-stage dementia.

I am aware that I have to strictly adhere to ethical issues especially relating to informed consent (from the individual clinicians and patients' relatives / legal proxy) and confidentiality and that I have to consult my research supervisor throughout the research process.

I would be grateful if you would allow me access to data collection from patients under your care. Your support for this study is greatly appreciated. If you have any difficulty, kindly contact my supervisor, Rev. Professor Emmanuel Agius.

Yours sincerely,

E. Agius

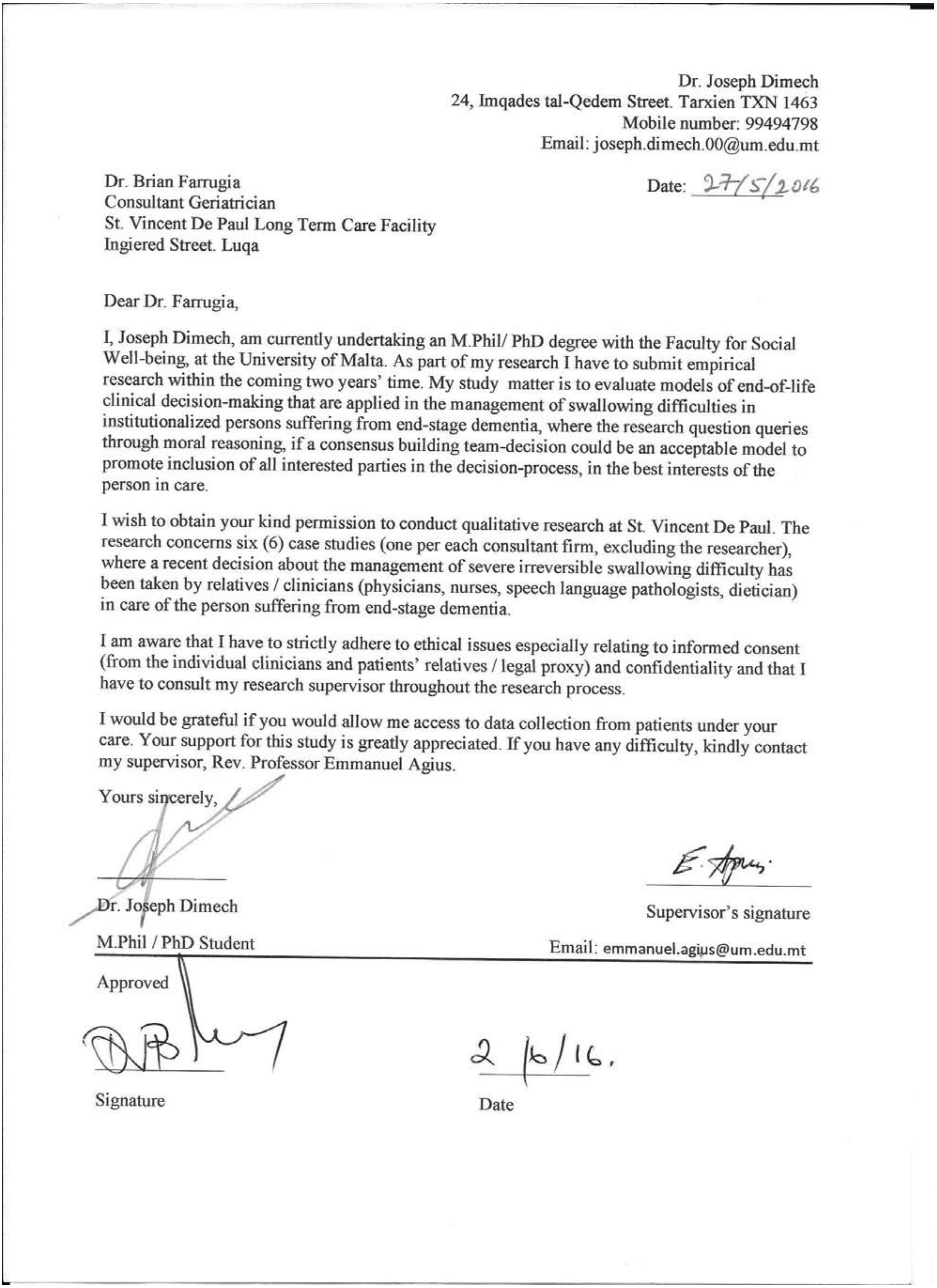
Dr. Joseph Dimech
M.Phil / PhD Student

Supervisor's signature
Email: emmanuel.agius@um.edu.mt

Approved

Signature

28/5/2016
Date



Dr. Joseph Dimech
24, Imqades tal-Qedem Street. Tarxien TXN 1463
Mobile number: 99494798
Email: joseph.dimech.00@um.edu.mt

Date: 27/5/2016

Dr. Brian Farrugia
Consultant Geriatrician
St. Vincent De Paul Long Term Care Facility
Ingiered Street. Luqa

Dear Dr. Farrugia,

I, Joseph Dimech, am currently undertaking an M.Phil/ PhD degree with the Faculty for Social Well-being, at the University of Malta. As part of my research I have to submit empirical research within the coming two years' time. My study matter is to evaluate models of end-of-life clinical decision-making that are applied in the management of swallowing difficulties in institutionalized persons suffering from end-stage dementia, where the research question queries through moral reasoning, if a consensus building team-decision could be an acceptable model to promote inclusion of all interested parties in the decision-process, in the best interests of the person in care.

I wish to obtain your kind permission to conduct qualitative research at St. Vincent De Paul. The research concerns six (6) case studies (one per each consultant firm, excluding the researcher), where a recent decision about the management of severe irreversible swallowing difficulty has been taken by relatives / clinicians (physicians, nurses, speech language pathologists, dietician) in care of the person suffering from end-stage dementia.

I am aware that I have to strictly adhere to ethical issues especially relating to informed consent (from the individual clinicians and patients' relatives / legal proxy) and confidentiality and that I have to consult my research supervisor throughout the research process.

I would be grateful if you would allow me access to data collection from patients under your care. Your support for this study is greatly appreciated. If you have any difficulty, kindly contact my supervisor, Rev. Professor Emmanuel Agius.

