Institutionalised older people's experiences and perceptions of death and their attitudes towards decision-making at end of life: a qualitative study.

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Declaration of Authenticity

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Abstract

End-of-life (EOL) discussions are not yet the norm across the Maltese Islands. This lack of communication of the patient's preferences, wishes and values can lead to ethical and moral dilemmas at EOL. Research reveals that there is a willingness amongst older adults to be included in the decision-making process. Acquiring a better understanding of their subjective meanings, perceptions, and values at EOL are prerequisites in institutions to enable person-centred care and a dignified death. This study aimed to explore the experiences and perceptions of institutionalised older adults on EOL including death and their attitudes towards decision-making in this stage of life, with the introduction of Advance Care Planning (ACP) as a novel tool to safeguard their autonomy and dignity till the end.

This study followed a qualitative approach, informed by an interpretative phenomenological analysis (IPA) design, in the quest to derive meaning from the participants' lived experiences. Ethical permissions were sought and obtained from the Faculty Research Ethics Committee on the 18th of February 2022. Six cognitively preserved older adults residing in Saint Vincent de Paul – Long term care facility (SVP) were interviewed. Data was collected via individual semi-structured interviews, transcribed verbatim, and translated accordingly. Data was analysed through IPA.

The findings revealed that even though older adults move to an institution to safeguard their well-being or to accompany their loved ones, it may still adversely affect their sense of self and autonomy. Death and dying were mainly perceived as the inevitable outcome of life and as an opportunistic release from suffering and pain. Three modalities of suffering experiences namely, family and personal past experiences and room-mates experiences of suffering in dying did strongly affect how respondents reacted to care preferences in the EOL. Preferences and wishes for their EOL care were revealed, ranging from achieving a good and dignified death to ideas about how to terminate their life, in the face of suffering. Moreover, older adults valued autonomy differently regarding decision-making in their EOL and identified their preferred roles and that of other stakeholders in the decision-making process. In addition, their fear of losing autonomy in their EOL was emphasised, with respondents looking favourably towards the introduction of ACP as a tool to control and sustain a voice in their EOL.

Death is an inevitable part of life, but the major concern amongst older adults residing in SVP is not the eventuality of death itself but rather how they approach and embrace it. The perception and experience of death and dying are subjective and EOL discussions are the way to help allay the anxiety of loss of control in the EOL, where ACP could serve as the key to translating such preferences into advance care directives that help sustain autonomy.

Dedication

This work is dedicated to all the older people residing in long-term care and nursing homes and to the body of local research in geriatric care.

Acknowledgements

First and foremost, I would like to express my deepest gratitude to both of my academic supervisors, Dr Joseph Dimech and Dr Christian Borg Xuereb, for their continuous courage, guidance, and support throughout this journey.

My sincere thanks go to all the stakeholders who contributed to the success of this study, especially to the gatekeepers for their time, dedication, and commitment.

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List of Abbreviations

ACP: Advance Care Planning

AD: Advance Directives

BIHR: British Institute of Human Rights

BMA: British Medical Association

CDE: Consensus Document Endcare

ECPR: European Charter of Patient’s Rights

EOL: End-of-life

GMC: General Medical Council

GSF-PIG: Gold Standard Framework – Prognostic Identification Guidance

HRA: Human Rights Act

IAHPC: International Association of Hospice and Palliative Care

LP: Locke & Parfit

LTC: Long-term care

LST: Life-sustaining treatments

NICE: National Institute of Care Excellence

NSO: National Statistics Office

NSPAA: National Strategic Policy for Active Ageing

POA: Power of attorney

SDM: Shared decision-making

SEA: Situated Embodied Agent

SEP: Stanford Encyclopaedia of Philosophy

SVP: Saint Vincent de Paul – Long-term care facility

WHO: World Health Organization

“Awareness of death clarifies our values. As a result, death can give meaning to life” (Koestenbaum, 1976, p. 72)

CHAPTER 1

INTRODUCTION

1.1 Background

The proportion of older people worldwide is constantly on the rise (WHO, 2021). This shift in demographics is affecting social and healthcare systems, particularly regarding the delivery of appropriate care to safeguard the well-being of older adults (Formosa & Scerri, 2020). This phenomenon of advanced ageing has led to a large percentage of older persons spending their last period of life away from home and living in an institution (Pivodic et al., 2015). In fact, studies have shown that over one-third of older adults aged 65+, die in such aged-care settings, marking a secular trend from dying at home to dying in an institution. This phenomenon suggests that the concept of death has been institutionalised, condoning long-term care facilities as a major site of death for older adults worldwide (Flo et al., 2016). At the same time, it is known that most of these aged-care facilities do not have palliative or end-of-life (EOL) policies to regulate care for the dying, resulting in the suboptimal delivery of EOL care (Sussman et al., 2020).

Older adults admitted to long-term care (LTC) suffer from a multitude of age-related comorbidities and chronic illnesses (Buurman et al., 2015) needing complex care. In addition, persons living in LTC do tend to suffer from a high prevalence of dementia which adversely affects the chances of not participating in the decision-making process pertaining to their current and future care (Winzelberg et al., 2005). Furthermore, older persons living in an institution do tend to suffer from negative psychological implications, as the new symbolic connections created with their new living environment could be perceived as a threat to their sense of self and personhood (Peace et al., 2005). Moreover, entry to LTC can be regarded as an admission to a ‘total institution’ (Goffman, 1961), in which a person’s autonomy, self-determination and freedom of action are often threatened, which might affect their mood and self-esteem through the lack of control on their own life (Ames, 1991).

In Malta, EOL discussions in the form of Advance Care Planning (ACP) and Advance Directives (AD) are not as yet the norm (Dimech et al., 2020), so human dignity in the EOL is threatened as the values, beliefs, feelings, interests, biography and preferences of care of older adults who lose decisional capacity tend to remain unknown. Having no legal framework to sustain the initiation of EOL discussions (Cassar, 2000), healthcare professionals have no guidance nor legal backup to promote a palliative approach, leaving a healthcare system that remains highly influenced by aggressive care strategies in the dying phase of life (Consensus Document EndCare (CDE), 2018). This dilemma translates into a complex decisional burden on healthcare professionals and relatives, where the latter have been proven to incorrectly predict their loved one’s EOL preferences in one-third of the cases (Shalowitz et al., 2006), leading to possible conflicts with healthcare professionals as to which care strategy to adopt (Winzelberg et al., 2005). Furthermore, in delivering care at EOL, the shift from life-sustaining treatment to comfort care is even more emotionally and clinically challenging, as both relatives and healthcare professionals, without the introduction of ACP, do not have any guidance on how to deliver care according to the older adult's values and preferences (Weissman, 2004). Moreover, since survival estimation is unpredictable in dementia, this renders the timing and initiation of such EOL discussion even more important to safeguard the human rights and dignity of this vulnerable cohort of older adults, particularly in LTC (Flo et al., 2016). As a result, the timely implementation of EOL discussions, in the form of ACP, has been proven to increase the quality of care (Bischoff et al., 2013), better satisfaction and respect for human dignity, whilst also resulting in less anxiety and stress for family members, as the patient's care preferences are known and more likely to be adhered to (Detering et al., 2010).

1.2 Motivation for the Chosen Subject

Throughout the decade of my experience, working as a senior staff nurse, in delivering and promoting care at SVP, I bore witness to countless instances where decisions at the end-of-life of the patients in care had to be taken without timely preparation and adequate consideration of their wishes, values, beliefs, feelings and biography. Apart from the conflicts that arose between the attending healthcare team and the family members, a recurrent question that haunted me in such instances was, 'What would the patient have wanted?' Given the lack of opportunities in the current healthcare system, I began to feel the need to attempt to give a voice to the older adults under our care, in an attempt to shed light on the thought processes that might affect their decision-making participation, with the intention to empower them to make informed choices and take control over their life till the end.

Despite these lacunae in care at the last phase of life, literature has shown that there is still a general willingness within the older population to be included in the decision-making process at EOL (Laakkonen et al., 2005). Older adults, compared to caring physicians, tend to view EOL through a different perspective giving a broader psychological and spiritual meaning to dying based on their lifetime experience. To this end, EOL discussions would act as a soul-searching activity allowing them to plan their own death based on a reflection of past events (Steinheiser et al., 2000). Through these discussions, older adults give documented significance and meaning to their past experiences, allowing them to cope with present and future care choices, according to their chosen preferences and values, thus sustaining autonomy once decision-making capabilities are lost (Chang & Pang, 2010).

Therefore, acquiring knowledge and a better understanding of older adults' views and perspectives about death and dying in their end-of-life phase are key considerations in institutions to enable appropriate person-centred care in this delicate phase of their life (Tjernberg & Bokberg, 2020). In addition, healthcare professionals, informal carers and family members also play a crucial role in shaping the EOL experience of the older adult and studies have shown that what matters at EOL could be diverse and subjective (Steinhauser et al., 2000).

Patient vulnerability, resulting from the inability to sustain their autonomy in EOL decision-making, is a significant lacuna in the current healthcare system. Many believe this ought to be addressed to better respect older adults' human dignity at this stage of life (CDE, 2018). In addition, ACP is known to help provide timely preparation for EOL and a good death, avoidance of futile prolongation of life, strengthening of social and personal relationships, relieving the decisional burden off family members, and providing peace of mind that future wishes are communicated and documented (Singer et al., 1998). From the older adult's perspective, ACP helps to achieve 'quality' EOL care as it helps to sustain older adults in the centre of the decision-making process (Singer et al., 1999), by empowering the aged to have control over their health and providing them with informed care choices (Higginson et al., 2017).

Previous research concerning the views of older adults on death, dying and their EOL phase are limited (Hallberg, 2004), and this could be attributed to either the researchers protecting older adults from exposure to such a sensitive topic, or to a general disinterest of society on the last phase of life of these vulnerable people (Dimech et al., 2020; Ternestedt & Franklin, 2006; Tjernberg & Bokberg, 2020).

1.3 Aims of the Study

In view of the above assertions, this qualitative study aimed to explore the perceptions and experiences of older adults on their end-of-life, with a focus on the concept of death and dying whilst residing in Malta's largest LTC. Furthermore, this study also explored the patients' preferences and attitudes towards decision-making at EOL, including various factors such as their willingness to participate in EOL discussions as well as social and spiritual factors that might affect their decision-making. This study also aimed to unravel their preferences for their chosen substitute decision-maker if and when they lose decisional capacity in future life-threatening events. Given the benefit known to be gained through patient participation in their EOL care, the concept of ACP was introduced. Subsequently, the study participants' willingness to be involved as well as factors leading to the uptake of such tool, were also explored.

This study helped to enable older adults living in an institution to voice their thoughts, values and preferences on their EOL, including all the associated concepts in a current healthcare delivery system where such opportunities are lacking. This helped to unearth the various medico-social and ethical dilemmas associated with EOL care from the residents' perspective.

1.4 Research Questions

This study aims to answer the following research questions;

‘What are the perceptions and experiences of institutionalised older adults on death and dying?’

‘What are the preferences for care in their EOL in view of their perception of death?

1.5 Methodology and Research Design

In view of the above research questions, a qualitative research design was employed, as it was deemed the most appropriate approach to achieving the aims of the study. This allowed the collection of rich and in-depth data from every subject, in exploring their world and experiences, and what meanings they attach to them accordingly (Denzel & Lincoln, 2005). An interpretative phenomenological analysis (IPA) was chosen as the methodological framework. This made sense given that, it involved the phenomenological requirement to understand and ‘give voice’ to the concerns derived from the participant’s shared lived experiences whilst also fulfilling the interpretative requirement of ‘making sense’ and contextualizing such claims (Smith, 1996). Logically, this was the most suitable approach as it is idiographic in nature, thus it allowed the exploration of the phenomenon under study at an individual level (Larkin et al., 2006).

1.6 Research Outline

This research dissertation was divided into 6 chapters, commencing with the introduction chapter, in which background information about the chosen subject and the main aims and objectives of the study are presented. Moreover, a brief explanation of the methodological framework and research outline was provided to assist the reader with the direction of the study.

The second chapter, the literature review, focused on an in-depth collection of relevant literature on the end-of-life phase whilst residing in an institution and the plethora of factors that might affect the decision-making capabilities of adults in this phase of life. Furthermore, the provision of long-term care in Malta, ethical and moral principles as well as the concepts of Advance Care Planning and Advance Directives were discussed in light of their need for and the importance of the scope of this research study.

The third chapter, methodology, focused on the methodological approach adopted in this study to attempt to answer the research questions imposed. This chapter elaborates on the research design used, sampling of research participants, instrumentation, data collection process, data analysis framework, ethical issues and the limitations and strengths associated with this study.

The fourth chapter presents the findings gathered from the data collection, through the data analysis framework employed within the IPA approach.

The fifth chapter involved a thorough discussion on the summary of findings produced by this study, where they are explained and interpreted in light of the issues identified in the literature review. Coherence and differences to the current literature available will be also discussed in detail whilst also acknowledging the strength of my findings amidst the gap in the current local scenario.

The sixth and final chapter provided a conclusion for this study, direction for further research, as well as recommendations for policy change, improved practice and education, based on the implications of this study.

CHAPTER 2

LITERATURE REVIEW

2.1 Chapter Introduction

In this chapter, an overview of the literature is provided on various topics relevant to the nature of the study. This review is divided into five sections, initially focused on the current local ageing and LTC situation followed by several key concepts related to EOL, the personal meaning encompassing death and a framework highlighting several aspects towards attaining a good death. Subsequently, a review of the literature is provided on the ethical principles underpinning EOL care and the human rights that ought to be respected in caring for persons in this stage of life. In addition, insight is also provided on various aspects of decision-making, highlighting the centrality of the person in care, followed by the final section, focused on anticipatory care options available, deemed to be essential in providing quality EOL care.

The databases used to gather the relevant literature to the nature of the study were HyDi, Google Scholar, PubMed, and Web of Science. The following keywords and phrases were used in various sequences and combinations to extract the most relevant literature available:

- Institutionalised *AND/OR* ‘living in an institution’ *OR* ‘residing in a long-term care facility’ *OR* ‘LTC’ *AND*
- ‘Older people’ *AND/OR* ‘older adult*’ *AND/OR* elderly *AND/OR* ‘elderly patient*’ *OR* aged *AND*
- Experiences OR ‘lived experience*’ *AND/OR* perceptions *OR* views *OR* ‘point of view*’ of death *OR* ‘death and dying’ *OR* ‘end of life’ *OR* ‘EOL’ *AND*
- Attitude* *AND/OR* preference* *AND/OR* control on ‘decision-making’ *AND/OR* control *AND*
- ‘Advance care planning’ *OR* ‘ACP’ *OR* ‘anticipatory care*’

In addition, literature was also extracted from reference list checking of the most relevant articles and from the various documents and articles that were provided directly by the academic supervisors.

2.2 Malta and Long-Term Care Provision

The Maltese archipelago, situated at the heart of the Mediterranean Sea, boasts of a geographical area of 316 km^2 (Zammit, 1986). Hosting a total number of 5 islands, the islands of Malta and Gozo, are deemed to be the main inhabit0ed islands, with an overall estimated total population of 516,000 (National Statistics Office (NSO), 2021), resulting in having the highest population density amongst all the states in the European Union (NSO, 2019). Interestingly to note, the 65+ age group makes up 18.9% of the total population, of these, 3,207 individuals, 2,223 females and 984 males are aged 90 years and over (NSO, 2021). Further to this, Formosa & Scerri (2020) added that demographic projections reveal that Malta will be one of the fastest ageing states in the EU.

Formosa (2016) remarked that religiosity is a dominant social force in the local context, having 98% of the Maltese population baptised in the Roman Catholic religion (Discern, 2006). In addition, other deeply embedded cultural values include family norms and traditions, which Abela (2005) stated that following Malta's admission to the European Union "are giving away to individualized values of self-determination and personal autonomy" (p. 12).

2.2.1 Ageing in Malta

In the face of this accelerated ageing population, Formosa & Scerri (2020) remarked that such a demographic shift may lead to concerns regarding the well-being of older adults. To this end, several policy initiatives were launched to enhance the well-being of older adults both in the community and in long-term care settings. With the premise of transforming Malta into an age-friendly nation and maintaining autonomy and independence till the latter stages of life, the National Strategic Policy for Active Ageing (NSPAA) (2014-2020) was launched, based on the following three pillars: 'Active Participation in the Labour Market', 'Participation in Society' and 'Independent Living'. Stemming from the last pillar, the policy document suggested recommendations of relevance to the context of this study, namely:

- "Maximizing autonomy in LTC;
- Raising awareness of elderly abuse and neglect;
- Investing further in EOL care." (p. 22)

With reference to 'Maximizing autonomy in LTC' and 'Investing further in EOL care', the policy document provided further recommendations for action, including promotion of autonomy, legislation favouring advance directives and enhancing EOL care strategies in long-term care (NSPAA, 2014, pp. 74, 79). Moreover, the latest version of the NSPAA 2023-2030, (2022) emphasizes further the need to improve EOL care, based on initiatives that enhance EOL care education for health professionals working in LTC, the provision of psychological support to bereaving older adults and the expansion of the 'durable power of attorney' to extend its scope to health-related decisions, in older adults lacking decision-making capacity (p. 69).

Despite the above-mentioned NSPAA recommendations and initiatives, older adults still find themselves in a dire situation as to this day, there is no national policy guiding EOL care in Maltese institutions (Dimech et al., 2020) and no legal framework supporting the introduction of Advance Directives in Malta (Consensus Document Endcare, 2018).

An interesting fact is that the NSPAA (2014-2020) recommended the implementation of measurable minimum standards for LTC to improve the quality of care and safeguard the rights of older adults living in residential long-term facilities (p. 75). To this effect, in 2015, the Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing, released the National Minimum Standards for Care homes for the Elderly to regulate and enhance the quality of care received in care homes. The 38 standards released in this document highlight the principles of person-centred care, dignity, privacy, physical and mental well-being, self-fulfilment, autonomy, empowerment, right to complain, legal recourse and active ageing. Yet, the largest LTC in Malta, SVP, was excluded, due to being labelled as a “suis generis” facility (p. 55).

Additionally, addressing the lacunae in EOL care, the Erasmus+ project of the Bioethics Research Programme of the Medical School on ‘Harmonisation of end-of-life care (EndCare)’, released a set of guidelines, referred to as the Consensus Document EndCare (CDE) (2018). These guidelines were aimed to guide healthcare professionals, in exercising their duty towards individuals in their EOL phase, given the multitude of complexities and dilemmas inherent to this delicate stage. These guidelines were released to serve as a steppingstone for the Medical Council, to endorse and lead to the enactment of the law in this regard. Alas, to date, the Maltese Medical Council has not yet endorsed such a consensus document (Mallia, 2021).