Yours sincerely,

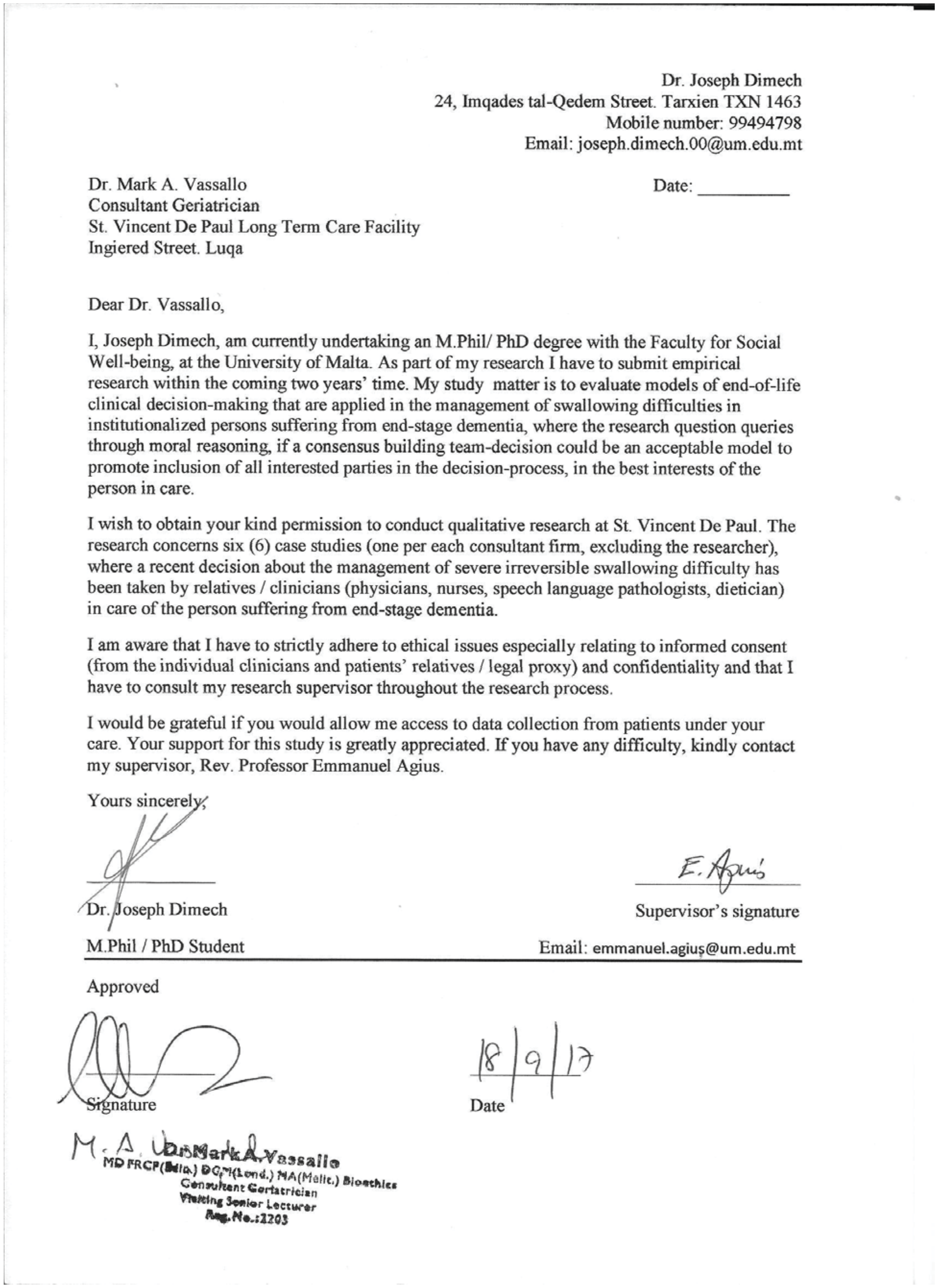
Dr. Joseph Dimech
M.Phil / PhD Student

Supervisor's signature
Email: emmanuel.agius@um.edu.mt

Approved

Signature

2/6/16.
Date



Dr. Joseph Dimech
24, Imqades tal-Qedem Street. Tarxien TXN 1463
Mobile number: 99494798
Email: joseph.dimech.00@um.edu.mt

Dr. Mark A. Vassallo
Consultant Geriatrician
St. Vincent De Paul Long Term Care Facility
Ingiered Street. Luqa

Date: __________

Dear Dr. Vassallo,

I, Joseph Dimech, am currently undertaking an M.Phil/ PhD degree with the Faculty for Social Well-being, at the University of Malta. As part of my research I have to submit empirical research within the coming two years' time. My study matter is to evaluate models of end-of-life clinical decision-making that are applied in the management of swallowing difficulties in institutionalized persons suffering from end-stage dementia, where the research question queries through moral reasoning, if a consensus building team-decision could be an acceptable model to promote inclusion of all interested parties in the decision-process, in the best interests of the person in care.

I wish to obtain your kind permission to conduct qualitative research at St. Vincent De Paul. The research concerns six (6) case studies (one per each consultant firm, excluding the researcher), where a recent decision about the management of severe irreversible swallowing difficulty has been taken by relatives / clinicians (physicians, nurses, speech language pathologists, dietician) in care of the person suffering from end-stage dementia.

I am aware that I have to strictly adhere to ethical issues especially relating to informed consent (from the individual clinicians and patients' relatives / legal proxy) and confidentiality and that I have to consult my research supervisor throughout the research process.

I would be grateful if you would allow me access to data collection from patients under your care. Your support for this study is greatly appreciated. If you have any difficulty, kindly contact my supervisor, Rev. Professor Emmanuel Agius.

Yours sincerely,

E. Agius

Dr. Joseph Dimech
M.Phil / PhD Student

Supervisor's signature
Email: emmanuel.agius@um.edu.mt

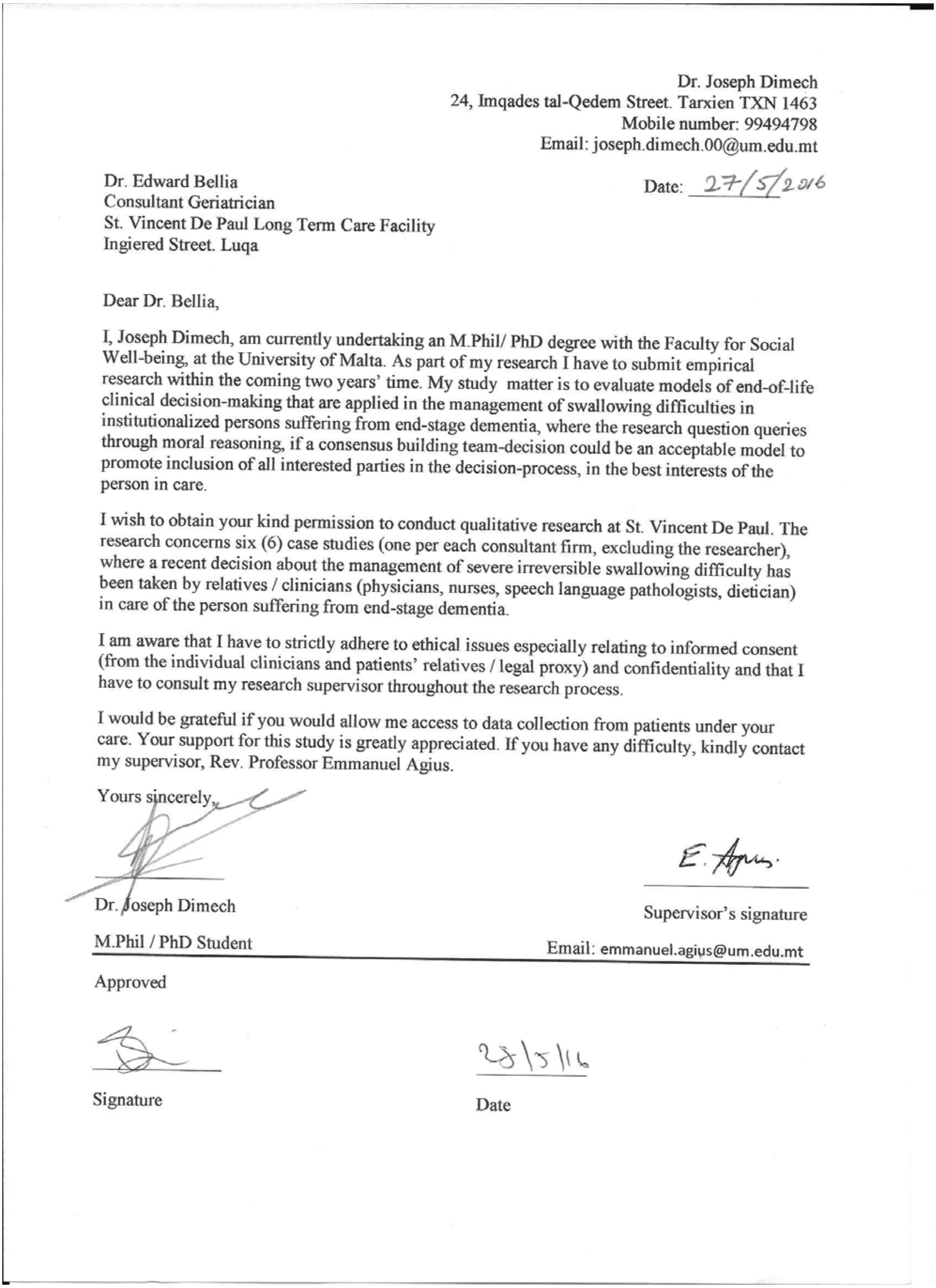
Approved

Signature

18/9/17
Date

M. A.

Dr. Mark A. Vassallo
MD FRCP(Edin.) DGM(Lond.) MA(Melit.) Bioethics
Consultant Geriatrician
Visiting Senior Lecturer
Reg. No.: 2203



Dr. Joseph Dimech
24, Imqades tal-Qedem Street. Tarxien TXN 1463
Mobile number: 99494798
Email: joseph.dimech.00@um.edu.mt

Dr. Edward Bellia
Consultant Geriatrician
St. Vincent De Paul Long Term Care Facility
Ingiered Street. Luqa

Date: 27/5/2016

Dear Dr. Bellia,

I, Joseph Dimech, am currently undertaking an M.Phil/ PhD degree with the Faculty for Social Well-being, at the University of Malta. As part of my research I have to submit empirical research within the coming two years' time. My study matter is to evaluate models of end-of-life clinical decision-making that are applied in the management of swallowing difficulties in institutionalized persons suffering from end-stage dementia, where the research question queries through moral reasoning, if a consensus building team-decision could be an acceptable model to promote inclusion of all interested parties in the decision-process, in the best interests of the person in care.

I wish to obtain your kind permission to conduct qualitative research at St. Vincent De Paul. The research concerns six (6) case studies (one per each consultant firm, excluding the researcher), where a recent decision about the management of severe irreversible swallowing difficulty has been taken by relatives / clinicians (physicians, nurses, speech language pathologists, dietician) in care of the person suffering from end-stage dementia.

I am aware that I have to strictly adhere to ethical issues especially relating to informed consent (from the individual clinicians and patients' relatives / legal proxy) and confidentiality and that I have to consult my research supervisor throughout the research process.

I would be grateful if you would allow me access to data collection from patients under your care. Your support for this study is greatly appreciated. If you have any difficulty, kindly contact my supervisor, Rev. Professor Emmanuel Agius.

Yours sincerely,

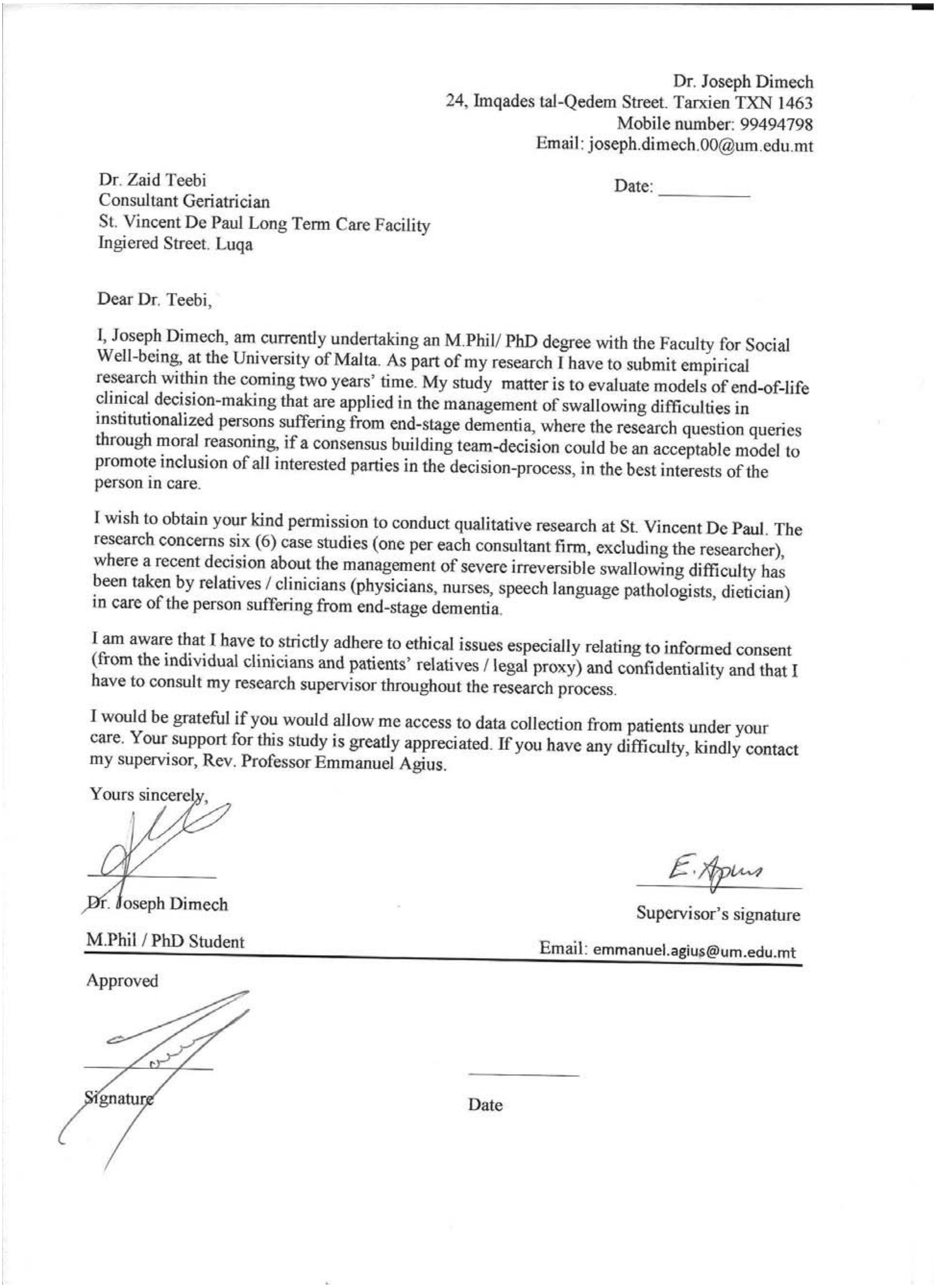
Dr. Joseph Dimech
M.Phil / PhD Student

E. Agius.
Supervisor's signature
Email: emmanuel.agius@um.edu.mt

Approved

Signature

28/5/16
Date



Dr. Joseph Dimech
24, Imqades tal-Qedem Street. Tarxien TXN 1463
Mobile number: 99494798
Email: joseph.dimech.00@um.edu.mt

Dr. Zaid Teebi
Consultant Geriatrician
St. Vincent De Paul Long Term Care Facility
Ingiered Street. Luqa

Date: __________

Dear Dr. Teebi,

I, Joseph Dimech, am currently undertaking an M.Phil/ PhD degree with the Faculty for Social Well-being, at the University of Malta. As part of my research I have to submit empirical research within the coming two years' time. My study matter is to evaluate models of end-of-life clinical decision-making that are applied in the management of swallowing difficulties in institutionalized persons suffering from end-stage dementia, where the research question queries through moral reasoning, if a consensus building team-decision could be an acceptable model to promote inclusion of all interested parties in the decision-process, in the best interests of the person in care.