2.2.2 Long-term Care in Malta

LTC refers to “a broad range of residential services designed to assist vulnerable persons over prolonged periods, ranging from the physically impaired to the cognitively challenged to those facing impending death and looking for service in hospice-type care” (Borg Xuereb, 2015, p. 305). Governmental-run and owned LTC facilities can be split into two different categories. On one hand, there are nine residential care homes, which are intended mainly to offer various levels of care and sheltered accommodation to older adults who may still maintain a degree of physical independence. On the other hand, there is SVP (Borg Xuereb, 2015), which was chosen as the facility where this research project was conducted.

SVP covers an area of 27 acres and is undoubtedly the largest LTC facility in Malta (Formosa, 2016). It is unique in its nature, as it is seen as a “hybrid” between a hospital and a nursing home (Parliamentary Secretariat for Rights of Persons with Disability and Active Ageing, 2021). Its main remit is to provide a comprehensive 24-hour holistic approach to care, whilst providing medical, nursing, and social care services, allowing service users to maintain and develop their maximal independence, dignity and choice to enhance the optimisation of the quality of life (Borg Xuereb, 2015; Formosa, 2016). As of the 17th of May 2023, the total number of beds was 1393, of which, 1323 were currently occupied, hosting 442 males and 881 females (Medical Records SVP, personal communication, May 17, 2023).

Admissions to SVP, have been recently restricted to highly dependent patients with a Barthel Score of 0-4, persons needing complex long-term nursing and medical care and for cognitively impaired persons, or exhibiting signs of severe challenging behaviour related to dementia, with an MMSE score of 0-4 (*Admission Criteria SVP*, 2018). All the above criteria are indicative of general frailty, which according to The Gold Standards Framework – Proactive Identification Guidance (GSF-PIG) (2022), persons admitted under such conditions, are likely to die within the next twelve months, and therefore would highly benefit from person-centred EOL care.

A whole population assessment (n= 1275) carried out by the Superintendent's Office in 2022, utilizing a modified version of the Crichton Scale (*SVP Dependency Evaluation*, 2022), to assess the dependency and lucidity levels of the residents showed that 60% of the total population at SVP were severely dependent or worse and 61% of the total population were moderately confused or worse (see *Figures 1 & 2)*.

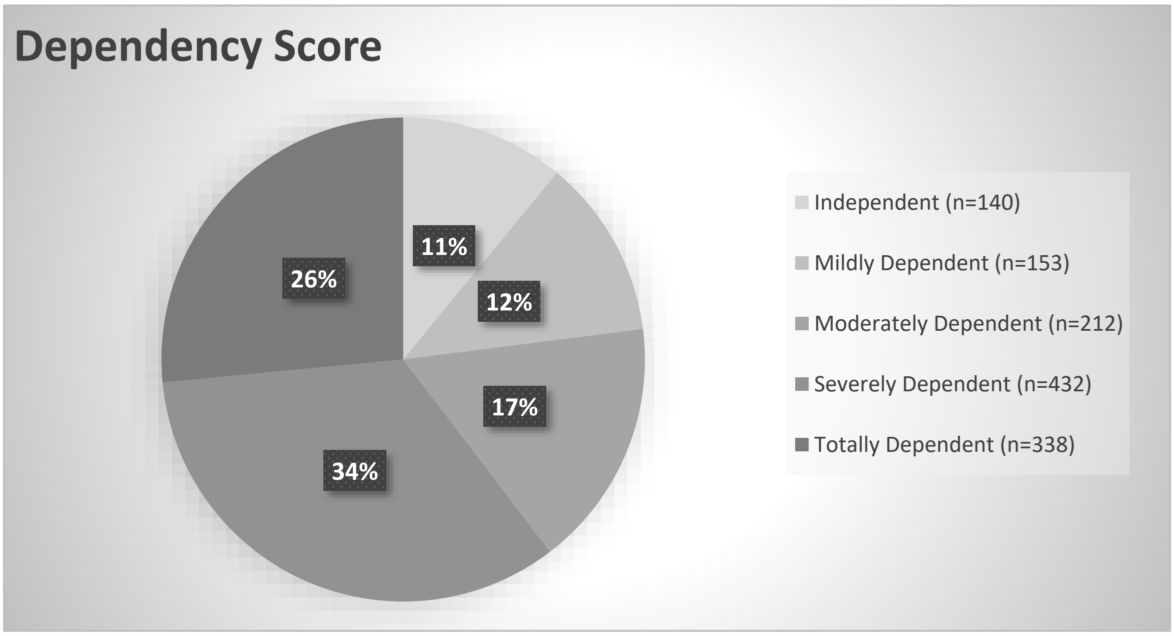

Figure 1 – Total SVP population dependency scores (SVP Dependency Evaluation, 2022)

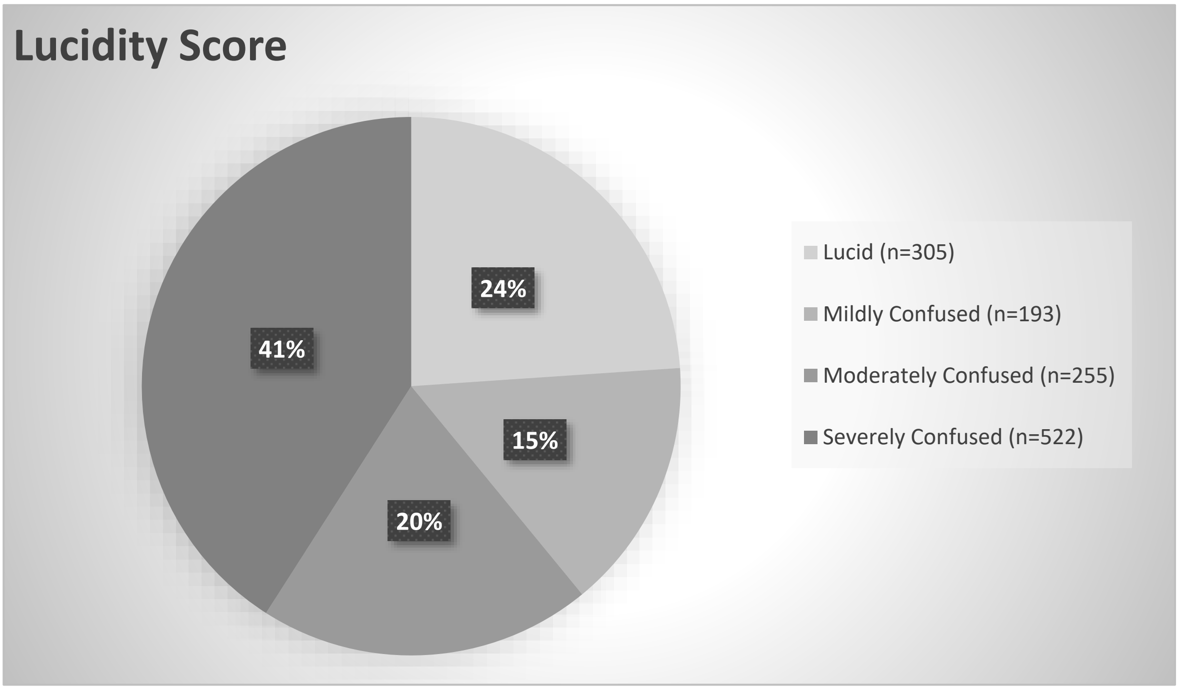

Figure 2 – Total SVP population lucidity scores (SVP Dependency Evaluation, 2022)

SVP currently consists of 48 wards, with certain wards catering for a variety of care needs such as three couple’s wards, one Covid-19 specialized ward and nine specific wards for the cognitively challenged. Other patient-related services are located on site such as the Geriatric Day Hospital and the Dementia Day Centre, which also provide a myriad of services both to in-patients and to out-patients on an appointment basis. Most of the general non-specific wards host an average of 32 patients each, mainly segregated into 4-bedded rooms. These wards can be either gender exclusive or mixed.

Each room in the general non-specific wards can be seen as a unique biological ecosystem as it can host residents with a myriad of needs and dependencies which can result in hosting independent walking residents with minimal care needed to bed-bound patients in need of complex medical and nursing care, all within the same four walls of the same room. Having cognitively intact residents residing with those who are not, may adversely affect the former (Tjernberg & Bokberg, 2020), as the higher percentage of time invested in caring for the complex needs of frail patients might have been invested in conversations about their existence and EOL, which could enhance their quality of life in an institution.

Moreover, de Medeiros et al (2020) stated that even though institutionalization might have a positive impact on the physical and psychological domains of various residents, it is strongly associated with a negative impact on the quality of life of the residents. This is seen to be associated with a reduced level of social engagement both with family and friends, once residing in a new living environment, which is commonly manifested in loneliness, possibly together with physical and/or cognitive decline (Naik & Ueland, 2020). It is further noted that even though such environments foster a community-like environment where building relationships is possible, residents are still noted to experience subjective feelings of loneliness (Morlett-Paredes et al. 2019). In addition, Olsen et al (2016) also stated that institutionalized people with dementia showed lower levels of quality of life when compared to home-dwelling people with dementia, as they experience less social contact with familiar people, lower levels of activity and a higher use of psychotropic medication. Subsequently, the introduction of palliative care interventions in institutions has been seen to result in a reduction in quality of life decline amongst residents due to the importance given to social participation and autonomy (Bokberg et al, 2019).

Aiming to help regulate the nursing care of dying patients, the nursing department at SVP (June, 2018), issued a standard operative procedure (SOP), titled *'Caring for Dying, Deceased Residents and their Relatives'*. This SOP focused on promoting various patient rights till death, namely "privacy, respect and dignity", where the best interests of the patients are safeguarded, and quality personalised care should be delivered accordingly to such interests.

Additionally, at the time of writing this dissertation, the only medical guideline document available at SVP on EOL care was 'The IAHPC Manual of Palliative Care (2013, 3rd ed.)', regarding which Lipman (2013) revealed that such manual should not be utilised as a reference or actual guide to care, especially before proper adaptation is performed in accordance with the local health care scenario.

Whilst Formosa (2016) remarked that over time major measures were taken to safeguard the human rights and dignity of institutionalized patients, Scolaro (2016) revealed that older adults at SVP were still vulnerable to a loss of dignity given their multiple co-morbidities and caring staff perceptions.

To this end, Formosa suggested that there is a need to develop policies to safeguard the human rights of persons needing LTC, particularly based on the rights for human dignity, self-determination, privacy, quality tailored care and the right to freedom of expression. Formosa added that such care orientation would help to empower older adults to live and receive care according to their beliefs, values, and preferences in these living milieus. Furthermore, he added that policies supporting a palliative care approach in the delivery of person-centred care in LTC should also be developed, to support older adults to maintain control over their lives, till the end, thus achieving a dignified death.

2.3 End of life and the Dying Experience

2.3.1 End of Life, defined

Research reveals that there are different meanings associated with the definition of the concept of EOL. These include the medical and legal perspective, disease prognostication with irreversible decline and life expectancy in terms of months or less, as well as a definition of the indicators of the onset of the EOL (Hui et al, 2014). Lamont (2005) remarked that the onset of this delicate period is rather challenging to recognize, yet he acknowledged an additional aspect in his working definition, namely, medical futility. On the other hand, Schüklenk et al. (2011) suggested that the EOL phase can be taken as a "continuum of events", commencing with the diagnosis of one or more serious diseases or injury, with an unpredictable illness trajectory period, eventually leading to death.

From a medical perspective, Lamont (2005, p. S-13) defined the EOL as "the period preceding an individual's natural death from a process that is unlikely to be arrested by medical care". Furthermore, the GSF-PIG (2022) utilized the United Kingdom's General Medical Council's (GMC) definition of EOL, which states that "people are approaching the EOL when they are likely to die within the next 12 months".

To this end, given the purpose of this study and the lack of uniformity in a standard definition, the working definition extracted from the CDE (2018) will be adhered to, where the concept of EOL is understood in the context of proximity to death, and defined "to mean a spectrum of recognition that death will be imminent within one year up to the point where death is imminent within a few days or a few hours (p. 11)."

The intersection between EOL and LTC has gained importance over the last decade, as research showed a secular trend away from dying at their preferred place of death, which is their domiciliary home, to favour dying in an institution (Dasch et al., 2015). Statistical evidence further revealed that 50-80% of deaths in Europe are experienced in institutional stays and LTC settings. Taking as an example Norway, half of the population dies in LTC facilities (Flo et al. 2016). What is interesting to point out is that many of such deaths occur within the first year of relocating into such living milieus (Froggatt & Payne, 2006; Van Den Block et al. 2007). In fact, Menec et al. (2009) indicated that 70% of all residents living in LTC die within months or years of residency, as a result of their multiple age-related co-morbidities and disabilities (Buurman et al. 2016).

Local mortality data further corroborate these statistics. In 2017, at SVP, out of a total of 361 admissions, 31% (n=113) passed away within 6 months of admission and a total of 45% (n=161) passed away within one year of admission (Dimech, 2017), clearly indicating that admission to a LTC facility is closely related to the EOL phase. This suggests that the concept of death, apart from being medicalised (CDE, 2018), is also institutionalised (Flo et al., 2016).

This high mortality rate in LTC creates a complex challenge in care provision as care staff are expected to deliver quality restorative care alongside quality EOL care (Sussman et al., 2017). In addition, LTC facilities in Malta are further challenged, as of yet, there is no national policy guiding EOL care (Dimech et al., 2020) and the current healthcare system is still "geared towards cure" (CDE, 2018, p. 13).

To this end, given the complexities inherent to LTC, various international professional bodies have advocated for the integration of a palliative care approach in such environments, as most residents are living with multiple co-morbidities and disabilities for which there is no cure and where death is a common occurrence (WHO, 2011; National Gold Standards Framework, 2012).

Palliative care has been defined as:

> "… an approach that improves quality of life 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 care:
>
> - affirms life and regards dying as a normal process;
> - intends neither to hasten nor to postpone death, and;
> - uses a team approach to address the needs of patients and their families, including bereavement counselling if indicated…" (WHO, 2011, p. 6)

Froggatt (2001) pointed out that the palliative approach is traditionally aimed at cancer patients but given that LTC milieus are increasing in significance given the elderly mortality rates, they present a unique opportunity for the provision of palliative care. In fact, older adults' perception of good EOL care goes in line with the aforementioned principles of palliative care (Singer et al., 1999), as they also, like the young, emphasize the importance of pain and symptom management, the achievement of a sense of completion, preparation for death, having their preferences for the EOL respected, being treated as a 'whole person', and coming to peace with God (Steinhauser et al., 2000).

2.3.2 Personal Meaning at EOL

The thought processes employed by older adults in their EOL can be understood through the concept of life review introduced by Butler (1963), where he stated that such a concept is a natural process, where all individuals approaching the end of their lives, recall, evaluate and analyse past events in view of achieving a much more profound self-concept. Moreover, the roots of this concept are derived from Erikson's (1997) life cycle developmental theory, whose eighth stage, 'integrity vs despair', explains that older adults must come to terms with their past experiences, in which, once such psychosocial crises are resolved, wisdom will ensue. Erikson explained this as being "a kind of informed and detached concern with life itself in the face of death itself" (p. 61), leaning towards a positive and meaningful outlook, in view of their impending death (Ternestedt & Franklin, 2006).

Furthermore, with the addition of the ninth stage of development in the life cycle, Erikson (1997) noted various challenges, such as loss of autonomy, loss of self-esteem, reduced hope, and trust. As a consequence, of this final stage of life, Erikson promoted the concept of gerotranscendence (Tornstam, 1997), which means the changes in perception leading to a feeling of spiritual connectedness with the universe, the finiteness of life, narrowing of personal space and the philosophical view of death as "the way of all living things" (p. 124). In relation to such a concept, Peck (1968) further expanded on Erikson's eighth stage, concerning the achievement of integrity, into three distinct tasks, with the last task being referred to as ego transcendence. Martin et al. (2015) define ego transcendence as the 'positive anticipation of death through legacy building based on a generative life (p. 17)', which is explained by Peck (1968) as the ability to cope with life's challenges constructively and positively, possibly leading to a positive outlook on the eventuality of death, based on the recollections of past lived experiences.

Therefore, given the above assertions, Hallberg (2003) suggested that death and dying should be understood from an insider's perspective, to clearly understand the subjectivity of the experience and to clearly understand what it means to achieve a good death.

To clearly understand this participant's view of death, one must first understand the meaning of suffering, since such a concept is often present in the dying process (Cassel, 1982). Suffering is defined as "a specific state of distress that occurs when the intactness or integrity of the person is threatened or disrupted (p. 531)" which is not only concerned with the physical dimension, but also related to psychological, existential, and social dimensions of the person (Cassel, 1982,1991). These dimensions relate to several aspects of personhood; the body, the lived past, the family's lived past, relationships, roles, the perceived future, culture and society, which according to Cassel, they are all susceptible to damage and loss, which may result as an insult to one's personhood. Kitwood (1997, p. 8) defined personhood as being "a standing or status bestowed upon one human being by others in the context of particular social relationships and institutional arrangements. It implies recognition, respect, trust."

Moreover, unravelling the personal meaning is deemed vital, as it is a fundamental dimension of personhood, which must be taken into account to completely understand the complexities of human illness and suffering (Cassel, 1982).

Therefore, the meaning of death and how it is perceived, resulting from the thought processes of older adults, can be understood through the Three-Component Model of Death Acceptance (T-CMDA) adopted from the Death Attitude Profile – Revised (DAP-R) (Wong et al., 1994). This model is based on the final stage of the dying process, acceptance, compiled by Kubler-Ross (1969). In her final stage of the dying process, Kubler-Ross (1969) defined death acceptance broadly as being psychologically prepared for the prospect of one's demise, whilst Klug & Sinha (1987) added, 'and the acknowledgement of the positive emotional assimilation of the consequences' (p.230).

The first type of death acceptance is referred to as 'Neutral Acceptance', where death is perceived as the natural, inevitable outcome of life, and is accepted rationally as part of life (Armstrong 1987, Kubler-Ross, 1981). Such perception of death may be rooted in Maslow's (1968) theory of self-actualization, where the fulfilment of the basic needs in life results in the acceptance of death as a natural outcome and meaning is fuelled in the remaining days of life. According to the T-CMDA (1994), the second type of death acceptance is referred to as 'Escape Acceptance', where Wong et al. (1994) explain that such attitude is usually exhibited when the perception of living under certain painful conditions, is feared more than the eventuality of death itself, therefore death is welcomed based on a negative outlook on the remaining life. The third component of the T-CMDA (Wong et al., 1994), is referred to as 'Approach Acceptance', where individuals accept death as being the gateway to a happy afterlife (Dixon & Kinlaw, 1983), in which such perception might be prevalent in persons with higher religious or spiritual commitments in life.