I wish to obtain your kind permission to conduct qualitative research at St. Vincent De Paul. The research concerns six (6) case studies (one per each consultant firm, excluding the researcher), where a recent decision about the management of severe irreversible swallowing difficulty has been taken by relatives / clinicians (physicians, nurses, speech language pathologists, dietician) in care of the person suffering from end-stage dementia.

I am aware that I have to strictly adhere to ethical issues especially relating to informed consent (from the individual clinicians and patients' relatives / legal proxy) and confidentiality and that I have to consult my research supervisor throughout the research process.

I would be grateful if you would allow me access to data collection from patients under your care. Your support for this study is greatly appreciated. If you have any difficulty, kindly contact my supervisor, Rev. Professor Emmanuel Agius.

Yours sincerely,

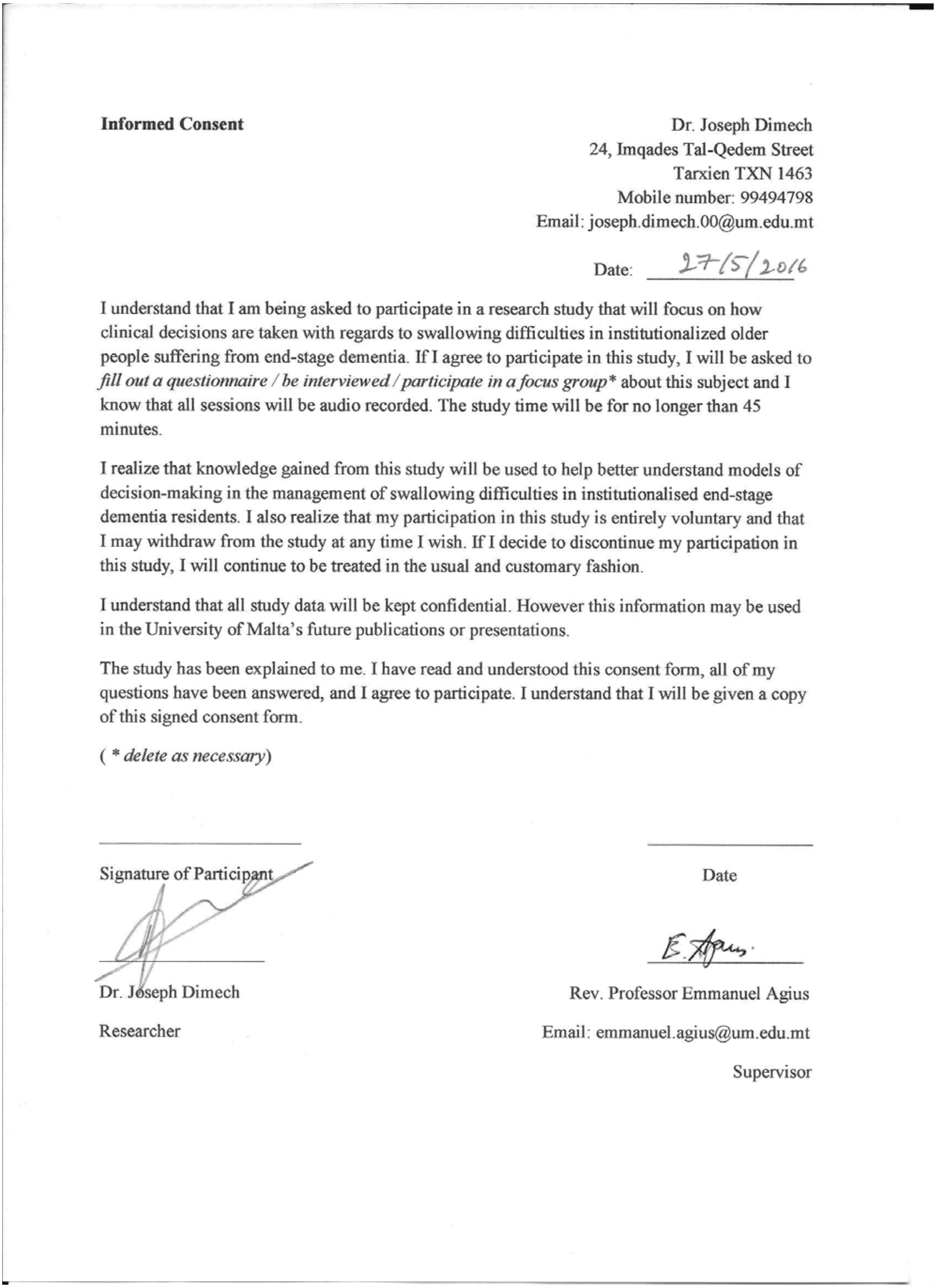
Dr. Joseph Dimech
M.Phil / PhD Student

E. Agius
Supervisor's signature
Email: emmanuel.agius@um.edu.mt

Approved

Signature

Date



Informed Consent

Dr. Joseph Dimech
24, Imqades Tal-Qedem Street
Tarxien TXN 1463
Mobile number: 99494798
Email: joseph.dimech.00@um.edu.mt

Date: 27/5/2016

I understand that I am being asked to participate in a research study that will focus on how clinical decisions are taken with regards to swallowing difficulties in institutionalized older people suffering from end-stage dementia. If I agree to participate in this study, I will be asked to *fill out a questionnaire / be interviewed / participate in a focus group** about this subject and I know that all sessions will be audio recorded. The study time will be for no longer than 45 minutes.

I realize that knowledge gained from this study will be used to help better understand models of decision-making in the management of swallowing difficulties in institutionalised end-stage dementia residents. I also realize that my participation in this study is entirely voluntary and that I may withdraw from the study at any time I wish. If I decide to discontinue my participation in this study, I will continue to be treated in the usual and customary fashion.

I understand that all study data will be kept confidential. However this information may be used in the University of Malta's future publications or presentations.

The study has been explained to me. I have read and understood this consent form, all of my questions have been answered, and I agree to participate. I understand that I will be given a copy of this signed consent form.

(* *delete as necessary*)

Signature of Participant

Date

E. Agius.

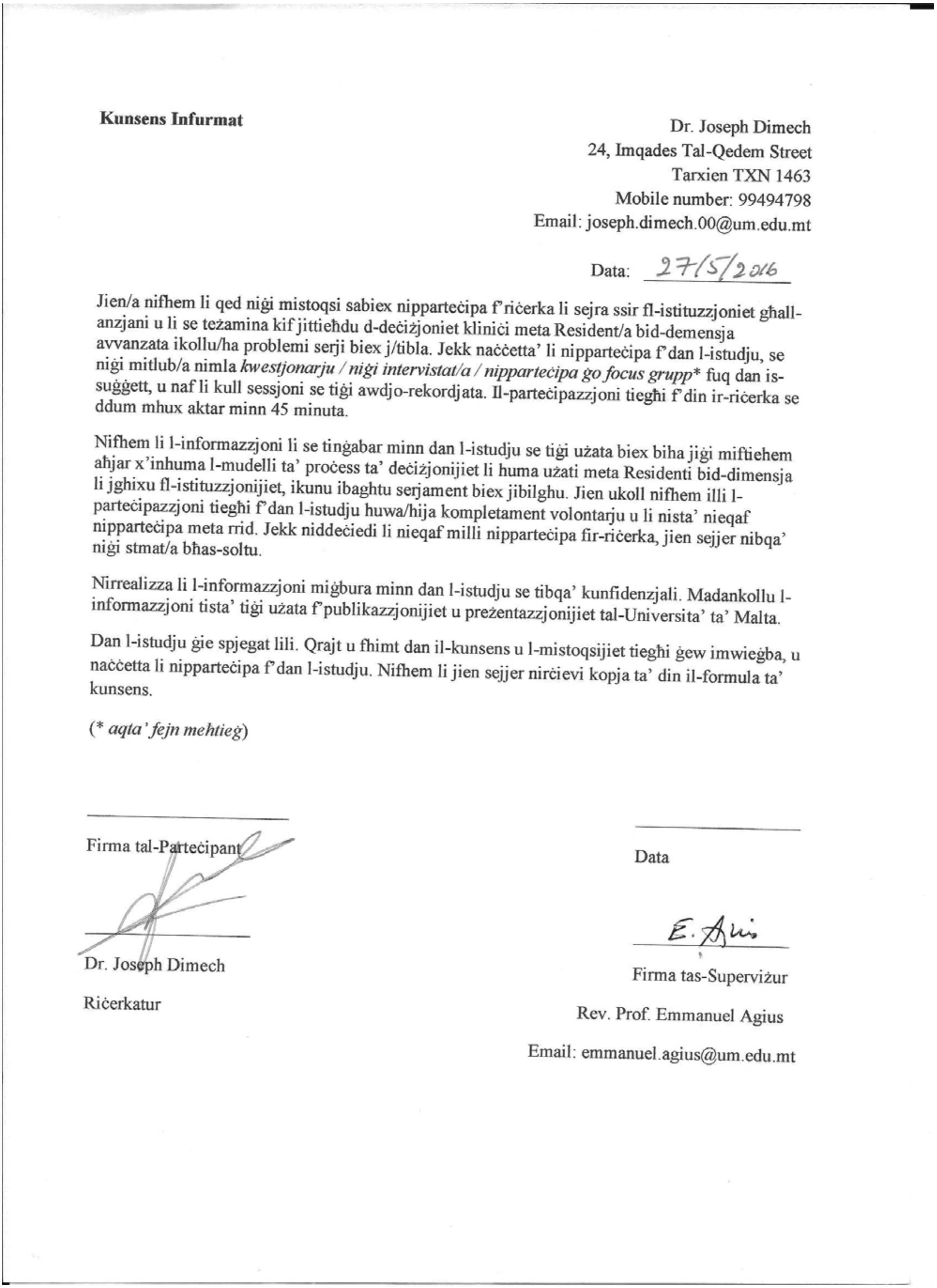
Dr. Joseph Dimech

Researcher

Rev. Professor Emmanuel Agius

Email: emmanuel.agius@um.edu.mt

Supervisor



Kunsens Infurmat

Dr. Joseph Dimech
24, Imqades Tal-Qedem Street
Tarxien TXN 1463
Mobile number: 99494798
Email: joseph.dimech.00@um.edu.mt

Data: 27/5/2016

Jien/a nifhem li qed niġi mistoqsi sabiex nipparteċipa f'riċerka li sejra ssir fl-istituzzjoniet għall-anzjani u li se teżamina kif jittieħdu d-deċiżjoniet kliniċi meta Resident/a bid-demensja avvanzata ikollu/ha problemi serji biex j/tibla. Jekk naċċetta' li nipparteċipa f'dan l-istudju, se niġi mitlub/a nimla *kwestjonarju / niġi intervistat/a / nipparteċipa ġo focus grupp** fuq dan is-suġġett, u naf li kull sessjoni se tiġi awdjo-rekordjata. Il-parteċipazzjoni tiegħi f'din ir-riċerka se ddum mhux aktar minn 45 minuta.

Nifhem li l-informazzjoni li se tinġabar minn dan l-istudju se tiġi użata biex biha jiġi miftiehem aħjar x'inhuma l-mudelli ta' proċess ta' deċiżjonijiet li huma użati meta Residenti bid-dimensja li jghixu fl-istituzzjonijiet, ikunu ibaghtu serjament biex jibilghu. Jien ukoll nifhem illi l-parteċipazzjoni tiegħi f'dan l-istudju huwa/hija kompletament volontarju u li nista' nieqaf nipparteċipa meta rrid. Jekk niddeċiedi li nieqaf milli nipparteċipa fir-riċerka, jien sejjer nibqa' niġi stmat/a bħas-soltu.

Nirrealizza li l-informazzjoni miġbura minn dan l-istudju se tibqa' kunfidenzjali. Madankollu l-informazzjoni tista' tiġi użata f'publikazzjonijiet u preżentazzjonijiet tal-Universita' ta' Malta.

Dan l-istudju ġie spjegat lili. Qrajt u fhimt dan il-kunsens u l-mistoqsijiet tiegħi ġew imwieġba, u naċċetta li nipparteċipa f'dan l-istudju. Nifhem li jien sejjer nirċievi kopja ta' din il-formula ta' kunsens.