2.3.3 The Dying Experience

Ternestedt & Franklin (2006) stated that a good or dignified death is achieved when the dying person is respected as being 'whole', highlighting the importance of respecting self-determination, symptom relief and the strengthening of personal and therapeutic relationships.

Munn et al. (2008) mentioned that LTC environments do affect the dying experience. Older people revealed that for them a good death is strongly related to the acceptance of the normality of dying and the inter-relationships experienced during the receipt of care. To this end, Emanuel & Emanuel (1998) developed a framework for a good death, which incorporated all the aforementioned characteristics of a good death, characterising the dying experience as multidimensional (see *Figure 3).*

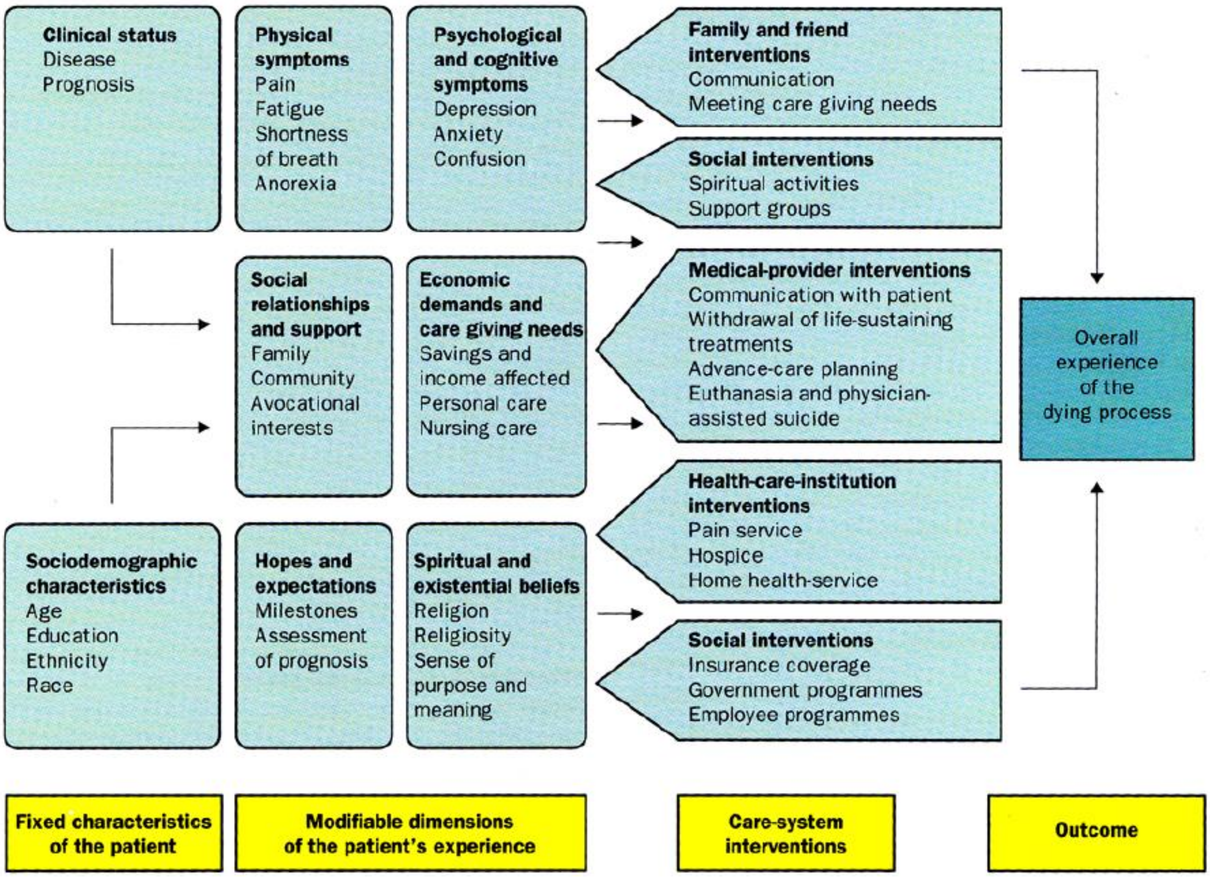

Figure 3 – Framework for a good death (Emanuel & Emanuel, 1998)

This framework aimed to improve the provision of care and the process of dying in three ways. Firstly, it emphasizes the modifiable dimensions of a good death, where the process of dying is evaluated beyond physical and psychological symptoms but is rather multifaceted to include the strength of social relationships, care giver needs, hopes and expectations and importantly, spiritual, and existential beliefs. Secondly, the dying process is not just merely seen as a medical experience, but it is also multifactorial, as it can be affected by the patients' social network, relationships with healthcare providers and the experience within the institutional setting. Thirdly, given the aim to improve the experience and care of dying patients, this framework outlines an efficient mechanism to implement and evaluate two elusive concepts, namely, the achievement of a good death and the diminution of suffering (Emanuel & Emanuel, 1998; Cassel, 1991).

It is also important to note that as part of the care-system interventions, the implementation of ACP is one of the components mentioned that improve the experience of the dying person, ultimately contributing to a good death (Emanuel & Emanuel, 1998).

In addition, Froggatt et al. (2017) explained that to successfully implement a palliative care approach within the LTC organisation itself (micro-level), as well as across the healthcare systems (meso-level), she suggested the use of tools and frameworks, to sustain wider macro-level initiatives in the form of legislation and policy directives, which are as yet to be introduced, locally.

The introduction of such medico-legal frameworks in Malta could help to promote the delivery of high-quality palliative care and provide the most suitable environment for older adults to truly achieve a dignified death.

2.4 Ethical Principles and Human Rights at End-of-Life

2.4.1 Ethical principles and the Related Philosophical Concepts

Ethics can be understood as the branch of knowledge that deals with moral principles concerned with the examination and understanding of moral life, which in turn govern everyone's social behaviour (Oxford Learner's Dictionary, 2022). Throughout the years, ethical principles have served as the foundation of contemporary medical ethics as they justify or defend moral rules and judgements. Beauchamp and Childress (2019) namely refer to respect for autonomy, non-maleficence, beneficence, and justice as being the four cardinal ethical principles in biomedical ethics.

In recent years, respect for autonomy has become the key concept of discussion, especially in the delivery of care in the last phase of life (Gómes-Vírseda et al, 2020). Autonomy is taken to be equivalent to "liberty, self-rule, self-determination, freedom of will and choice, dignity, integrity, individuality, responsibility" (Agich, 1994, p. 267). Likewise, autonomy is related "to actions, to beliefs, to reasons for action, to rules, to thoughts, to the will of other persons and to principles" (Dworkin, 1988, p. 6). Moreover, autonomy is understood to be based on the conditions of independence, competency, and authenticity (Burnor & Raley, 2018), further translated into ethical-legal standards, such as informed consent (Gómes-Vírseda et al, 2020).

These conceptions associated with autonomy relate to the philosophical concept of agency, where the agent is the person with the capacity to act, whilst 'agency' is understood as the manifestation of the action taken (Schlosser, 2019). This leads to the identification of human beings as "autonomous agents" (Beauchamp & Childress, 2019, p. 106). This line of reasoning has sparked major debates over the years in clearly defining what makes an individual a person, in view of the loss of agency associated with cognitive decline in dementia.

Hughes (2001), in an attempt to recapture the clinical reality of human experience, described two different views of the person with dementia, the Locke and Parfit (LP) view (Locke, 1998; Parfit, 1984) and the Situated Embodied Agent (SEA) view. The LP viewed the person in relation to their psychological state and connectedness, where a person is still deemed as being a person wherever there is a continuum of the conscious state, thus identity is maintained throughout. This view sustains the fact that if there is a loss of a person's memories, beliefs, and purpose, this leads to differences from the former self to the current self, and thus the concepts of personhood and identity are lost. In contrast, Hughes (2001) promoted the SEA view, where the person is not just regarded from the psychological continuity perspective, but rather as an embodied human agent in which they act and interact given the culture and the lived history they are situated in.

Yet, these theoretical definitions of autonomy do not clearly depict the reality that is experienced in LTC. Agich (2003) argued that the conjunction between autonomy and LTC can be viewed as a paradox, where theoretical definitions of autonomy must be scrutinised and re-defined given the context and culture individuals are residing in. Thus, the traditional view of autonomy is often seriously compromised by the reality lived in LTC, where individuals are dependent on the institution in the delivery of care and daily function whilst human agency is markedly challenged by the vulnerability and frailty of the individual (Agich, 2003). To this end, Agich (2003) remarked that this dependence shown by patients in care, should not be regarded as a threat to their autonomy, but rather as a component of human development and an essential characteristic that defines a human person as being an ‘integrated biopsychosocial entity’ (p. 103).

Apart from cognitive impairment that affects the individual’s ability to be autonomous, Agich (2003) also noted that LTC can also pose a threat to a person’s autonomy as it can be regarded as a ‘total institution’ (Goffman, 1961). Thus, practices in such social arrangements do tend to lead to the overall control and isolation over the individual’s life from the rest of society’s norms, resulting in adversely affecting their identity, control, dignity, mood and self-esteem (Ames, 1991; Osterlind et al, 2016)

To this end, Agich (2003, p. 99) proposed an alternate view of autonomy, defined as “actual autonomy”, where the characteristics of living in this social milieu are given importance, whilst allowing for the treatment of every individual as being a unique person, in the light of having identifiable rich past histories and experiences in an interdependent culturally mediated social world. This further relates to the concept of relational autonomy, where individualism is rejected, and emphasis is directed towards connectedness and interdependence. Thus, in this view, autonomous beings do not create relationships, but rather relationships create autonomous beings (Burnor & Raley, 2018). This model acknowledges the role of additional stakeholders in the decision-making process, where the influence of others is not regarded as paternalism, but rather as an extension of the autonomous being receiving care (Walter et al., 2013).

Subsequently, in EOL care, relational autonomy has been proposed as the foundational notion of palliative care, shared decision-making and the concept of ACP (Gómes-Vírseda et al, 2020).

Beneficence relates to the notion of doing good, preventing, and removing harm from others. About the aforementioned ethical principles, ethical and moral care ought not to be solely based on the respect for the autonomy of patients and the avoidance of harm, but also on the obligation to positively contribute to the patient’s well-being (Beauchamp and Childress, 2019). Akdeniz et al. (2021) stated that through the principle of beneficence at EOL, there is an obligation on the physician to ‘defend’ the most useful and beneficial intervention or treatment to any given person. In the delivery of optimal EOL care, beneficence and non-maleficence do play a crucial role, as through beneficence focus is directed on the relief of symptoms that may impair the quality of life of the dying patient, whilst, through non-maleficence, efforts are directed toward the relief of symptoms that may harm the dying patient (Elshamy, 2017).

Non-maleficence relates to the obligation to not cause harm to others, which in principle supports several moral rules which can be translated into the delivery of EOL care, including the avoidance of the causation of pain and suffering (Beauchamp & Childress, 2019). In relation to beneficence, this principle is invoked in the delivery of care when a balance needs to be struck between the benefits and the risks or burdens of any specific course of action taken on behalf of the patient (Finlay, 2019). The principle of non-maleficence is debated in instances where decisions must be taken in withholding or withdrawing treatments, especially in patients in their EOL where the prognosis might be bleak. Dilemmas arise when treatment decisions must be taken on behalf of the patient, as withdrawing futile treatment could be seen as an act of mercy concerning the diminution of suffering and with respect to the patient's dignity. On the other hand, withdrawing treatment, such as mechanical ventilation, even though performed on behalf of the patient's best interest, may be perceived as a precipitating factor in the patient's eventual death (Beauchamp & Childress, 2019).

The principle of justice refers to the fair and equitable distribution of healthcare resources in view of what is justly owed or due to individuals. This principle asserts the fact that "persons in whichever respects are deemed relevant should be treated equally." (Beauchamp and Childress, 2019, p. 251)

2.4.2 Human Rights and EOL

Rights serve as a defence mechanism against "oppression, unequal treatment, intolerance, arbitrary invasion of privacy, and the like" and they can be defined as "justified claims to something that individuals or groups can legitimately assert against other individuals or groups". Therefore, a right determines the choices of individuals in choosing what is morally acceptable or not. (Beauchamp & Childress 2019, pp. 367-368).

In EOL care, human rights are at the epicentre of law, policy, and practice, in which they support healthcare providers in the delivery of appropriate person-centred care. All human rights treaties are underpinned by the FREDA principles (Fairness, Respect, Equality, Dignity and Autonomy) (Belchamber, 2017) which further highlights the importance of beneficence and autonomy in view of safeguarding the well-being of the persons in care. In the United Kingdom, the Human Rights Act (HRA), is the law governing the protection of human rights and it has derived its 16 rights from the European Convention on Human Rights. From this list, the British Institute of Human Rights (BIHR) has emphasized the importance of 6 key rights (also known as Articles) relevant to the field of EOL in view of safeguarding respect and dignity in the last stage of life. Therefore, under this law, persons in their EOL have the:

- Right to Life (Article 2)
- Right not to be tortured or treated in an inhuman or degrading way (Article 3)
- Right to Liberty (Article 5)
- Right to respect for private and family life, home, and correspondence (Article 8)
- Right to freedom of thought, conscience, and religion (Article 9)
- Right not to be discriminated against any of the human rights listed here (Article 14)

Moreover, the European Charter of Patient's Rights (ECPR, 2002), mainly based on Article 35 in the National Institute for Health and Care Excellence (NICE) Charter of Fundamental Rights proclaims in favour to guarantee a "high level of human health protection". These 14 patient rights, serve to guide national health services providers to deliver the best possible quality of care. To this end, the following rights are deemed to be the most relevant to adhere to, when caring for patients, especially in their EOL:

- Right to Access
- Right to Information
- Right to Consent
- Right of Free Choice
- Right to Safety
- Right to Avoid Unnecessary Suffering and Pain
- Right to Personalized Treatment

Further to this, the Maltese National Patient's Charter (2016) was launched based on the founding principles of the aforementioned treaties. This highlights the importance given in Malta to participation, informed consent, and the quest to safeguard human dignity and the fundamental rights of patients receiving care.

For patients lacking mental capacity, the British Medical Association (BMA) has enacted several rights for patients receiving treatment, mainly founded on the fundamental principles of autonomy and informed consent, further showcasing the importance of dignity, liberty, patient autonomy and the inclusion of relatives as part of the shared-decision process (BMA, 2019). Beauchamp and Childress (2019) added that in the case of mental incapacity, health professionals and proxy decision-makers have the right to respect and exercise the patient's rights to claim, apprehend and exercise such fundamental rights without discrimination.

Disregarding such foundational rights in the delivery of care could be regarded as a ‘violation’ or ‘infringement’ of human rights (Beauchamp and Childress, 2019), leading to the suboptimal delivery of care, especially in relation to vulnerable older adults at EOL, leading to a further loss of dignity and autonomy at such a delicate stage of life.

2.5 Decision-making at EOL

Decision-making has been around since the beginning of days, dating back to Greek mythology, where they highlighted such concept as one of their key themes (Emanuel & Scandrett, 2010). Moreover, throughout evolution, the successful execution of decision-making by individuals must have been quite developed, as decisions were strongly related to their immediate and long-term survival (Emanuel & Scandrett, 2010). Interestingly, they further noted that human ability for decision-making is derived from "multiple levels of consciousness: intuitive, driven by subconscious processes; gut level, driven by adrenal hormones; cognitive and uniquely rational; and cognitive but socially influenced in complex ways. (p. 1)"

Waldrop et al. (2015) conceptualised decision-making, not as a stand-alone one-time event, but rather as a dynamic process which occurs over time. It is further understood as a collaborative process of exercising the right to choose out of the availability of a selection of options whilst being able to evaluate the pros and cons of every available option (Braun et al., 2009).

2.5.1 The Anatomy of Decisions

Emanuel & Scarlett (2010) emphasized the complexity of decision-making, especially in the delivery of care at EOL. Firstly, decisions are changeable as people seem to change their minds. This happens, both in the face of prognostic uncertainty and also amidst a wider range of medical treatments available at EOL. Secondly, decisions are malleable, thus susceptible to the influence or coercion of others, and thirdly, several important care decisions are required at a time when the decision-making capacity of the patient is either hampered, marginal or lost. The problems created by loss in decisional capacity, render the timing of such decisions to be crucial, to give voice to the patient to participate and elicit one's values, beliefs and preferences for their immediate and future care.

The malleability of decisions can be understood through the different physician-patient models that have been utilised as approaches in medical decision-making over time. Emanuel & Emanuel (1992) stated that there are 4 different physician-patient models, namely paternalistic, informative, interpretive, and deliberative. In the paternalistic approach, the physician takes full responsibility and authority of clinical decision-making, wherein the tension between the patient's autonomous choice and his/her well-being, precedence is given to the latter. On the other hand, the informative model adopts a different approach, where the values of the patients are known, whilst the physicians act solely as technical experts in providing all the known facts and truthful information for the patients to make their own choice. Thus, in this model, we see a shift of power from the physician to the patient, where autonomy is highlighted through the patient's control over decisions related to their health.

2.5.2 Shared Decision-making

Allen et al. (2012) noted that whilst health service providers have an ethical and legal obligation to include patients in their own medical decisions, Winzelberg et al. (2005) stated that emphasizing solely on patient autonomy, has only served a small fraction of patients in their EOL phase. Winzelberg et al. (2005) suggested that a balance ought to be reached as a standard between the patients' and families' sense of autonomy and the physician's control over medical treatment options.

These notions have led to the process of 'shared decision-making' (SDM), which is defined as "an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences" (Elwyn et al., 2012, p. 1361). In this process, both the patient and healthcare provider ought to acknowledge that equipoise exists, where the perspective of the patient in being responsible to articulate one's goals, values and preferences about their health are incorporated with the perception of the clinician, responsible to narrow down the treatment and diagnostic options, to those that are medically appropriate and reasonable (Allen et al., 2012; Elwyn et al., 2012).

In ensuring that the patient's values, goals and preferences guide clinical decisions, SDM endorses the notion of patient-centred care as one of the guiding principles (Allen et al, 2012), whilst the balance between powers is achieved by supporting autonomy with the build-up of good relationships, where both individual competence and interdependence on others are respected. This approach relates to the key concepts of relational autonomy and self-determination (Elwyn et al., 2012).