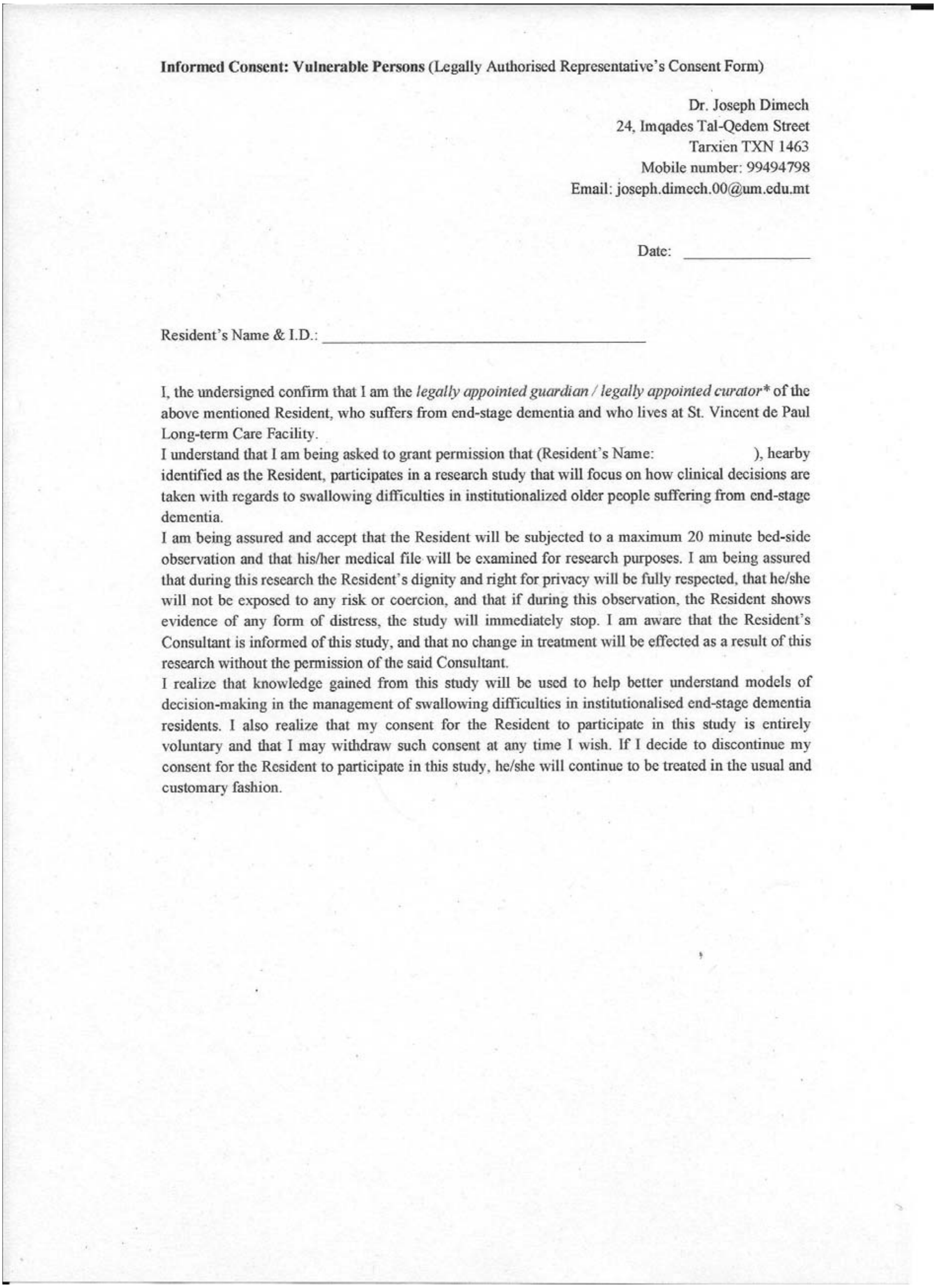
(* *aqta' fejn meħtieġ*)

Firma tal-Parteċipant

Data

Dr. Joseph Dimech
Riċerkatur

E. Agius
Firma tas-Superviżur
Rev. Prof. Emmanuel Agius
Email: emmanuel.agius@um.edu.mt



Informed Consent: Vulnerable Persons (Legally Authorised Representative's Consent Form)

Dr. Joseph Dimech
24, Imqades Tal-Qedem Street
Tarxien TXN 1463
Mobile number: 99494798
Email: joseph.dimech.00@um.edu.mt

Date: _______________

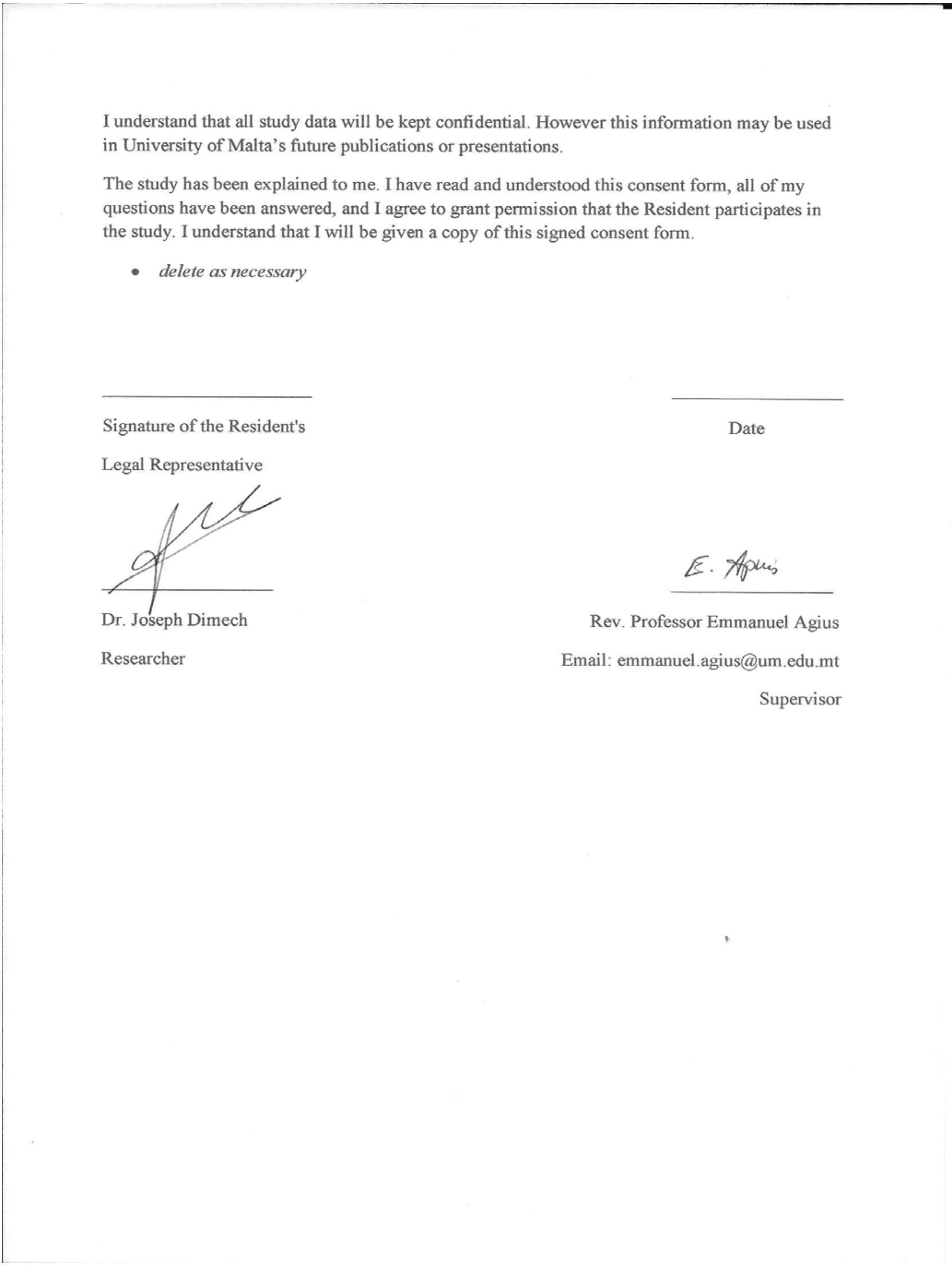
Resident's Name & I.D.: ______________________________________

I, the undersigned confirm that I am the *legally appointed guardian / legally appointed curator** of the above mentioned Resident, who suffers from end-stage dementia and who lives at St. Vincent de Paul Long-term Care Facility.

I understand that I am being asked to grant permission that (Resident's Name:), hearby identified as the Resident, participates in a research study that will focus on how clinical decisions are taken with regards to swallowing difficulties in institutionalized older people suffering from end-stage dementia.