The SDM model, involves a preparatory phase of interaction between all the relevant stakeholders in the decision-making process, having the patient at the centre of the whole process. During this phase, decision-making authority or designation is assigned according to the patient's attitude and preferences, this is the mainstay in the formulation of Advance Directives and/or identification of designated proxy/surrogate decision makers, which are particularly relevant in EOL decision-making.

In facing a terminal illness, Hughes and Baldwin (2006) emphasized the need that the patient is to be informed of their diagnosis, prognostic trajectory and all the treatment options available before decisions are to be taken, in the quest to achieve a quality death that respects the patient's dignity.

Frank (2009) pointed out that several negative factors might affect the decision-making authority of the patients, in taking control of their own decisions. These include denial and non-acceptance of current health status, poor coping mechanisms and sense of well-being and feelings of insecurity and unpreparedness. This fact raises a question regarding the desired level of control and to what extent certain patients value their autonomy at EOL.

2.5.3 Decision-making Roles and the Value of Autonomy

Winzelberg et al. (2005) stated that patients express heterogeneous attitudes towards the value of autonomy as a decision-making priority, thus qualifying elderly patients in their EOL to be characterized as either "activists" or "delegators" (p. 1047). These two distinct categories were further explained by Braun et al. (2014), with sub-categories of these two different attitudes towards decision-making at EOL, being identified as highlighted in *Table 1*.

Decision-making role	Sub-category
Activists	- *'Autonomists'*, where the individuals take full responsibility of their own choices. - *'Altruists'*, where decisions were taken by the individual, not to transfer the decisional burden to the other stakeholders.
Delegators	- *'Authorizers'*, where authority is transferred by explicit authorization. - *'Absolute Trusters'*, where authority is transferred implicitly. - *'Avoiders'*, where the individual accepts the decision of the surrogates by default (p. 337).

Table 1- Decision-making roles at the EOL (Braun et al. 2014)

With the approach to the EOL, Winzelberg et al. (2005) highlighted that patients may show conflicting goals as they might avoid transferring the decisional burden to their loved ones to relieve the extra stress in such an emotionally fuelled phase; yet, at the same time, they expect their loved ones to make medical decisions on their behalf when decision-making capacity is lost. This responsibility placed on relatives goes in line with the Maltese Mental Health Act (2012) which stipulates that when patients lack mental capacity, the responsibility of care decisions is shared between clinicians in association with the closest family member/s unless a previously stipulated proxy was appointed in writing by the patient. This presents several challenges, mainly in the lack of a medico-legal framework to regulate ACP, as the goals and values of the designated proxy decision-makers may be in conflict with the values and goals of the patient, now lacking decisional-capacity (Karlawish et al., 1999).

To this end, once decisional capacity is lost, two different approaches towards decision-making exist, namely, substitute judgement and decisions taken in the patient's best interests. Substitute judgement refers to decisions taken by the surrogates on behalf of the patient on the presumption that, if the patient was fully able to understand his/her condition, the same decision would be taken, based on the patient’s values and wishes (Lang & Quill, 2004). Advance directives are therefore seen as tools that can aid the surrogates to exercise substituted judgement decision-making, in having the patient’s goals, values and preferences listed as guidelines to plan future care (SEP, 2009). However, in those situations where the patient’s wishes and values are not known, decisions must be taken in the patient’s best interest, where the surrogates use their own and the patient’s values to take the best possible decision on behalf of their loved ones (Lang & Quill, 2004).

Ultimately, whilst all attempts must be made to respect the patient’s preferences, a balance should be reached to address the benefits and burdens of possible care options, to relieve suffering and maximize dignity and quality of life. This concept in shared decision-making is acknowledged by the Maltese Mental Health Act (2012), as the multi-disciplinary team and the proxy/relatives of the patients should come to a mutual understanding in achieving a care plan that respects the best interests.

Concerning the above, Agius (2015) suggested that a consensus-building decision-making-process should be followed in EOL decision-making for patients lacking decision-making capacity that includes the following four elements, namely, ‘management plan for treatment’, ‘continuous assessment of the clinical situation’, ‘spirit of collaboration between the treating team’ and the ‘participation of family members (pp. 46-47)’. In conclusion, in deliberating difficult decisions at EOL, the consensus-building decision-making model is deemed to safeguard the overall rights and best interests of the patient in care (p. 52).

2.6 Planning Ahead

Although ageing and dying are natural processes of life (Ke et al., 2016), advances in medical and technological fields have altered the boundary between life and death, leading to different expectations with regard to preferences of care and the use of often futile aggressive medical treatment at the EOL phase (Sechaud et al., 2013). Gjergberg et al. (2015), remarked that disproportionate prolongation of human life does tend to increase critical events at the last stage of life. At the same time, cognitive decline does tend to create complex challenges in delivering care that respects the patient's values and preferences. This has enacted the need for high-quality care to be provided in institutions, where the focus is to promote the active involvement of the patient in their care plan, leading to the introduction of ACP in such settings (Froggatt et al., 2009).

2.6.1 Advance Care Planning

ACP is defined as an ongoing and dynamic communication process whereby patients, having decisional capacity, can reflect on their diagnosis and prognosis, leading to their definition of goals and preferences for future medical treatment and care, for when decisional capacity is lost. Such discussions are often done in the presence of their family/loved ones and their healthcare providers (Rietjens et al., 2017). Davison and Torgunrud (2007) stressed the fact that the goal of ACP is not just the mere fact that individuals are presented with the option to refuse treatment, but rather as a tool that defines quality EOL care. This is emphasized by the holistic depth that ACP provides, as it addresses the individual's concerns spanning across the physical, psychological, spiritual, and social domains. At the same time, ACP further encourages the individual to appoint a representative to bear witness and respect their preferences in the eventuality when decisional capacity is lost (Rietjens et al.).

Through the exploration of the person's values, this process underlines the importance of reflection, articulation, and discussion of personalized EOL care preferences in the quest to achieve a common ground of understanding (Emanuel et al., 2000). The introduction of ACP in LTC honours the recommendations provided by the NICE guidelines as it emphasizes the right of every individual to partake in discussions and the formulation of informed decisions about their immediate and future care (NICE, 2018). This direct involvement of the individual in discussing future care provision thus allows the person in care to exercise a fundamental aspect of the caregiving process in providing informed consent for current and future health-related decisions. Consequently, ACP introduces a power shift, where patients are not just bystanders and passive recipients of care, but rather active participants that engage directly in their future care plan by making known their interests, values, and wishes for their EOL (Butterworth, 2005).

The implementation of ACP in institutional care has been proven to increase the satisfaction of both the patient and their family members (Detering et al.,2009). Moreover, factors that contribute to the attainment of a “good death” are defined by patients themselves thus leading to a better sense of control over their care. As a result, the involvement of the patient in ACP, not only helps to avoid a disproportionate prolongation of dying, but also helps to diminish unnecessary decisional burden off their loved ones, leading to the strengthening of inter-personal relationships and management of symptoms (Steinhauser et al., 2000).

ACP has also been proven to reduce stress, anxiety, and depression in family members once the decisional capacity in the patient is lost. This is because EOL decisions done by the family can be tailor-made to follow the past expressed wishes and values of the patient (Wright et al., 2008). Such an approach in decision-making through substituted judgement further increases the relevance of such practice in institutions, given the associated mortality rates in such milieus.

Engaging in EOL discussions through ACP is not a straightforward process, as various factors affect patients’ predisposition to draw up such a document. Sharp et al. (2013) indicated that even though there is a minority of older adults who might feel uncomfortable being involved in such discussions, most older adults wish to discuss their EOL preferences and have them documented in an ACP, yet they do not have the possibility to do so.

Cultural factors of how we practice medicine, such as paternalism (Dimech et al, 2020; Chang & Pang, 2010) could affect the availability and utilisation of such a tool in healthcare systems, even where ACP is readily available. Further resistance to the use of ACP could be attributed to the personal preferences and values of the patient and the propensity to protect the family members and the person in care from difficult and emotionally fuelled conversations regarding EOL (Sussman, 2020). Moreover, the uncertainties associated with disease prognosis and survival estimation may further hinder the initiation of ACP. This increases the chance of marginalising the voice of older adults in care, due to the possible loss of decisional capacity resulting from disease progression. The consequences of such uncertainty and fear to face future care decisions often ends up resulting in the patient receiving unwanted care (Sharp et al., 2013).

2.6.2 Advance Directives

The most common expression of the process of ACP is the formulation of Advance Directives (AD) (Vandervoort et al., 2012). An AD can be defined as legally binding written statements, or directives, concerning the preferences for future medical treatments or interventions, which come into force when the patient loses the decision-making capacity to decide at that point in time (van Wijmen et al., 2010). ADs can take three different forms:

I. The ‘living will’, which allows the individual to execute a written document to express their wishes and preferences to withhold or forgo EOL treatment in the eventuality of loss of decision-making capacity.
II. The ‘lasting power of attorney for healthcare’, which involves a written document where the patient appoints a ‘healthcare proxy’, in which the appointed individual would make future health-related choices on their behalf, once decisional capacity is lost, which might also extend to estate and financial matters (Adorno et al., 2009).
III. The ‘durable power of attorney’ (DPOA) allows the individual to point a trusted proxy in handling any or all financial and estate-related matters (Rosnick & Reynolds, 2003).

In Malta two different POA formats exist, the *Generic task specific Power of Attorney* and the Lasting/Durable Power of Attorney enacted through the amendment to the Civil Code (1864A, 2016).

Despite the known benefits of ADs, Cassar (2010) emphasizes the fact that the “Maltese Law is silent (p. 49)” on such matters and there is no legalisation backing up the use of ADs in the local healthcare system.

Given the lack of presence of legally endorsed documented patient’s preferences for their EOL, in the current healthcare system, once decisional capacity is lost, the attending healthcare team refers to the patient’s family members to gain insight into their views, which may not necessarily reflect the patient’s wishes and values. Thus, without tools such as ACP the patient’s autonomy and human dignity at EOL are still under threat (Dimech et al., 2020).

2.7 Chapter Conclusion

This chapter provided an overview of the most relevant literature in relation to the context of this study. In the following chapter, the Methodology, the research design, and several other features of this study are thoroughly addressed and explained.

CHAPTER 3

METHODOLOGY

3.1 Chapter Introduction

This chapter presents a detailed overview of the methodology employed to carry out this research study. Following a description of the aims and objectives, the design and method that is most appropriate to satisfy these said criteria will be explained and reasons in favour of the suitability of the chosen research design will be further discussed. Moreover, this chapter will include specific sections explaining all the different components of the design process including a definition of the population chosen for the study, the sampling techniques utilised, the creation of the instrument used to carry out data collection, the process of data collection, subsequently leading to an overview of the whole data analysis process. Ethical considerations will also be discussed, given the sensitivity of the phenomenon, the vulnerability of the chosen population and all the accesses and permissions needed to be granted to conduct this study. Finally, this chapter will also provide a section on how quality and vigour will be guaranteed by fulfilling certain requirements to honour the chosen research design.

3.2 Aims and Objectives of the Study

This study aimed to explore the experiences and perceptions of institutionalised older adults on EOL including death and their attitudes towards decision-making in this stage of life. The following objectives were drawn up to inform the aims of this study:

- To explore the meaning and values older persons give to their EOL through their lived experience and whilst residing in a LTC facility,
- To explore the perception of death and dying through their experiences,
- To explore the treatment/care preferences and expectations for EOL,
- To explore the preference of older persons residing in a LTC facility on their substitute decision maker, in the eventuality of cognitive impairment at EOL
- To explore their perception of the concept of ACP.

3.3 Research Design

In view of satisfying the exploratory nature of this research project, a qualitative approach was deemed to be the best fit as the main scope of this study was not to test any specific hypothesis through the collection of empirical data but rather generate in-depth and rich data from every single subject, to create, interpret and formulate meanings associated with their lived experiences (Bryman, 2012). Therefore, qualitative research, emerging from two distinct ontological and epistemological positions, namely, constructivism and interpretivism, allowed the researcher to use a naturalistic and interpretative approach, to create meaning, and understand the phenomena under study from the point of view of the chosen participants (Bryman, 2012). Moreover, qualitative studies required the tailored use of specific data collection methods, which allowed the researcher to create an empathetic bond with the chosen participants, aiming to understand their world and experiences, through their lens and the plethora of meanings they associated with them accordingly (Denzin & Lincoln, 2005).

To my knowledge, there are no local studies which explored the older adult's experiences and perceptions of the EOL phase and their death and their preferences and attitudes to decision-making in this delicate phase of life, whilst residing in LTC. Similar studies conducted abroad on the same phenomenon in the same living milieu were conducted, and all employed a qualitative research design to best fit their requirements, thus also informing and guiding this present research study (Fleming et al., 2016; Bollig et al., 2016; Hanson et al., 2019; Tjenberg & Bokberg, 2020; Jiao & Hussin, 2018).

3.3.1 Methodological Framework

To fulfil the set aims of this study, an Interpretative Phenomenological Analysis (IPA) approach developed by Smith (1996) was adopted to guide this research study, as it is concerned with how individuals make sense of their experiences, in a given context, in relation to the phenomenon under study (Smith et al., 2009). Derived from Heidegger's philosophical underpinnings, an IPA approach was deemed the most suitable framework as it is derived from three major theoretical axes, namely, phenomenology, hermeneutics and idiography.

3.3.2 Phenomenology

The first major theoretical axis underpinning IPA is phenomenology, which can be defined as the 'philosophical approach to the study of experience' (Smith et al., 2009, p. 14). It is focused on the various aspects of what constitutes the human experience, especially things that matter, which form the lived world. Thus, through phenomenology, rich and in-depth data could be gathered, allowing for the thorough examination and comprehension of human lived experience. Building on Husserl's work, which involved the focus on an experience and its perception from a descriptive and transcendental standpoint, Heidegger, suggested that human beings should be viewed as embedded and immersed in a lived world, thus resulting in personal and subjective perceptions of experiences, resulting from their relationship with the lived world. Thus, phenomenology provides the basis for understanding the complexities and uniqueness of each individual's lived experiences and the range of subjective meanings in direct relationship with the physical and social world (Smith et al., 2009, p. 24)

3.3.3 Hermeneutics

Closely related to phenomenology and Heidegger, the second major theoretical axis underpinning IPA is hermeneutics, the theory of interpretation. IPA contributed to the fact that all human beings are ‘sense-making creatures’, thus sense-making was derived from the accounts that the participants provided. Thus, it is also recognized that all information relevant to any experience is the result of what the participant reveals about the experience, which subsequently, allowed the researcher to interpret the same account to understand the experience from their point of view. Therefore, in IPA, the researcher was engaged in a ‘double hermeneutic’ circle, where the participants are attempting to interpret and give meaning to their lived experiences, whilst the researcher attempts to make sense of and interpret what the participants are interpreting of their lived experiences. This allowed the researcher to take on a dual role, employing the same personal and mental capabilities of the participant in deriving meaning from their narratives, referred to as first-order, whilst also applying the same thought processes systematically and self-consciously in attempting to make sense of what the participant is trying to make sense of, referred to second-order (Smith et al., 2009, p. 9,24).

3.3.4 Idiography

The third major theoretical aspect contributing to IPA is idiography, which focused on the particular. This aspect was operated on two levels. Firstly, in view of capturing the actual depth and detail of every experience shared by the participant, a systematic and thorough process of analysis was adhered to. Secondly, it allowed for the commitment to clearly understand the particular experiential phenomena, from the perspective of every single participant, in a particularly given context, which in this case is death, EOL and decision-making in Malta’s largest LTC, from the point of view of the resident’s themselves (Smith et al., 2009, p. 34). Hence, a homogenous sample was chosen for this study, as homogeneity was defined by choosing participants as uniformly as possible with respect to the phenomenon and location under study, by which such similarities would allow for the examination of the psychological variability within the same group (Smith et al. 2009).

3.4 Sampling & Recruitment

In the following section, the researcher will discuss the sampling technique utilised in conformity with the requirements of the chosen methodological approach. The recruitment process will be also delved into including the inclusion and exclusion criteria adopted for the selection of participants.

3.4.1 Sampling Technique

This study used a mixture of purposive and convenience sampling to recruit participants. Purposive sampling was used as the participants had to be chosen within the strict criteria chosen for this study, based on the goals of the research, given their ability to directly answer the research questions posed. Additionally, convenience sampling was also used as the first six older adults that contacted the researcher were recruited for the study (Bryman, 2012).

Following institutional access and ethical clearance, a meeting was held with all the gatekeepers chosen for this study, to explain the criteria needed for participant selection and the time frame allotted for recruitment. Three gatekeepers were chosen, following their approval to be part of this study via the information sheet provided to them. Two gatekeepers were consultant geriatricians and the third was a senior nursing manager (Appendix 3), all working at SVP. An information sheet containing the inclusion and exclusion criteria was handed to all gatekeepers, to recruit participants from their cohort of allocated wards. The gatekeepers were also handed a copy of the participants' information sheet (Appendix 4a & 4b), the participants' consent forms (Appendix 5a & 5b) and a support service information letter (Appendix 6a & 6b), which will be described in the Ethical Issues Section. All the participants' documents were produced in both English and Maltese versions for ease of reference and a better understanding of the study.

In view of respecting the requirements of IPA, purposive homogeneous sampling (Smith et al. 2009) was chosen as it allowed the researcher to recruit participants who can offer detailed insights on EOL within the institutional context chosen and for whom the research question was relevant and meaningful (Smith et al., 2009). Participants were chosen purposely upon referral by the gatekeepers and homogeneity was defined by the following inclusion and exclusion criteria.

3.4.2 Inclusion and Exclusion Criteria

Inclusion criteria for participant selection:

- Older adults ≥ 65 years old (WHO, 2001)
- Able to provide informed consent for study onboarding
- RUDAS score of ≥ 23
- No cognitive impairments
- Residing in SVP for ≥ 1 year, due to symptoms of relocation stress subside within 6 months (Wu & Rong, 2020)
- Older adults that can verbally communicate in Maltese and/or English language.

Exclusion criteria:

- Older adults that are unable to provide informed consent
- RUDAS score of ≤ 22
- Older adults with known cognitive impairments and dementias
- Older adults that are unable to verbally communicate
- Older adults with known speech difficulties and hearing problems
- Older adults residing in SVP for < 1 year.

The uniformity of the participants selected was maintained purposely in respecting the inclusion and exclusion criteria chosen so that the psychological variability within the group could be explored in detail from the patterns of convergence and divergence discovered through the analytic process (Smith et al., 2009).

3.5 Instrumentation

An interview schedule (Appendix 7a & 7b) was devised to guide the data collection phase, in view of answering the research question proposed in this study and as informed by the interpretative phenomenological approach chosen (Smith et al., 2009). Moreover, the formulation of the interview schedule was based on the following three factors; firstly, on the extensive research conducted on the phenomenon of EOL within the institutional context and the revolving concepts which contribute to the complexity of such a stage in life. Secondly, the researcher's preunderstanding of the concepts related to EOL in an institution and the availability of policies that allow older adults to voice their preferences for care at EOL, given the decade of experience working as a nurse in the context chosen for this study. Thirdly, the contribution of both dissertation supervisors, who have endless expertise on EOL, the institutional context and previous research project experience.

Throughout the extensive literature search conducted, several key concepts were identified that were relevant to the phenomenon of EOL within the institutional context, in line with similar studies conducted abroad (Bollig et al., 2016; Pleschberger, 2007). Concepts that were included to guide the formulation of the interview questions were the concept of death and dying and the achievement of a dignified death, EOL discussions, shared decision-making, decision-making authority, and the novel concept of ACP. Questions were designed in an open-ended style allowing the participants to tell their stories and experiences, at length, allowing them to freely express themselves and attach meanings to their narrative.

The scope of developing this interview schedule was to facilitate the interaction between the participant and the researcher in allowing the participant to feel at ease and give in-depth accounts of the phenomenon of EOL from their personal accounts. The interview guide consisted of twelve (12) questions, some containing several probes for in-depth investigation. Given the vulnerability of the participants and the sensitivity of the phenomenon, the interview schedule was formulated in a logical sequence, starting from the first two questions being quite descriptive, to allow the participant to feel comfortable talking, engage in conversation and initiate a good rapport with the interviewer (Smith et al., 2009).

Following the first two questions in the schedule, which allowed the participants to delve into their lived experience living in an institution, accounts of experiences about deaths in the ward and how these experiences affected them were discussed, amidst their perceptions and expectations of the EOL care derived from their experiences on a ward level. Following a discussion about the concept of death and EOL care, the interview questions were then directed towards their views on decision-making at EOL and to whom they entrust their decision-making authority in view of exploring their perception of autonomy in this stage of life. In conclusion, the last question revolved around the novel concept of ACP, with the participants encouraged to discuss their views and perceptions of the scope of this tool, in favour of having their preferences known for their future care. Therefore ‘funnelling’ was employed in which with the aid of the interview schedule, the interview started with general open narratives and was directed to more specific and sensitive concepts (Smith et al., 2009).

The interview schedule was devised in two languages, primarily in English, given the language in which the research was conducted to devise the schedule and secondly in Maltese, as it was the native language for both the participants and the researcher, to facilitate open communication and fluency in dialogue.

3.5.1 Pilot Study

The first interview was treated as a pilot study. Piloting was introduced as it tested the feasibility of the interview schedule and informed any modifications such as paraphrasing some of the interview questions and adding timely prompts (Bryman, 2012). The pilot study was also an important part of the data collection process as it gave the researcher the first-ever experience of interviewing older people on a sensitive topic and practising the most suitable approach in introducing such concepts in a one-to-one interview (Pleschberger et al. 2011). It also gave the researcher a first-hand experience of exploring sensitive concepts in a cultural context where such discussions are not the norm. Thus, this allowed the researcher to adopt a much more confident stance in the following interviews and preparedness for any uncertainties expected. The data obtained from the pilot study was included with the main findings as no changes were made to the existing interview schedule.

3.6 Data Collection

Once the gatekeepers identified potential participants to take part in this study, the participant's information sheet was provided to them, with the gatekeepers also verbally explaining the scope of the study and the relevant contact details pointed out in view of requesting additional information. Chosen participants who wanted to take part in this study, contacted the researcher via the contact details provided in the information sheet and an introductory meeting was set up, where the researcher introduced himself as a university student and allowed ample time to address any queries or thoughts that the participants had, particularly in view of the sensitive nature of the topic chosen. Upon understanding the scope of the study and their willingness to participate, a consent form was provided and then signed by the participant and the details of the actual interview date, time and location were agreed upon.

Appointment meetings for the interviews were set at the participant's convenience, mainly held in-between institutional care and social routines. Interviews were held either in the participant's rooms or in a separate room in their own ward provided specifically for the interviews. Before every interview, the purpose of the study was explained again by the researcher, emphasizing the voluntary aspect of the interview, and explaining in detail the rights of the participants, mainly in view of opting out of the interview at any desired time, without any retribution or consequences on the care they would receive. No compensation was offered for their participation in this study. Participants were also made aware, as also was stipulated in both the information sheet and the consent form, that the interview was to be audio recorded and transcribed verbatim for data analysis purposes. They were also made aware that total confidentiality was to be maintained and pseudonyms were to be assigned to each different participant.

Data was collected via one-to-one semi-structured interviews guided by the self-devised interview schedule. Semi-structured interviews were deemed the most suitable data collection method, as with the aid of the interview schedule, it allowed the use of open-ended questions in which the participants were given the freedom to express themselves in depth and without any predefined answers or narratives (Bryman, 2012). Open-ended questions allowed the participants to enter a reflexive process in allowing them to think about the past and/or current lived experiences in relation to the concept of EOL. Subsequently, probing with timely prompts, further helped to direct the interview process in the desired direction to aid in answering the primary research questions (Smith et al., 2009). Interviews lasted between 45 minutes to 125 minutes. The researcher took the stance of an active listener to help establish the development of the conversation and allowed the participant to give as much depth as possible in view of analysing the psychological content of each response (Pleschberger et al, 2011). The researcher employed a reflexive stance during the interview, in which the researcher's pre-understandings and experiences on EOL were bracketed off and allowed the data to be constructed without the researcher's influence (Shaw, 2010). Non-verbal facial expressions and body movements were also noted in the field notes.

3.7 Data Analysis

Following the data collection phase, all audio-recorded interviews were transcribed verbatim, and analysis was performed via the 6-step analytic process guide for IPA informed by Smith et al. (2009).

In IPA, the process of analysis consisted of inductive and iterative procedures which allowed the researcher to initially develop 'an insider's perspective' from the personal accounts given by the participants, in view of fulfilling the phenomenological requirement. The analysis then proceeded to honour the interpretative requirement, in which the researcher attempted to make sense of the participants' concerns and experiences, in this particular context, in view of shedding light on the research questions of this study. These two distinct positions in the analytic process were very detailed and labour-intensive and were informed by procedures of coding, organising, integration and interpretation of the extracted data (Reid et al., 2005).

3.7.1 Data Analysis Process

Step 1 – Reading and re-reading

This initial step involved active engagement with the participant's data in reading the transcript on multiple occasions to develop a better understanding of the data and the structure of the conversation. This facilitated the analysis of the general flow of the interview and permitted the researcher to understand specific narratives and how these could be linked together in the same transcript. This initial step also facilitated the recognition of when trust was developed in the interview, in view of exploring the rich intersection of data, whilst also exploring for contradictions and paradoxes in the data set.

Step 2 – Initial noting

In this step, the researcher examined the semantic content and language use of the transcript on an exploratory level by noting anything of interest or relevance and keeping an open mind. This step aimed to provide a detailed set of notes and comments on the data set, in which the researcher familiarized himself with the transcript and allowed the researcher to start developing a better understanding of how the participants talked, understood, and viewed EOL and developed comments derived from the participant's explicit meanings.

Exploratory commenting consisted of the examination of the data set via three distinct processes:

- Descriptive – comments focused on the descriptive nature of the text related to different topics and concepts derived from descriptions of the participant.
- Linguistic – comments derived from analysing the semantic content and language use by the participant.
- Conceptual – comments derived from the analysis of texts at an interrogative and conceptual level.

After the analysis of the whole transcript, the researcher combined the three different types of exploratory comments to explore links and connections derived from the participants' narrative in a critical attempt to immerse himself in the participants' life world, resulting in conducting a deeper analysis of the data.

Step 3 – <u>Developing emergent themes</u>

In this step, the researcher reduced the volume of data gathered from the original transcript and initial noting, by identifying and combining exploratory comments in view of mapping interrelationships, connections, and patterns, whilst maintaining complexity. This process consisted of breaking up the narrative flow of the conversation into different parts, assigned to different specific themes, and organized systematically. In this step, there was a shift from the phenomenological requirement to examine data derived directly from the participant to a more interpretative focus where the researcher organized and interpreted the meaning of the data, from exploratory notes to themes. The focus of this step was to analyse each segment in its own right and in relation to the whole narrative of the interview.

In this step, the process of the hermeneutic circle was introduced, where the specific parts were interpreted in relation to the whole, whilst the whole was interpreted in relation to the parts. The themes generated in this step represented the synergistic combination of both the description and interpretation processes, transforming loose initial notes and comments into emergent themes representing an understanding. The emergent themes were listed on a specific margin beside the exploratory comments, in bold.

Step 4 – <u>Searching for connections across emergent themes</u>

In this step, emergent themes were drawn together in a systematic order employing specific analytic skills and generated 'super-ordinate' themes. Abstraction involved the grouping of similar emergent themes together into clusters, in which the cluster represented a 'super-ordinate' theme, given a separate name. Subsumption allowed an emergent theme to be transformed into a super-ordinate theme, as related themes were clustered together under the same meaning. Moreover, polarization, contextualization, numeration and function were all employed to a certain degree in the formation of the final super-ordinate themes.

Step 5 – Moving to the next case

In this step, the researcher moved on to analyse the next transcript and the same process was repeated for every individual case. In respecting the idiographic commitment of IPA, each case was analysed on its own terms in view of respecting each participant’s individuality and their personal accounts of EOL and the related concepts. This involved the ‘bracketing’ of ideas and themes that emerged from the first case, so as not to influence or saturate the meanings and experiences discovered in the following sets of data.

Step 6 – Looking for patterns across cases

In this final step of the analytic process, similar themes across cases are clustered together into super-ordinate themes for the group and presented in the form of a table, also illustrating individual themes for each participant. Hence the outcome of the analytic process aimed to showcase a balance of convergence and divergence within the same sample in shared group themes, whilst also pointing out how these themes represented a particular participant’s account in an idiographic manner.

3.8 Research Trustworthiness and Rigour

Throughout the completion of this study, the quality, trustworthiness and rigour of the research project were assessed via the core features of high-quality IPA studies developed by Smith (2011), drawn on generic qualitative criteria developed by Yardley (2000). The criteria developed by Smith (2011) focused specifically on IPA studies, and thus was deemed the most suitable guide in achieving a good-quality study. The list of criteria, their definition and how this was achieved throughout the study are listed below in *Table 2*.

Core Criteria	Definition	The process adopted in this study to highlight the criteria
Clear focus	*The study should provide details of particular aspects rather than have a general focus.*	This was achieved by focusing on the specific concepts related to EOL and decision-making within the LTC context and the uniqueness of the experiences of the participants in relation to them.
Strong data	*Generation of good and strong data sets via good interviewing skills.*	This was achieved by conducting research prior to the data collection phase on the most appropriate approach to interviewing vulnerable people on EOL-related topics. This was put to practice, whilst also maintaining an active listener stance during the interview, allowing the participants to provide their in-depth lived experiences.
Rigour	*The study should provide some measure of prevalence for a theme and the data corpus should be well presented in the analysis section.*	This was achieved by providing data extracts from each participant as evidence for each theme. Extracts were selected carefully to indicate patterns of convergence and divergence, given different polarizations, whilst also maintaining representativeness and variability within the sample of participants. Multiple extracts were linked to each theme to allow the reader to grasp the breadth and depth of each theme.
Sufficient space for the elaboration of each theme	*The study should provide a clear selection of the most relevant themes backed up by sufficient data rather than having a multitude of superficial themes.*	This was achieved by carefully grouping themes together into super-ordinate themes when sufficient similarity was analysed. Through subsumption, themes were also reconfigured to represent super-ordinate themes and importance and relevance were given to them accordingly. The prevalence of themes was also considered as an indicator of relevant importance for inclusion in the results.
Type of analysis	*Analysis should be interpretative and not just descriptive.*	The hermeneutic aspect of IPA was respected in view of providing interpretative commentary following the extracts from the corpus of data. Extracts from different participants for each theme with interpretative commentary were provided to clearly show the relevance and construction of each theme. The researcher engaged in a double hermeneutic process to engage with the meanings derived from the participant’s transcripts.
Analysis – convergence and divergence	*In studies with more than 1 participant, a skilful demonstration of both patterns of similarity among participants as well as the uniqueness of the individual experience should be demonstrated.*	Throughout the analysis process, this was achieved by clearly grouping themes according to their similarity and differences and showing levels of convergence and divergence within the same theme. The researcher also aimed to represent how participants manifested the same theme in particular and different ways.
Write-up	*The study should provide a well-wrought and sustained narrative.*	This was achieved by clearly engaging with the corpus of data generated and providing a structured narrative of all the relevant data extracted. The researcher, as a result, showed that he has captured in detail the experiences of older adults on EOL and presented such findings in a clear and structured format.

Table 2 - Evaluation guide for high-quality IPA Studies (Smith, 2011)

3.9 Ethical Considerations

Prior to the commencement of this study, institutional access was sought and obtained from the Chief Executive Officer (Appendix 2a), Medical Superintendent and Data Protection Officer (Appendix 2b). Ethical clearance was sought and obtained from the Faculty for Social Wellbeing's Research and Ethics Committee (FREC) at the University of Malta on 18th February 2022 (Appendix 1). The gatekeepers were also invited to an informal meeting by the researcher and briefed about the purpose of the study before their engagement.

One of the gatekeepers was currently allocated to the same ward as the researcher, Fatima Ward, SVP. To avoid participant selection bias, no participants were selected from Fatima Ward.

Moreover, every participant was given a written explanation of the study in the information sheet provided and a thorough oral explanation before every interview. To note, participants' information sheets were provided in both English and Maltese languages and written in larger fonts for ease of engagement. All the participants signed the consent forms provided before their participation and after clearly understanding the components of the study. Participation was voluntary and it was clearly explained that they could halt the interview at any point and refrain from having any of their data used for this study, without any form of retribution. It was also clearly explained how the data was to be managed, who had access and that all data generated for the scope of this study would be deleted by the end of the year, 2023.

In view of the sensitive nature of the study, the researcher held a discussion with both supervisors in this regard, as the participants might need to talk to a professional following any psychological distress the interview might have caused. Since all the participants resided at SVP, it was decided to engage the in-house psychiatric firm of Professor David Mamo to assist in such a matter. Professor David Mamo was contacted via email and accepted to deliver debriefing sessions to the participants of this study if the need arose, and as a safeguard set by the researcher to preserve the overall well-being of the participants (Appendix 6c). To this end, all the details of how such service was to be accessed were listed in the support services sheet provided to each participant after each interview including the contact details of the researcher.

Throughout the data collection phase, the issue of 'boundary management' was a challenge (Pleschberger et al., 2011), as the researcher had to balance out his professional identity role as a nurse with his current role as a researcher. Defined as a 'researcher versus therapist dilemma' (Alty & Rodham (née Gadd), 1998), research on sensitive topics might have led the participant to deviate from the scope of the interview and view the researcher as a therapist and divert the scope to that end. This might have led to the contamination of the data generated; thus, safeguards were put in place to counteract such issue. This was primarily dealt with by explaining to every participant that the role of the researcher was to conduct the research for the scope of the dissertation, rather than a therapy session, before every interview and emphasizing that such an issue is understood.

3.10 Strengths and Limitations of IPA

IPA, based on its philosophical underpinnings (Shinebourne, 2011), was considered the most suitable approach for this study, as it allowed Maltese institutionalised older adults to voice their thoughts and experiences, for the first time, on the EOL phase and death, through their past lived experiences and their current living experience, whilst residing in LTC. It also allowed the participants to express their preferences of care and wishes regarding the choice of substitute decision-maker in view of the possibility of cognitive impairment, whilst also voicing their thoughts on the concept of ACP, as a means to safeguard their autonomy and dignity for their future care and eventually obtaining a dignified death.

Furthermore, in adhering to this inductive approach, especially in following the suggested guide for data analysis, the subjectivity of the participant's personal accounts was given prominence and it shed light on how this vulnerable cohort of older adults are experiencing and giving meaning to their last phase of life. In addition, since this is the first study of its kind in Malta, in a healthcare system where EOL discussions are as of yet not the norm, it provided the first-ever local perspective on the phenomenon under study, which could not be extracted from international studies.

Limitations were also encountered related to the methodological approach chosen. One main limitation noticed was the relatively small number of participants chosen for this study. Six (6) participants were chosen according to the guidelines by Smith et al. (2009), and this denied the possibility of the findings being generalizable on a larger scale. Countering such fact, Finlay (2011) explained that the scope of qualitative studies is not to discover the 'how much' and 'how many' questions related to a hypothesis, but it aims to explore the 'what', 'why', 'how' questions in exploring, understanding, and interpreting the phenomenon under study from the point of view of the participants. Moreover, given the applicability of the findings, Smith et al. (2009) further note that findings in IPA should not be considered in terms of empirical generalizability but rather in terms of theoretical transferability. This is achievable when the readers link the findings of the IPA study, with their own professional and personal experiences and current literature and thus allowing them to evaluate its transferability to another subject, in this case, to other older adults residing in LTC.

Another limitation noted was due to one of the inclusion criteria chosen for this study enrolment, namely the 4th criterion listed, 'No cognitive impairments'. This resulted in excluding all the residents with known cognitive impairments, thus excluding more than half of the residents residing at SVP.

Since interviews were the chosen data collection method, participants had to be chosen based on their ability to maintain a lengthy conversation, recall, and discuss in-depth past lived experiences.

3.11 Conclusion

This chapter provided a detailed account of every component of the methodological framework chosen in relation to answering the research questions. IPA informed all the methodological steps taken in conducting this research study and a detailed explanation is also given of how the quality of this study was assured throughout the whole process. Ethical issues encountered and how these were dealt with were also discussed in this chapter. In conclusion, the strengths and limitations of IPA were highlighted with rationales given for every decision taken in conducting this study.

Following the above account of the methodology chosen for this study, the following chapter will provide details of the analysis conducted and the findings generated from the corpus of data gathered from the interviews.

CHAPTER 4

FINDINGS

4.1 Chapter Introduction

Following a detailed description of the analytic process in the previous chapter, this chapter provides an account of the findings generated from the research, shedding light on how older adults residing in SVP perceive EOL and death through their personal lived experiences and how such recollections shape their attitudes towards their decision-making role in this delicate phase of life. Moreover, a brief descriptive overview of each participant is provided in a case summary format, supported by a table representing additional participant data.

4.2 Participants' Data Profile

For this study, the six study participants were all given a personal code, used by the researcher for data analysis purposes and pseudonymized with fictitious names to maintain confidentiality and respect the experiences they shared. All the participants were initially engaged by the gatekeepers and subsequently chosen to take part once contacted from their own end, voluntarily. All six participants fell within the brackets of the inclusion criteria provided for this study, consisting of three females and three males. *Table 3* represents the participants' data.