I am being assured and accept that the Resident will be subjected to a maximum 20 minute bed-side observation and that his/her medical file will be examined for research purposes. I am being assured that during this research the Resident's dignity and right for privacy will be fully respected, that he/she will not be exposed to any risk or coercion, and that if during this observation, the Resident shows evidence of any form of distress, the study will immediately stop. I am aware that the Resident's Consultant is informed of this study, and that no change in treatment will be effected as a result of this research without the permission of the said Consultant.

I realize that knowledge gained from this study will be used to help better understand models of decision-making in the management of swallowing difficulties in institutionalised end-stage dementia residents. I also realize that my consent for the Resident to participate in this study is entirely voluntary and that I may withdraw such consent at any time I wish. If I decide to discontinue my consent for the Resident to participate in this study, he/she will continue to be treated in the usual and customary fashion.



I understand that all study data will be kept confidential. However this information may be used in University of Malta's future publications or presentations.

The study has been explained to me. I have read and understood this consent form, all of my questions have been answered, and I agree to grant permission that the Resident participates in the study. I understand that I will be given a copy of this signed consent form.

- *delete as necessary*

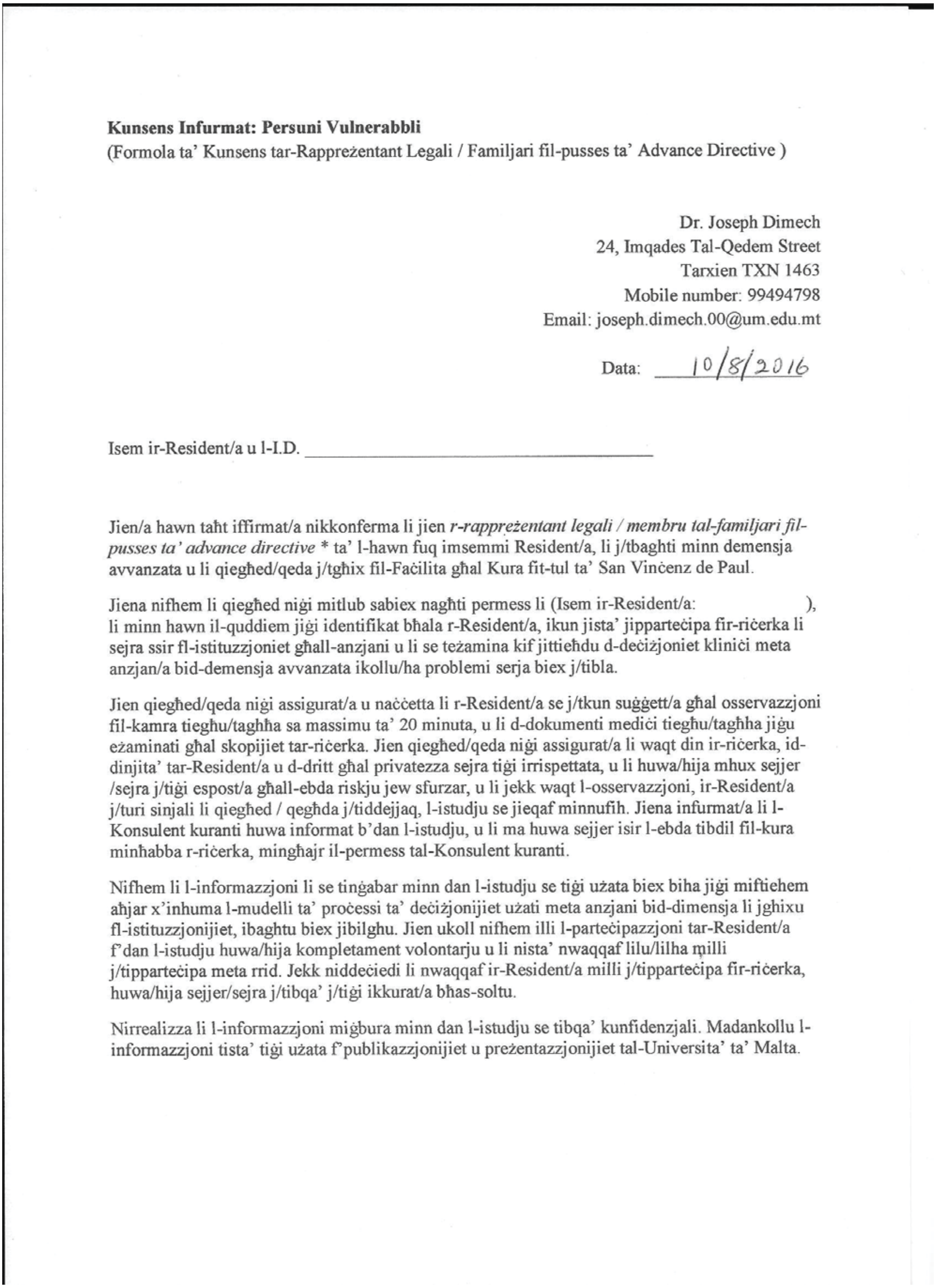
Signature of the Resident's
Legal Representative

Date

Dr. Joseph Dimech
Researcher

E. Agius

Rev. Professor Emmanuel Agius
Email: emmanuel.agius@um.edu.mt
Supervisor



Kunsens Infurmat: Persuni Vulnerabbli
(Formola ta' Kunsens tar-Rappreżentant Legali / Familjari fil-pusses ta' Advance Directive)

Dr. Joseph Dimech
24, Imqades Tal-Qedem Street
Tarxien TXN 1463
Mobile number: 99494798
Email: joseph.dimech.00@um.edu.mt