Age	**79**	**93**	**80**	**76**	**74**	**88**
Sex	F	M	M	F	F	M
Institutional Length of Stay	2 years	1 year 4 months	1 year 6 months	1 year	13 years 6 months	1 year 6 months
Ward Type	Couples	General/Mixed	General/Mixed	Couples	Female	General/Mixed
Marital Status	Married	Widower	Widower	Married	Married	Widower
Children	2	5	3	3	1	4
RUDAS Score	26/30	26/30	28/30	28/30	24/30	28/30
Medical Conditions/ Co-morbidities	Dyslipidaemia Hypertension Atrial Fibrillation	CA Prostate Angioplasty Gout	CA Prostate Hypertension	Dyslipidaemia	Angioma x2 Paraplegic Stoma	Multiple Organ Failure Ischaemic Heart Disease Hypertension Atrial Fibrillation
	P1 – Jane	**P2 - Paul**	**P3 – John**	**P4 - Sue**	**P5 – Angela**	**P6 - Yuri**

Table 3 – Participants' Data

4.3 Participants’ Idiographic Overview

Box 1, below, provides a brief descriptive segment on each participant to establish a better understanding and connectedness with the protagonists of this study.

P1 - Jane

Jane is a 79-year-old caring lady, ex-housewife, fully independent, residing in a couple’s ward accompanying her 95-year-old husband for the past two years. They have been married for the last 57 years, where she currently still provides care to her dependent husband daily. She was admitted to SVP to accompany her husband. She enjoys visits from her children once to twice a week. Her husband was not included in the study.

P2 – Paul

Paul is a 93-year-old gentleman, ex-businessman, fully independent, residing in a 2-bedded room in a general ward for the past one year and four months. He was admitted to SVP to reside with his frail wife, who unfortunately passed away one month after their admission. They were happily married for 70 years. He is very vociferous about the perseverance of his human rights whilst residing in SVP and he also enjoys weekly visits by his children.

P3 – John

John is an 80-year-old gentleman, ex-teacher, fully independent, residing in a 2-bedded room in a general ward for the past one year and six months. He was admitted to SVP to preserve his well-being. He is a widower, lost his wife sixteen year ago. He is a very intellectual person who still enjoys acquiring new knowledge to this day. He also enjoys multiple weekly visits by his children.

P4 – Sue

Sue is a 76-year-old lady, ex-employee in catering and textile business, fully independent, residing in a couple’s ward accompanying her frail husband for the past year. She was admitted to SVP due to her decreased mobility and to care for her husband on a daily basis. She is a strong mother figure and still enjoys her social circles outside of SVP due to her ability to still possess a driving license. She also enjoys regular visits from her children weekly. Her husband was not included in the study.

P5 – Angela

Angela is a 74-year-old lady, ex-housewife, semi-dependent, residing in a 4-bedded room in a female’s ward for the past thirteen years and six months. She suffered a medical emergency at the age of twenty-six, which rendered her paraplegic for the remainder of her life, following the birth of her only son, eight months prior. She was admitted to SVP to preserve her well-being and not to be a burden to her son. She is a very resilient woman and enjoys regular visits by her son on a weekly basis.

P6 – Yuri

Yuri is an 88-year-old gentleman, ex-businessman and hospice volunteer, semi-dependent, residing in a 4-bedded room in a general ward for the past one year and six months. He was admitted to SVP to preserve his well-being after a near death experience at Mater Dei Hospital. He is a widower, lost his wife thirteen years ago, suffering from end-stage dementia. He is a family-oriented person with strong ties to spirituality. He also enjoys frequent visits by his children on a weekly basis.

Box 1 - Participants’ idiographic overview

4.4 Themes Overview

Following the analytic process suggested by Smith et al. (2011) for an IPA study, the following five super-ordinate themes emerged consisting of several sub-themes each, listed below in *Table 4*. These themes sought to answer the two proposed research questions for this study;

- What are the perceptions and experiences of institutionalized older people on death and dying?

- What are the preferences for care in their EOL in view of their perception of death?

Super-ordinate Themes	**Sub-ordinate Themes**
I. The Last Refuge	- *Well-being at EOL* - *Roles within an institution* - *The last living milieu* - *Normality of Death* - *Death, 8 feet away*
II. Death and Dying – The Insider's Perspective	- *Familial death experiences* - *Release from suffering and pain* - *Losses at the twilight of time* - *Inevitable outcome of life* - *Self-actualization - the fulfilled life* - *Spirituality and comfort*
III. EOL Care Preferences – The Ideal Death	- *Avoidance of prolonged suffering and pain* - *Wishes for euthanasia and physician-assisted suicide* - *The blessing of a sudden death* - *Taking matters into my own hands – suicide* - *A good death*
IV. Attitudes to Decision-making at EOL	- *No opportunities for EOL communication* - *Decision-making roles* - *Shared decision-making; the role of clinicians and relatives* - *Trust and truthful information* - *Proxy decision-maker*
V. ACP to Mitigate the Anticipatory Fear of Loss of Autonomy	- *Losing decision-making capacity at EOL* - *Lack of awareness of anticipatory care options* - *ACP: the light at the end of the tunnel* - *Having a voice amidst a sea of silence* - *Peace of mind at the end* - *Achieving a good and dignified death*

Table 4 – Overview of the final themes

4.5 Themes Explained

4.5.1 Theme I – The Last Refuge

This emerging theme aims to provide an understanding of the relationship between older adults and their current living milieu at EOL, a LTC institution. It was important to understand the general well-being of the participants, following their move to an institution, as mentioned, they experienced various threats to their human rights, which created various conflicts that were deemed an insult to their personhood and sense of self. It was also clear that their roles within their family and society were still present after a move to an institution, which further supported their resilience and contributed to their general well-being. Moreover, there was a general acceptance that their current living milieu was to be their place of death, subsequently remarking that the frequency of death itself was not a one-off event but rather a very tangible eventuality, with several first-hand witnessed events that placed death, just 8 feet away.

Well-being at EOL

There was a general sense of positive well-being amongst the participants, with the majority expressing their strong sense of independence and agency amid a cohort of residents with cognitive disabilities, which seemed to affect their perception of living life in an institution. John remarked, *"I am very happy living here, I do not complain about anything, till I have up here still functioning (points at brain)".* This response indicated a sense of positive well-being related to the fact that he still has cognitive capacity.

Moreover, this also translated into loneliness within an institution as Yuri remarked, *"I am living here, and there are certain types of people here, no one to speak to, maybe just a couple here and there"* On the other hand, whilst Jane was happy in her current living milieu, she also noted several communication barriers with the ward staff as she remarked, *"and what if I speak up?".* This implied that even though she has a voice, her voice is not heard and the presumption of falling on deaf ears. The constraints of an institution were also made evident when Sue remarked, *"but since I have that little freedom to get out of here with the car, I was hesitant to speak up, since they wouldn't trust me driving".* This suggested that communication barriers exist between residents and ward staff, amid situational barriers imposed by the institution. This led to an adverse effect on her independence and freedom of movement, translating into a sense of fear of imprisonment, and suggesting her need to escape.

Roles within an institution

Given that most of the female participants resided in a couple's ward with their spouse, their caregiving role at EOL to their spouse was noted to be their main purpose whilst residing in an institution. This caring role is further related to their overall sense of positive well-being. Sue remarked, *"at the same time, I am happy because my husband is here and I am taking care of him myself!"*, implying that her caregiving role is fundamental for her well-being and such role is her main scope in residing with her husband.

On the other hand, the male participants, given they are all widowers, focused more on their strong sense of fatherhood towards their children, in providing continuous support and wisdom when needed. It was also noted that the male participants, focused most of their energy on self-development, having as an example John, who at the age of 80, still attends online algebra lectures, to further his knowledge and keep himself busy.

The last living milieu

There was a general acceptance amongst the participants that the institution was their last living arrangement, thus it was also envisaged as their probable place of death. John related an episode when his daughter asked him about his previous residence, he replied, *"don't keep anything for me, I am going to remain here…",* affirming that the institution was chosen to be his last residence. This is corroborated by Yuri's remark, *"but now I'm here, and here is my home now, I would be happy to die here",* further implying that the institution was now his new home and that death is welcomed in his last living arrangement.

Normality of death

All the participants clearly remarked on two important factors related to being witness to the eventuality of death in an institution, primarily its frequency and secondly its perceived impact at ward level. Whilst Angela remarked that during her 13-year stay she said, *"yes, I witness a lot"*, John went further into detail when he stated, *"since I have been here, I witnessed a minimum of ten deaths"*, implying that he has witnessed a minimum of ten deaths in his 18-month stay at SVP. In addition, Paul remarked that death is, *"one of those things, one of those daily things that could happen, nothing in particular…".* This suggested that apart from being a common occurrence, death is not perceived as something out of the ordinary but a phenomenon that is to be expected within an institution.

Death, 8 feet away

Stemming from the previous finding, it was deemed important to illustrate not only the perceived frequency of death at ward level but also their first-hand experiences on how the dying process and death are witnessed and their subjective description of it. Angela shared one out of her multiple experiences:

> *"A person next to me passed away, then I saw her head, all yellow then, she (the nurse) pulled her from her leg, and she doesn't feel anything, I witnessed this and I said, 'koss uuu, how we end up, our face all jaundiced, that's why they say 'safra mewt'. It was evident that she was dead, and after a while, she continued to pull her and started taking care of her deceased body, inserting cotton wool in her nose and things of that sort. Then I realised, 'oh my we are so finite!'"*

This close depiction of death, amongst other similar shared experiences, contributed to the perception of the dying experience for those that are still in the realm of the living, further affirming the depletion of the physical being at the last stage, threats to human dignity and re-affirming the finiteness of life (life not eternal), in an environment where death is perceived as a normal and common occurrence. The meaning of such experiences is seen to be internalized and understood as being a possible outcome for the participant's impending eventuality of death.

4.5.2 Theme II – Death and Dying – The Insider's Perspective

This theme illustrates how the participants constructed their perception of death and dying throughout their lived experiences and in conjunction with the current experiences they are facing at SVP. These findings suggest that there are two different attitudes towards death acceptance at their current old age. The first is death as an escape from the painful existence of life at the latter stages, and the second is death as a natural ending of a long life lived.

Familial death experiences

All the participants shared various experiences of deaths in their family, mentioning events related mainly to the death of their spouses, parents, and siblings. It was clear to note that these experiences were mainly described through the lens of suffering, where longevity and a painful EOL were seen as a curse, thus an eventuality that needs to be avoided. Short-lived lives with sudden death were seen mainly as a blessing and a desired outcome in the face of avoiding suffering. To this end, John described the experience of his wife's final days:

> *"My wife had a cancer in her spine, they gave her nine months to live, managed to survive for four years, and in the first 3 years we used to go to the United Kingdom back and forth without any issues, but in the final year, they told her that the cancer has spread throughout all her bones. I used to take care of her, bathe her, but in the last two months I couldn't because she shouted 'ajma, ajma, ajma'. I used to pray to God to have mercy on her and take her, there was no hope, so it depends on how you are feeling, if until you die, you do not suffer, it doesn't matter, but if you die whilst you are suffering, you will be done with it, it's better…"*

It was observed that the presence of suffering at the end of life, does leave an impact on the family members that are left behind, also leading to the internalization of the perception of death on their own impending dying experience.

In fact, Sue remarked,

> *"Just like what happened to my mum, at 58 years of age, passed away, all the family was gathered around her, it was Saturday night, as soon as we arrived home, they called us and we went and we found her cadaver on the bed, it was horrendous for us, but at least she did not suffer…"*

This clearly remarked that the suddenness of death, although depicted as still being a horrid experience by those who are living, is still perceived as a dignified death, in view of the absence of suffering in her later stages.

Release from suffering and pain

There was a general acceptance amongst all the participants that death is perceived as an opportunistic ending to a painful existence in the EOL. It was interesting to discover that the participants associated the concept of suffering with death from three different perspectives, which ultimately internalize their perception of suffering before their own impending death.

The first perspective was self-experiences of suffering, which does contribute to the perception of death as a release from painful existence in this life. Yuri remarked, *"you don't know how much I suffered when I was in the hospital, I do not know how I didn't die, I used to pray to God to release me"*. In this near-death experience, filled with suffering, supernatural forces were called upon, to act as a catalyst to end their life, to stop suffering.

Secondly, familial death experiences were associated with their embodiment of suffering and fuelled their perception of death as an abrupt end to a painful life.

Thirdly, following their experiences of suffering on the self and as witnessed as part of the dying experience of their loved ones, their current living environment at this stage of life also played a crucial role in their embodiment of suffering as John remarked, *"and I know of people who endured pain here, shouting, all the time shouting, 'ajmaaa, ajmaaa'. He passed away, I said, he is resting now"*. This suggested that even though the other perspectives might have been formed by past experiences, their current living situation of witnessing death and suffering is further contributing to their perception of suffering in preparation for their EOL.

Losses at the twilight of time

Most of the participants revealed that the eventuality of death is perceived as a threat to human rights through loss of autonomy and a challenge to their dignity, as Angela remarked, *"upon death, they dress you up as they wish, they take you where they like and they do whatever they please with you…"* In addition, apart from the loss of loved ones, another consequence of death was related to the loss of their current living milieu at the EOL as the living partner is subsequently transferred to another ward. This finding was revealed by both Jane and Sue, as Jane pointed out:

> *"Their death, is not the only horrible thing, the other thing is, that whoever is left behind, you see him going, eyes full of tears because he has to leave here as well, because everyone gets used living here, you won't know where you are going, where they are going to send you, where they will place you, it's too horrendous…"*

Sue added, *"you could feel their remorse, apart from losing their loved ones, they are also losing us, our company…"*. As both Jane and Sue reside in a couple's ward, it was observed that in their EOL, once residents residing in that ward lose their loved ones, they have to experience another trauma, whilst still in their bereavement phase, that of losing their current living milieu by being transferred to another ward. Such abrupt transfer also affects the social connections built at ward level, which insult is added to multiple strata of losses in their bereavement.

Inevitable outcome of life

The findings strongly suggest that most of the participants view death as the inevitable outcome of life as Yuri remarked, *"I accept it, because I ponder, that is where my path will lead to, everyone has to, whoever is born must die, I accepted the fact that one day I have to die, today or tomorrow, whomever you are."* This finding is corroborated by other similar expressions from the other participants, where death is perceived as the end of their natural life cycle. Waiting for its uncertain arrival Sue said, *"we know that one day, death will come, and you have to accept it, I have to experience it, one day…"*. This suggests that there is a certain acceptance of the eventuality of death, in a living environment where death is witnessed as the end for the living.

Self-actualization - the fulfilled life

Concerning the perception of death as the inevitable outcome of life, some of the participants expressed their thoughts on death as being the end of a fulfilled life, as Jane remarked, "*I can say that I have done my time, I will be 80 soon, isn't it enough, from now onwards, He knows…"*, suggesting that her life cycle, due to her advanced age is complete and death is welcomed at any point in time. This view was corroborated by Jane's remark, *"as long I'm at peace with God and my family, knowing they are settled, I wouldn't be hesitant to die, I've done my time and my life is complete"* This suggests that fulfilment at EOL is connected to the peace of mind that their siblings are not dependent anymore on their parents whilst also being at peace with God.

Spirituality and comfort

Throughout the conversations with the participants, there were several mentions of God, as being the force to call upon when there is excess suffering and pain in the last stages of life. Jane shared her experience of visiting an older woman in another nursing home, before she died the older woman stated, *"pray for me, not for good health but rather for God to have mercy on me and take me, I am so sad and alone…"*. This suggests that God is called upon to end her relative's life, in view of solitude and sadness in her final stages of life. Moreover, John remarked, *"If I'm in pain, I would thank God that I am reaching the end of my life because I would be getting rid of my pain",* indicating further that God's intervention to allow death is welcomed in the face of pain in their EOL.

On a different note, from all the participants, Angela was the only one who expressed fear of her impending death as she stated, *"death, scares me a bit, but it scares me, not because I'm going to die, because I know there is the soul, and the Final Judgement, how will He perceive me, how will He judge me at this point…"* It is interesting to note that Angela, being observed to be the most spiritual participant of the study participants, associated meaning with her impending death, not from the land of the living but rather from the fear of the eventualities that might occur in the afterlife. Additionally, Paul revealed conversations with God where he remarked:

> *"No, myself, I perceive death from a religious perspective, that's the first thing, and whenever I can, I tell Him, that by now He should already have sent for me, by now He should have sent me to hell, because of what I have done in my life, sometimes I wonder, how He lets me live…"*

This also suggests that in the face of a long life, Paul who was the oldest at 93 years of age, questioned existential matters that are prominent in his thought process about his EOL, whilst also debating God's purpose to let him live a long life.

4.5.3 Theme III - EOL Care Preferences – The Ideal Death

This theme gives an account of the EOL care preferences chosen by the participants in view of their impending death, through their perception of death and dying in a healthcare system where EOL policies are not yet available, resulting in accounts of older adults, expressing ideas about how to take matters in their own hands. Moreover, these preferences could all be understood as a means to avoid suffering, pain, distress, and futile life and ultimately achieve a good and dignified death.

Avoidance of prolonged suffering and pain

There was a general concern amongst all the participants, that the time before their death, might be riddled with the uncertainty of pain and suffering. Having such experiences internalized, the participants revealed their thought processes and their expressed need to avoid such an undesired end for their own life. This avoidable pain and suffering were related to medical treatment futility in the EOL, as Jane remarked:

> *"Let me die, if I am still going to die, because if I would know that I am going to suffer and be cured, I would suffer with a chance of cure, but if I am going to suffer and still die, just let me die in peace"*

This is also corroborated by Paul's remark when he stated:

> *"Care at the end of life, until my mind still reasons, make me as comfortable as I can be, keep suffering away from me as much as possible, that's it, not if you are going to find a cure for me or not…"*

These statements revealed that in the face of a bleak future, where the hope of recovery or cure is not a possible reality, there is a general preference to avoid suffering at all costs, receive adequate symptom management, maintain a sense of control and coming to peace with God as the main contributing factors in achieving a good and dignified death.

Wishes for euthanasia and physician-assisted suicide

In the face of an uncertain future and in a healthcare system unequipped to address such sensitive needs, some of the participants have revealed their preferences to consider the termination of their own life. Yuri remarked, *"I wished, I wished not long ago, that they would give us a pill in the evening, so I sleep and never wake up, a pill to sleep forever…"* Yuri revealed that older adults do have preferences for their EOL care and wish to make their voice heard, but with no available EOL options, they end up expressing ideas that favour unlawful pathways to terminate their own life. This was requested in the form of physician-assisted suicide, where he would have asked his ward doctor to provide him with the means, so he could take the matter into his own hands.

In addition, Jane also remarked:

> *"If I would be experiencing intolerable pain, I prefer they would kill me themselves, if I'm in that much pain. If you would know that there is no chance for a cure, that's how I see it. If you are not going to be cured, they would know for certain that you will die, why give you more, to prolong your life another week, just let me die and let me live my last week…"*

Jane's remark, which goes in line with other chosen similar preferences by other participants, reveals another chosen pathway to self-terminate her own life, euthanasia, wherein she invokes the assistance of the medical team to terminate her life, in the prospective eventuality of a painful end without the prospect of cure. It is also interesting to remark on her perception that in the EOL there is an awareness of the eventuality of death, thus the futile prolongation of life at that stage could result in unnecessary suffering.

The blessing of a sudden death

It was also interesting to discover that some of the participants expressed the preference for a sudden death as a means to avoid all the uncertainties preceding their death. Mainly derived from her recollections of familial death experiences, Sue remarked:

> *"I wish I do not end up in that situation, I wish we had the opportunity to choose, I would tell them I prefer to drop dead and be done with it…not regressing slowly and slowly, not being able to do anything, not able to do this and that. If I'm suffering, I would prefer not to prolong my life…"*

This further revealed that older adults are asking for EOL care options to safeguard their well-being and dignity in their EOL, but in the current reality where no options or discussions are available, the option of a sudden death, is seen as an ideal means to an uncertain end. Moreover, corroborating with Sue's remark, in avoiding the prolongation of futile life, Yuri also stated, *"in my state, I am waiting for that day, that I wish to sleep and never wake up…"*. further shedding light on similar preferences, as never waking up from his sleep is perceived as a blessing, in the face of an uncertain future.

Taking matters into my own hands – suicide

The findings also reveal that one participant, John, expressed the wish to consider terminating his own life, by having thoughts of committing suicide as he revealed:

> *"If I would still have mental capacity and I would be in pain, knowing my end is near and there is no hope, I would discuss with the doctor not to give me any medicine that would prolong my life, I would prefer simply to pass on, slowly, slowly. But in the eventuality of intolerable pain and there is no medicine to help me or anything, I wouldn't know what to do, I might insert my finger in a light bulb socket and be done with it."*

It is important to note the thought process that went through John's mind is that in the eventuality of a painful EOL, he is willing to discuss with the medical team to withhold futile medical treatment to avoid prolongation of life, but in the possible reality of having to withstand unbearable pain, he is willing to take matters into his own hands.

A good death

The findings indicated that most participants have considered various illegal or immoral pathways to terminate their life, in the face of unbearable pain, suffering, and a futile prolongation of life. Their main goal at EOL was to achieve a good and dignified death. Angela remarked, *"I would tell them, 'no, I don't want those invasive lines or things of this sort, let me just die naturally',* revealing that she prefers to avoid aggressive medical treatments in her EOL in favour of a good and natural death.

Moreover, Paul also remarked*, "I would prefer palliative care, because if it's possible, I would prefer to be left in peace"*. By so doing, Paul addressed his preference for palliative care for his EOL to help him achieve a good and dignified death and avoid pointless suffering. Similar thoughts were shared by Jane when she stated, *"let me die in peace"* and by John, narrating the painful EOL experience of his father-in-law when he stated, *"and don't give him any medication to prolong his life, let him simply pass on slowly slowly…"* This is further indicative of the fact that futile medical interventions at the EOL are seen as a barrier in the achievement of a good death.

4.5.4 Theme IV – Attitudes to Decision-making at the EOL

This theme sheds light on the availability of EOL discussions within an institution and which decision-making roles the participants prefer to adopt within the decision-making process involving EOL decisions. Moreover, the findings reveal the role of clinicians and relatives within the decision-making triad at EOL, with an indication of the preference of involving proxy decision-makers and the thoughts about truthful information and the element of trust within this phase of life.

No opportunities for EOL communication

There was a general agreement amongst participants that EOL discussions are not the norm within the institutional setting. Emphasizing the fact that they are given no opportunity to participate in EOL discussions, Sue remarked, *"till now, I never had the opportunity, you are the first person with whom I am discussing such things"* In addition, as the majority have expressed, John questioned the availability of adequately trained staff to hold such conversations and their expressed need for such intervention as he added, *"that's it for me, the opportunity to speak to someone, I really enjoy this opportunity, because you can express yourself with someone who understands you, because in here, with whom can I speak?…"* Some of the participants further added that the concept of death is only mentioned when a resident passes away, with some of the participants also mentioning the lack of availability of other residents to hold these types of conversations with, due to being surrounded by cognitively impaired residents.

Decision-making roles at EOL

To clearly understand the different decision-making roles chosen by the participants at EOL, a typology utilized by Braun et al. (2014) was adopted in this section to differentiate between Activists and Delegators. The findings revealed that most of the participants chose to be activists, falling within the Autonomist sub-category as John revealed, *“till I have cognitive capacity, I take the decisions”*. Angela, on her part, fell within the Altruist sub-category as she stated, *“if my son has to take the decision with his wife, I do not want my son to feel guilty for taking the decision himself…”* This interestingly revealed that she wants to remain in control, not to exercise her autonomy but rather to relieve the burden of decision-making from her son.

On the other hand, Paul was the only participant who fell within the Delegator category, revealing he is an Absolute Truster as he admitted:

> *“I do not want to take any decisions beforehand, they do what they think is in my best interest and that’s it. I accept the decisions of whoever is concerned, doctor, family members, absolute trust”.*

This highlighted the variation in the decision-making thought processes that older adults apply for their prospective decisions to control their care, shedding further light on the importance of trust in the EOL.

Shared decision-making; the role of clinicians and relatives

The findings further revealed that there was a general indication that shared decision-making for EOL decisions is the chosen way forward in EOL decision-making. There was general agreement amongst the participants regarding their preference to be involved in the decision-making process, where the doctor and nurses act as medical experts, as Sue remarked:

> *“If I am capable, I want to be involved, I do not want to be presumptuous and take the decision by myself. I would ask the doctor and nurses for their help, because they have much more experience than me, so I want some explanations, to be involved and discuss with me, I want that…”*

Following the preference of the choice of clinicians for their medical expertise within the decision-making triad, the participants also choose their most trusted relatives to act as their proxy for non-medical decisions in the EOL, as Paul remarked:

> *“In that instance, we (siblings) share medical preferences between us. For personal matters, they all take interest in me, maybe two of them in particular, in fact much more, so I trust them more, I would confide with those that show interest…”*

Trust and truthful information

It is also relevant to mention, a concern shared amongst some of the participants, where they gave preference to the process of shared decision-making, as opposed to paternalistic approaches to decision-making that exclude the patient from the decision-making process. To this end Jane remarked:

> *"Just like back in the days, making a fool out of you, they tell you, you don't have anything and the family members would know everything and you won't have a clue. But if they would tell my children first, they would tell the doctor not to tell me, for me not to exaggerate things…"*

This adds to the importance of the concept of trust between the different stakeholders participating in the decision-making process at the EOL, highlighting the need for transparency in information sharing and the awareness of past practices that are still vivid in the participant's minds. This also highlighted the wish of the participants to be informed about their diagnosis.

Proxy decision-makers

In the eventuality of loss of decision-making capacity, most of the participants have revealed a general preference for having their family members as their substitute decision-makers as Paul highlighted:

> *"Then if I am not capable to choose, yes, I want that my family members would discuss between themselves and with the relevant medical personnel, whatever, I am ready to tell them from now, that I would accept whatever comes out of that conversation and from the discussions with the medical team, I accept everything…"*

It was also relevant to mention that proxy decision-makers were entrusted to have discussions with the medical experts before taking any decisions on their behalf. With no anticipatory care options available, as is advance care planning where future care preferences are documented, there was the feeling amongst some participants, that there was no choice but to trust the decisions of others at that stage, as John remarked, *"If I am not capable to take decisions for myself because I would not have brain capacity, there is no choice but to trust others, whether you want or not".* Corroborated by similar comments by other participants, it was emphasized that once cognitive impairment becomes a reality, there was no choice but to trust the choices of their family members.

4.5.5 Theme V - ACP to Mitigate the Anticipatory Fear of Loss of Autonomy

This theme illustrates another major concern amongst the participants, namely the possibility of loss of decision-making capacity at the EOL. In addition, there was noted the appreciation of the lack of education and awareness on anticipatory care options that could safeguard and maintain their voice, once decisional capacity is lost. In addition, to address their concerns, the participants had the opportunity to share their thoughts on the applicability of ACP, and in which manner such a tool could be utilised with profit.

Losing decision-making capacity

The findings revealed that one major concern among the participants studied, was the possibility of losing cognitive capacity and the subsequent loss of their voice regarding preference for future care, in their EOL. Referred to by the researcher as ‘the pending fear’, this feeling was shared amongst all the participants, for instance, Yuri remarked: *“the person has a brain, then you will have to see how it will end, either for the good or for the bad, it’s frustrating, who knows, I do not want to experience that…”* This was further corroborated by other comments throughout the interviews. Various participants stated concern on this point, these included, *“till I have a good memory” (Jane), “till I can still think” (John),* and *“till your brain still reasons well” (Sue)*. This fear was noted to be internalized in two different ways, firstly from previous experiences of deceased family members suffering from end-stage degenerative diseases and secondly from their current living milieu, where they witnessed other older adults suffering from degenerative diseases, affecting their voice in their EOL.

Lack of awareness of anticipatory care options

Upon the introduction of the concept of ACP, there was a general sense of surprise amongst the participants, as their general assumption was that once their voice was lost in their EOL, they are then at the mercy of others, with regard to decision-making for their future care. This element of surprise was highlighted by Yuri when he remarked, *“OHH MY GOD!!, these things do not even cross my mind, but you are making me aware of them (laughs), it’s obvious, you have to try to improve your life as much as you can…”*, further implying that once he was aware of such concept, it is seen as an opportunity to improve his quality of life at the end.

Moreover, Jane added, and mentioned the issue that advance wishes are turned into directives for the end of life:

> *“if you lose cognitive capacity, you wouldn’t know what happens to you, documenting your preferences or not, they would still do whatever they like. So, are you saying that if I document my preferences beforehand, they will adhere to my preferences?”*

Apart from her unawareness of the availability of ACP, she also seemed to be in disbelief that her preferences could still be given prominence once her decision-making capacity is presumed to be lost. This also sheds light on the perception of some of the older adults, who assumed that with loss of cognition, there is also the loss of autonomy and control.

ACP - the light at the end of the tunnel

Following the participant’s understanding of the applicability and scope of ACP, the majority showed a sense of relief and a positive outlook towards the use of such a tool, as John remarked:

> *“I would document my preferences, then if I lose cognitive capacity, it is dependent on the others to adhere to my preferences…but at least my family would know what my wishes were before I lose decision-making capacity…”*

This highlighted the importance of ACP as a tool to document their wishes and preferences, in the case of cognitive impairment, to further respect their autonomy at EOL.

On the other hand, Paul questioned the depth of the tool as he remarked:

> *"I see it as too restrictive, if it doesn't have twenty volumes, it does count, you can't have it in twenty volumes, to cover all the possibilities of human thoughts. If you are going to restrict it to a few questions, I am very much against this document…"*

This was fascinating to reveal, as Paul was not against the scope of the tool perse, but rather against his perception of ACP, as it did not provide him with all the possible healthcare scenarios at the EOL. This also shed light on the need for further education and awareness of anticipatory care options and their actual content.

Having a voice amidst a sea of silence

Moreover, some of the participants revealed how the introduction of ACP would reinforce different facets of autonomy, as Sue stated, *"I'm in favour of at least giving us a choice, then if others want, they can accept or not"*, implying that with the availability of this tool, their freedom of choice is also respected in their EOL. In addition, Jane remarked, *"and not let them do with you as they please",* further implying that such a tool would provide a unique opportunity to maintain control over their own body once decision-making capacity is lost.

The majority understood the fact that ACP is a novel concept that could finally give them a voice, amidst a healthcare system which is silent on the matter and within an institution, where silence prevails once mental capacity is lost.

Peace of mind till the end

Some of the participants also revealed that the introduction of this ACP tool would provide them with peace of mind at the end, as Sue stated, *"at the least, you would have prepared the way of how you wish to be cared for in your last phase of life"* Apart from exercising autonomy till the end, ACP was also seen to provide peace of mind in the still cognizant person, as the participants expressed their thoughts regarding the uptake of ACP as a means to plan their own care once decision-making capacity is lost. It also served as an opportunity to let their loved ones know, how they wished to be cared for in their final days.

Achieving a good and dignified death

Furthermore, the introduction of ACP was seen as a unique opportunity to finally have a say on their own impending death, as Jane remarked, *"die in peace and without suffering"*, indicating that ACP provided the opportunity to achieve a good death and most importantly, the means to avoid the possibility of suffering at the EOL. Angela further revealed that ACP is a needed opportunity to avoid futile and aggressive treatments in instances where there is no hope for a cure, further spelling out the need to avoid suffering and pain in the last stage of life when she stated:

> *"When I would arrive to a point, where death is certain and there is no recovery, I would prefer not having any medical devices attached and things of that sort….so yes I would want to document that, till my brain still functions…"*

4.6 Chapter Conclusion

Following a brief descriptive segment on each participant, this chapter aimed to provide a detailed walkthrough on how older adults residing in SVP perceive and relate to death and how these conceptions are subsequently translated into subjective attitudes towards decision-making at the EOL. In addition, the concept of ACP was introduced, shedding light on varied thoughts of how such a tool could prove to be a newfound asset amidst an uncertain phase ahead.

The following chapter focuses on discussing the study findings with reference to the existing literature, in view of substantiating these findings and further shedding light on the subjective perception of local older adults on their last phase of life.

CHAPTER 5

DISCUSSION

5.1 Chapter Introduction

This chapter discusses the research findings derived from the analytic process of the interviews conducted in relation to relevant literature and in the quest to provide the most suitable answers to the research questions proposed. Given the paucity of local research in this field, in providing older adults with the opportunity to discuss certain marginalized concepts in the local health scenario, similar findings will be discussed in relation to the currently available world literature. Moreover, light is shed on an array of new findings inherent to the subjectivity of the local older adults, residing in Malta's largest institution.

5.2 Theme I - The Last Refuge

The participants revealed that a move to an institution was mainly backed up by the notion to preserve their overall well-being and maintain independence. Contrastingly, there were observed several responses indicating that a move to a LTC facility could pose a threat to the integrity of the person and their meaningful existence. Considering John's example, his sense of well-being was related to the fact that he retained mental capacity and autonomy. This was also noted in a similar study conducted by Hanson et al. (2019) whose study participants related their overall well-being to the blessing of still possessing compos mentis whilst also maintaining their independence. In their study, Ternestedt & Franklin (2006) also indicated that self-determination is a key component for the preservation of their well-being within institutions, as with the retainment of their daily habits, older adults fuel meaning into their current existence. This in turn provided them with meaning and strength, which translated into resilience in old age.

Moreover, the overall well-being of certain participants was threatened by loneliness, as Yuri described his detachment from social engagement at ward level, which was mainly attributed to the fact that he is surrounded by mentally incapacitated patients. This is corroborated by the same findings in Tjenberg & Bokberg's (2020) study, where they revealed that life in an institution, was characterized by negative experiences such as co-habitation with residents having cognitive impairment. This led to social isolation and loneliness for those who were still cognitively preserved. In addition, similar to findings in this study, Morlett Paredes et al (2019) revealed that even though the institutional setting provided a community-like environment, residents still felt a feeling of emptiness, lack of meaning and diminished hope, which is seen to be counteracted by personal psychological traits such as spirituality.

Vaughn et al. (2015) added that loneliness and social isolation can be associated with symptoms of depression among older adults, hence, increasing the possibility of having a negative impact on the institutionalized older adult's well-being. Similarly, Osterlind et al. (2016) revealed that older adults do experience loneliness whilst residing in LTC, both from a social and an existential perspective, possibly leading to further threats to their self and their identity. Jannson et al (2017) further added that loneliness, apart from being associated with poor self-rated health and psychological well-being, it also predicted a higher mortality rate within institutional settings.

In addition, the study findings revealed that their current living arrangement also posed threats to their independence and freedom of movement, when certain institutional barriers were imposed on their living experience, as emphasized by both Paul and Sue. These findings corroborated to similar findings in Osterlind et al. (2016), where the participants also revealed a certain feeling of entrapment imposed by the institutional culture, leading to further marginalization from their previous social routines connecting them to the outside world.

These findings may also be considered through the concept of 'total institution' by Goffman (1961), where, as narrated by the study participants, they do mainly move to an institution to preserve their well-being and security, but such move has endangered their control over their own life, adversely affecting their autonomy and freedom of action. This may impact the older adult's mood and self-esteem (Ames, 1991), where the symbolic and imaginative connections created with their current living milieu were seen to pose a threat to their sense of self and personhood (Peace et al., 2005).

Jane and Sue also revealed that their current social roles and relationships within the institution influenced their well-being. As several participants still resided with their spouses, it was noted that they had a higher sense of purpose and meaning in their lives, which led to a stronger sense of personhood. Maintaining such social relationships in their daily lives was also noted to result in the preservation of their self-identity in the latter stages of their life (Rogers, 1990, Kitwood, 1997, McCormack et al., 2012).

Once the concept of death was introduced, in relation to their current living milieu, most of the participants expressed their thoughts about their own impending death. Most of the participants chose SVP as the last place where they preferred to receive care for their EOL rather than being transferred to an acute setting, implying that such a living milieu was also chosen to be their preferred place of death. Mathie et al. (2011) and Smedback et al. (2017), also discussed this preference, where their participants revealed that they would prefer to die in an institution, where they tend to build therapeutic relationships with their care providers, rather than being transferred to an acute setting for their final days of life.

This study also revealed the perception of exposure to death within SVP, from the point of view of older adults. It was observed that exposure to people dying in an institution was a close encounter, just eight feet away. It was also revealed that the occurrence of death is quite common in this setting and is regarded as something normal that is to be expected within such a living environment. This phenomenon showed parallel findings in Munn et al. (2008), who remarked that the normality of death was defined through their experiences of the frequency of deaths and their physical proximity to other residents experiencing the dying process. The participant's perceptions of the frequency of death may be further corroborated by results from several quantitative studies (Broad et al., 2013; Pivodic et al., 2015), which indicate that institutions are increasingly becoming the most common place where people die. This is also reflective of the increased trends of dying away from home, favouring dying in an institutional setting (Dasch et al., 2015).