Data: 10/8/2016

Isem ir-Resident/a u l-I.D. ______________________________________

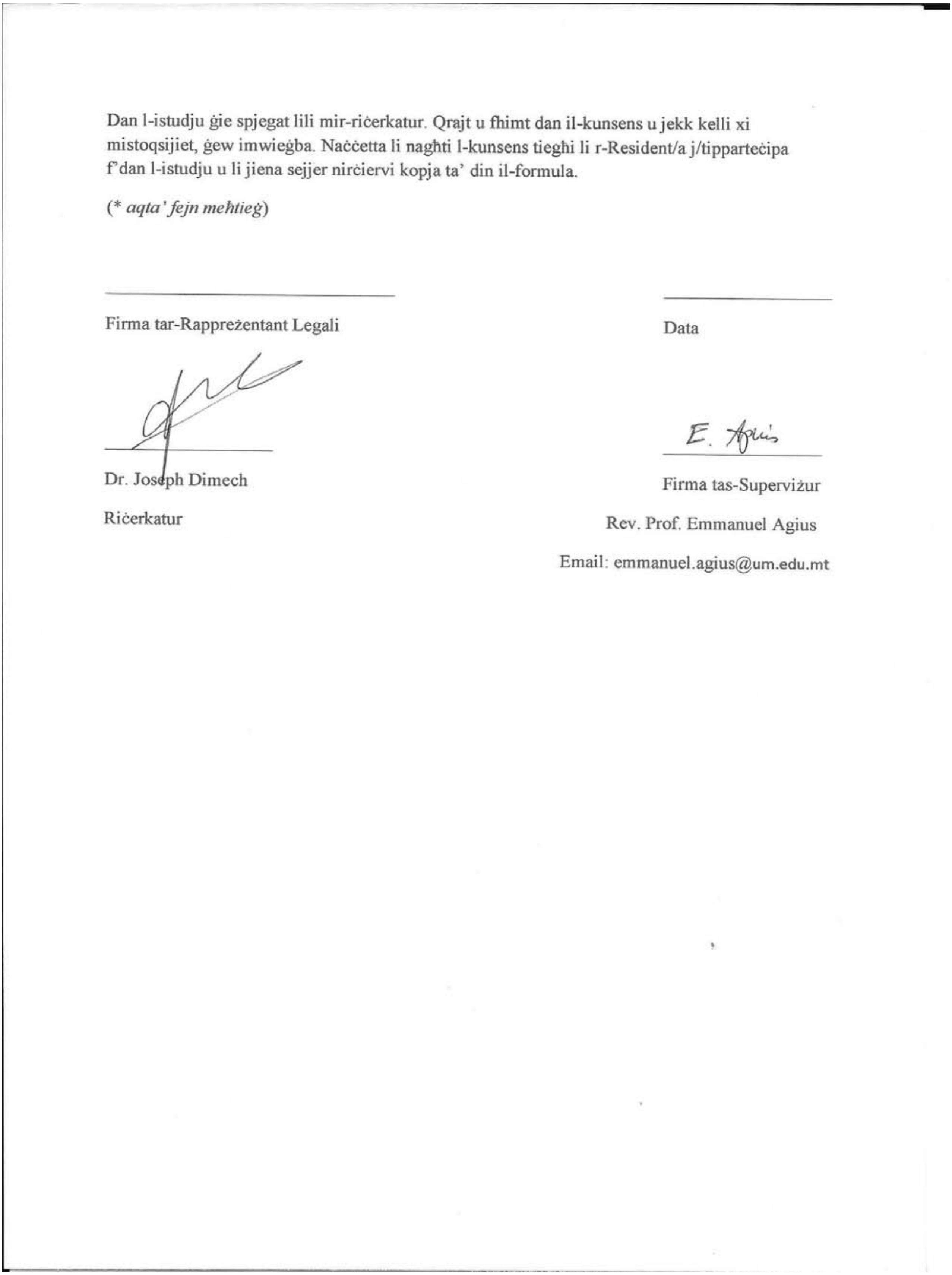
Jien/a hawn taħt iffirmat/a nikkonferma li jien *r-rappreżentant legali / membru tal-familjari fil-pusses ta' advance directive* * ta' l-hawn fuq imsemmi Resident/a, li j/tbaghti minn demensja avvanzata u li qiegħed/qeda j/tgħix fil-Faċilita għal Kura fit-tul ta' San Vinċenz de Paul.

Jiena nifhem li qiegħed niġi mitlub sabiex nagħti permess li (Isem ir-Resident/a:), li minn hawn il-quddiem jiġi identifikat bħala r-Resident/a, ikun jista' jipparteċipa fir-riċerka li sejra ssir fl-istituzzjoniet għall-anzjani u li se teżamina kif jittieħdu d-deċiżjoniet kliniċi meta anzjan/a bid-demensja avvanzata ikollu/ha problemi serja biex j/tibla.

Jien qiegħed/qeda niġi assigurat/a u naċċetta li r-Resident/a se j/tkun suġġett/a għal osservazzjoni fil-kamra tiegħu/tagħha sa massimu ta' 20 minuta, u li d-dokumenti mediċi tiegħu/tagħha jiġu eżaminati għal skopijiet tar-riċerka. Jien qiegħed/qeda niġi assigurat/a li waqt din ir-riċerka, id-dinjita' tar-Resident/a u d-dritt għal privatezza sejra tiġi irrispettata, u li huwa/hija mhux sejjer /sejra j/tiġi espost/a għall-ebda riskju jew sfurzar, u li jekk waqt l-osservazzjoni, ir-Resident/a j/turi sinjali li qiegħed / qegħda j/tiddejjaq, l-istudju se jieqaf minnufih. Jiena infurmat/a li l-Konsulent kuranti huwa informat b'dan l-istudju, u li ma huwa sejjer isir l-ebda tibdil fil-kura minħabba r-riċerka, mingħajr il-permess tal-Konsulent kuranti.

Nifhem li l-informazzjoni li se tinġabar minn dan l-istudju se tiġi użata biex biha jiġi miftiehem aħjar x'inhuma l-mudelli ta' proċessi ta' deċiżjonijiet użati meta anzjani bid-dimensja li jgħixu fl-istituzzjonijiet, ibaghtu biex jibilgħu. Jien ukoll nifhem illi l-parteċipazzjoni tar-Resident/a f'dan l-istudju huwa/hija kompletament volontarju u li nista' nwaqqaf lilu/lilha milli j/tipparteċipa meta rrid. Jekk niddeċiedi li nwaqqaf ir-Resident/a milli j/tipparteċipa fir-riċerka, huwa/hija sejjer/sejra j/tibqa' j/tiġi ikkurat/a bħas-soltu.

Nirrealizza li l-informazzjoni miġbura minn dan l-istudju se tibqa' kunfidenzjali. Madankollu l-informazzjoni tista' tiġi użata f'publikazzjonijiet u preżentazzjonijiet tal-Universita' ta' Malta.



Dan l-istudju ġie spjegat lili mir-riċerkatur. Qrajt u fhimt dan il-kunsens u jekk kelli xi mistoqsijiet, ġew imwieġba. Naċċetta li nagħti l-kunsens tiegħi li r-Resident/a j/tipparteċipa f'dan l-istudju u li jiena sejjer nirċievi kopja ta' din il-formula.

(* *aqta' fejn meħtieġ*)

Firma tar-Rappreżentant Legali

Data

E. Agius

Dr. Joseph Dimech

Riċerkatur

Firma tas-Superviżur

Rev. Prof. Emmanuel Agius

Email: emmanuel.agius@um.edu.mt

June 18, 2018

Permission Letter to Reproduce the Functional Assessment Staging Scale (FAST)

Dear Dr. Joseph Dimech,

You have my permission to reproduce the Functional Assessment Staging Scale (FAST) for the purposes described in your email below. Since you will be using the scale in association with your educational activities, my only requirement is that the scale be properly cited and the copyright is noted in all reproductions.

The reference and copyright notice for the FAST is as follows:

Reisberg, B. Functional Assessment Staging (FAST). Psychopharmacology Bulletin, 1988; 24:653-659.

The copyright notice for the FAST is:

"Copyright © 1984 by Barry Reisberg, M.D."

You should also note after the copyright notice in each form "Reproduced with permission".

The notices above should appear in all scale reproductions.

Kindly reply with an acknowledgement of the requirements stated above. Once this acknowledgement is received, the permission becomes effective for a period of 7 years.

Sincerely,

Barry Reisberg, M.D.

Professor of Psychiatry
Director, Fisher Alzheimer's Disease Program
Clinical Director, Aging & Dementia Clinical Research Center
Emeritus Director, Clinical Core, NYU Alzheimer's Disease Center
New York University Langone Medical Center

145 East 32nd Street, Room 508
New York, NY 10016

Tel: 212 263-8550
Fax: 212 263-6991
Email: barry.reisberg@nyumc.org