Whilst also acknowledging such trend for dying in an institution, Kalseth & Hoverson (2020), emphasized the fact that obtaining knowledge on the place of death is of key importance as it is known to impact the appreciation of death and dying namely, the quality of the dying experience, the involvement of the family in care, the design of health services and health policies. To this end, even though SVP was found to be a common place where people die, there is still no national EOL policy to regulate EOL care (CDE, 2018), this seemingly indicates the delivery of unstandardised EOL care (Sussman et al., 2020).

5.3 Theme II - Death and Dying – The Insider's Perspective

The study findings revealed that the meaning of death and the dying process is personal and subjective and that the acceptance of such eventuality is closely related to the older adult's pursuit of meaning in life and the achievement of integrity, which can be understood through the psychological development theories of Erikson (1997) and Peck (1968).

The findings revealed that death is mainly viewed from two perspectives, as a release from suffering and pain in the last stages of life and as the inevitable outcome of life which can be understood via the T-CMDA by Wong et al. (1994). The first major perception of death can be related to the 'Escape Acceptance' component of the T-CMDA (Wong et al. 1994) as most of the participants have chosen this path given the possibility of suffering and pain preceding their own impending death. The personal meaning behind this perception of death is seen to be derived from three different perspectives, in which the participants have related several past and currently lived experiences, that they are keen to avoid thus opting for death as the preferred escape.

The study findings unearthed three different perspectives of how institutionalised older adults derive the personal meaning of suffering and how they individually or collectively influence the person's perception of what makes a good death. The three perspectives, which I termed the 'Triad of Suffering Experiences' is the result of the participants' thought processes understood through the life review theory by Butler (1963), where older adults have related to the past and present experiences of suffering and pain arising: in the first option from personal experience of suffering in the past, secondly on the experience of suffering on their loved ones, and thirdly as a component of their current experience of suffering seen in other residents who passed away whilst sharing and living in the same room in the institution.

The first perspective that was observed in the study findings was suffering on the self and physical body, which goes in line with similar findings from Chochinov et al. (1995), Kelly et al. (2002) and Bollig et al. (2016). Here the threat of integrity on the physical being instilled fear in the participants themselves, which they were keen to avoid, thus choosing death as an alternative route. Yuri's near-death experience imbued with pain and suffering was noted to have affected his thought process, and as a safeguard to avoid such instances again, death was called upon to release him from such an unwanted reality.

The second perspective by which the participants have internalized the personal meaning of suffering is from the witnessed events of pain and suffering in the EOL of their loved ones, especially their spouses and younger siblings. Jane, Angela and John's narratives revealed that the uncontrolled suffering, pain and anguish in the finite minutes of the life of their loved ones, was too much to bear, thus this affected the eventuality of suffering and pain to their perception of death, resulting in their expressed preference of avoiding such eventuality in their eventual death. Cassel (1982) explained that suffering can occur in relation to any aspect of the person, where threats to loved ones can be understood as threats on the self, as family members could be seen as an extension of the person itself. Moreover, this perspective of suffering could also be understood from the participants' viewpoint as being an insult on their perceived future, family ties, roles, and relationships. As the findings indicate, familial experiences of suffering are perceived as a substantial threat to their personal integrity, thus expediting death is considered the preferred option. In fact, when relaying several familial death experiences, the participants highlighted two different polarities of meaning, being the swiftness of death without pain and suffering as a blessing and experiences where suffering preceded death, expressed as being an undesired outcome.

Thirdly, apart from suffering on the self and loved ones, the study participants also associated this consideration with suffering they witness first-hand in their daily lives in other residents whilst residing in an institution. This connection can be understood via the SEA view of the person (Hughes, 2001), as it suggests that the person must be understood as being situated and embodied in the context of time and place and "understanding persons involves an understanding of the narratives in which they are embedded" (p. 88). Therefore, this connectedness of the suffering experience of study participants with other residents who passed away can be related both on the personal/physical level and the living environment they are sharing. Subsequently, in Cassel's (1982) view, threats on the other residents could be perceived by the participants as threats to the integrity of their perceived future related to the social environment they are residing in, thus translated as possible insults on their own future self through symbolic connections. Therefore, in line with the participant's perceptions, they are not essentially longing for death, but rather view death as the perfect escape from the cruelties that might be expected before their impending death.

The study findings revealed that death is accepted as the natural and inevitable part of life, as Jane and Yuri, amongst others remarked, explained as 'Neutral Acceptance' in the T-CMDA (Wong et al. 1994). The literature review has shown that other studies have identified similar views regarding the perception of older adults on death and dying, where the eventuality of death itself is not feared, but worries seem to revolve around the dying process (Leichtentritt & Retting, 2000, Bollig et al., 2016, Ternestedt & Franklin, 2006, Tjernberg & Bokberg, 2020). This view of death can be substantiated by the theory of self-actualization (Maslow, 1968), where self-actualization can only be achieved when individuals come to terms with their personal mortality, therefore not threatened by personal death. In addition, Frankl (1965) also suggested that in finding meaning in life, one's fear of death is removed, increasing one's well-being.

Angela shared an alternate view of death and dying, which could be partially explained via the T-CMDA (Wong et al. 1994), 'Approach Acceptance'. This participant was not concerned with a happy afterlife, but rather fearful of the unknown following the death of the physical body. As identified in other studies (Engel et al., 1998), God was viewed as a comforting figure in this transition between the living and the dead. In addition, these findings concur with findings from Hallberg (2003) as individuals with a higher level of religiosity like Angela, were reported to view the afterlife either as a reward or a punishment.

Jane and Sue also viewed death and dying as the permanent loss of their current living environment, as a consequence of their availing of a flatlet in a couple's ward. According to the current institutional protocols, once one of the members residing in a two-bedded flatlet in a couple's ward passes away, the remaining person is transferred off within days to a general ward, to make space for another couple. This was seen as a major concern by these participants as apart from the devastating loss of their loved one, the eventuality of death, was also seen to break down the new social and symbolic ties built within their ward environment. Therefore, such concern was identified as testimony where residents build personal and subjective meaning around the multidimensionality of death within this living environment. This goes in line with the work of Cassel (1982) who depicted the components of the threats to the person, to be perceived as threats to their future, relationships, environment, and comfort.

5.4 Theme III – EOL Care Preferences – The Ideal Death

Some participants, namely John, Paul and Angela chose to avoid life-sustaining treatments (LST), as this was considered a risk factor in prolonging their futile life at the end, therefore increasing the risk, of prolongation of suffering. Similarly, Ke et al. (2016) suggested that patients at this stage need to perform a balancing act between quantity and quality of life at the end, where participants in their study opted for quality over quantity of life. This preference for a quality death was also reported in other studies (Hanson et al., 2019, Gonzalez-Gonzalez et al., 2020).

In addition, some of the study participants were also in favour of receiving adequate pain and symptom management, in their final days, without the risk of disproportionately extending their life. Since there is a close relationship between pain and suffering (Cassel, 1982), John, Paul and Jane, preferred the provision of appropriate pain management to relieve them of suffering. This concurs with findings from Bollig et al. (2016) whose participants opted for adequate pain management for their final days, as pain relief was considered to be beneficial to the achievement of a good natural death.

Maintaining a sense of control over the EOL phase was also mentioned by all the participants, as this was given a lot of importance in relation to their preserved decisional capacity. Study respondents ranked autonomy highly. This maintenance of control echoes how respondents expressed their EOL preferences. In addition, respondents expressed their preferences to delegate EOL decision-making to proxies they trust if they were to lose mental capacity for decision-making. These findings echo the findings from Malhotra et al. (2012), where apart from achieving a sense of control, in having their voice heard throughout the EOL phase, adequate pain and symptom management and the avoidance of the futile prolongation of life, were all chosen as preferences and therefore considered key factors in the delivery of quality EOL care, as informed by the participants in this study.

Moreover, coming to peace with God, in the EOL phase was also mentioned by Sue and Angela, as one of their preferences before the eventuality of death, concurring with results from Steinhauser et al. (2000). Such preference was given importance in achieving a sense of completion and fulfilling their existential and spiritual needs in their final days. This goes in parallel with the findings of Gott et al. (2017) as such preference was also ranked highly amongst their EOL care preferences, which can be also related to specific sociocultural contexts in which such preferences are formulated.

In a healthcare context where the availability to document EOL care preferences is scarce, John, Yuri and Angela also mentioned various methods of how they would consider ending their life abruptly in the face of an uncertain future and fear of suffering. Wishes to terminate their own life through euthanasia, physician-assisted suicide and suicide were consistent with similar findings in Cicirelli

(1997). Similar pathways were chosen in view of the perception of diminished quality of life at the end and hopelessness in their diagnostic trajectory. Moreover, in her study, Chochinov (2003) confirmed that hopelessness is a strong predictor for individuals requesting any form of a hastened death. This can be related to spiritual and existential suffering experienced by the participants as Chochinov (2006) added that hopelessness amongst other manifestations such as anxiety and depression were linked to psychological suffering within the patient's experience.

To this end, the findings of this study concur with the findings from Kelly et al. (2002) and shed light on relevant factors associated with the wish to hasten death. These include concerns with physical symptoms and psychological suffering, whilst having less confidence in symptom control and less social support at the end. This may shed light on why participants opted to consider the termination of life, particularly based on several bad past experiences of suffering in the EOL of their loved ones, and the suffering and pain witnessed in their ward. One must relate this phenomenon to the fact that in our country we still are regulated by a healthcare system where EOL policies are non-existent (CDE, 2018). These might all be precipitating factors in expressing such preferences.

On the contrary, none of the participants in Bollig et al. (2016) study expressed the wish for any active means to terminate their life. One possible explanation could be that in Norway, EOL discussions in the form of ACP are already available within institutions, whilst in Malta, older adults in institutions are still faced with a healthcare system still "geared towards cure" (CDE, 2018*,* p. 13). Thus, the older adults in this study may be seen to be at a disadvantage, when faced with uncurable diseases that limit life expectancy.

It was observed, that throughout their narrations, participants all opted for good and natural death as their most preferred choice on how they would wish to leave this world. As explained above, this was requested in the form of adequate pain and symptom management, the avoidance of life-sustaining treatment and interventions, addressing spiritual and existential beliefs and, achieving a sense of control over their EOL phase, as also explained in the domains by Singer et al. (1999) and Chochinov (2006). Moreover, the value of a natural minimal suffering death was mentioned by Gardner & Kramer (2010) and Fleming et al. (2016), where the swiftness or suddenness of death was also mentioned as an important factor, which also goes in line with the wishes of some of the participants in my study.

All the aforementioned factors in the achievement of a good death were mentioned by Emanuel & Emanuel (1998) in their framework of a good death *(Figure 3)*, in which 'care-system interventions' need to be adopted in order ameliorate the 'modifiable dimensions of the patients' experience'. Consequently, in the absence locally of ACP, which was considered as one of the major care-system interventions in Emanuel & Emanuel, the local healthcare system is seemingly failing to provide the adequate means to modify the ‘six dimensions of the patient’s experience’ according to their personal and subjective meaning, resulting in the unfavourable or unwanted outcomes in the participants’ dying experience.

This might also explain why participants also opted to consider active means to end their life, given that the current healthcare system they are paying for, does not meet the requirements and care goals they set for their own EOL phase. To this end, one must also note that the preferences mentioned by the participants in this study resonate with the definition and scope of palliative care (WHO, 2011). This indicates that the current system of delivering care in institutions does not meet the requirements and needs of the service users, hence seemingly receiving suboptimal EOL care, threatening their autonomy and dignity. This change in approach to favour palliative approaches to care is also advocated by Froggatt et al. (2020) as institutions are increasingly becoming death sites for older adults.

5.5 Theme IV - Attitudes to Decision-making at EOL

The findings revealed that all the participants were in favour of SDM as regards the ideal process for decision-making and this concurs with the findings from Gjergberg et al. (2015). This was deemed as the ideal process since the participants wished to be informed about their current disease prognosis and available treatment options, whilst sharing information with both the clinicians and family members, in line with their preferred goals of care (Weissman, 2004).

In addition, the findings revealed that the participants preferred the clinicians to be involved based on their clinical expertise and also in view of their knowledge regarding their current health status and possible future diagnostic trajectory. This echoed the findings of Bollig et al. (2016) who found that clinicians ought to be included in the decision-making process based on their technical expertise and the perceived lack of knowledge of both the patients and their family members.

Subsequently, family members were seen as being necessary to be involved by many respondents in EOL discussions. This was consistent with the findings of Hanson et al. (2019). Bollig et al. (2016) further indicated that family members wish to be involved in the decision-making process but would rather discuss possible treatment options with the clinicians first, since they possess the medical expertise, before their possible participation in the process, since both would act in the best interests of the participants, in respecting their dignity and well-being till the end.

This study also highlighted the preferred decision-making roles the participants wished to assume with regard to anticipatory health-related decisions, in the eventuality of losing decision-making capacity. Two distinct roles were observed, which related to the typology of findings in Braun et al. (2014), as being ‘activists’ and ‘delegators’. This is consistent with the findings by Winzelberg et al.

(2005) since patients do not value autonomy equally. In line with Braun’s typology, most of the participants enrolled for my study expressed their preference as being activists in decision-making in their EOL. Activists, according to Braun et al. (2014), assume the responsibility for the final decision themselves, thus expressing their authority as means of exercising their autonomy.

There are two different decision-making styles mentioned within the parameters of ‘activists’, Autonomists and Altruists. Jane, John, Sue and Yuri, associated more with autonomists, by expressing their preference for control till the end, and would prefer that their preferences and wishes are adhered to in view of respecting their autonomy. This relates to similar findings from Gjerberg et al. (2015), who mentioned that some participants wanted to assume full responsibility for these types of decisions. Angela considered herself an Altruist, as she preferred to take final decisions herself, to relieve the burden of decision-making off her son, since she stated it was her responsibility, which resonates with similar expressions in Braun et al. (2014).

On the other hand, Paul, fell within the bracket of ‘delegator’, as he strongly suggested that he would entrust future health decisions, to whoever has the authority, based mainly on trust and the unpredictability of future decline, as also revealed by Gjerberg et al. (2015). To this end, this participant assumed the style of Absolute Truster, showing similarity to the findings of Braun et al. (2014). In this case, the strong relationship with his siblings was highlighted by his transferring all the decision-making authority onto them once decision-making capacity is lost. In addition, the participant also mentioned that in view of anticipatory health-care-related decisions, he would entrust his siblings to discuss with the relevant medical experts about the best possible course of action to be taken in his best interests.

This resonates with the consensus-building approach mentioned by Karlawish et al. (1999) to be followed once decisional capabilities are lost. Such a decision-making approach is based on what is known about the patient by well-meaning relatives with regard to preferences, values and other relevant knowledge, in combination and agreement with expert guidance from the clinicians. Moreover, Dimech (2019) stated that such an approach in the EOL, is the most suitable decision-making model, especially in patients with end-stage dementia, where a balance is achieved between all the stakeholders concerned, whilst the interests and dignity of the patients are still safeguarded.

One possible barrier to allowing older adults to exercise their decision-making autonomy in the current healthcare system may be related to the lack of availability of EOL discussions in institutions, as revealed by Jane, John, Sue and Yuri. This goes in line with similar findings in (Gjergberg et al., 2015, Towsley et al., 2015 & Hanson et al., 2019). Mirroring several responses in this study, Hanson et al. (2019) indicated that EOL discussions are seen as natural conversations brought up in old age, whilst in contrast, some of their findings also reveal that older adults living in institutions may at times avoid such conversations, as they might result in anxiety and depression.

On the contrary, most of the participants in this study were surprisingly grateful for such an opportunity to discuss their EOL, as the interview process was considered their first-ever opportunity to discuss matters related to their own EOL phase. This resonates with findings from Mathie et al. (2015), where the participants also found that their respective study was seen as an opportunity to have their first-ever EOL discussion, which was assumed as an opportunistic opening to discuss their past, present and eventually have someone with ample time to just listen to them.

Even though there was a general readiness to participate in EOL discussions, John and Sue questioned if there would be any available or trained staff to have these types of conversations with, even though their general relationship with the staff was good and satisfactory. This finding was also mentioned by Mathie et al. (2015) where staff is perceived as too busy to hold these types of conversations with residents since staff would be investing more time with dependent patients with complex needs. This conflict of responsibilities among staff was also highlighted by Tjenberg & Bokberg (2020). In fact, John and Yuri mentioned that co-residing with residents suffering from cognitive disabilities, adversely affected cognitively healthy residents, since the staff dedicated most of their time to handle the needs of higher dependency residents, to the detriment of the provision of time to discuss thoughts about their existence and EOL, which might have increased their quality of life at the end.

Another explanation related to time availability to sustain these discussions locally could be the result of the paucity of healthcare professionals working in institutions, which is not reflective of the total population and care needs of older people (Thake et al., 2020).

This lack of discussions could also be related to cultural norms (Ke et al.,2016), both as a nation and within the institution, as some of the participants indicated that the topics of death and EOL are considered as being not the norm, with one participant also mentioning that such topics are ignored. Even though we are considered a Western country, Malta still resembles Eastern cultures in view of considering topics related to death and dying as a taboo (Ke et al., 2016), thus being marginalized as a barred topic for discussion (Dimech, 2019). This notion is seen to be absorbed within the institutional walls, given that some of the participants revealed that their first proper discussion about EOL issues was held with the interviewer of this study, therefore quite late in their life cycle.

In addition, having no national EOL policies to guide and manage care for older adults in their EOL (CDE, 2018), could also add depth to this finding, as without policies in place, such conversations are just left to chance and/or missed (Towsley et al., 2015). Consequently, one might assume that discussions about death and dying are silenced within institutions, leading to the lack of opportunity for expressing their existential thoughts and meanings (Osterlind et al. 2016), resulting in the possible deprivation of their self-image (Djivre et al. 2012).

5.6 Theme V - ACP to Mitigate the Anticipatory Fear of Loss of Autonomy

The study findings revealed that one major concern amongst all the participants was the fear of losing decision-making capacity within their EOL phase, threatening their autonomy and human dignity. This finding resonates with findings from Hanson et al. (2019) and Tjenberg & Bokberg (2020), where apart from their fear of losing physical function in their EOL which threatens their independence, they also are concerned about their cognitive health in their last stage of life. Relating to the findings of this study, this fear amongst the participants might be linked with their expressed preference of maintaining a sense of control over their last period of life, in which, if their fear materializes into actual reality, their need for control over their remaining period of life, is jeopardized. This fear of losing autonomy might also be related to their fear of being exposed to suffering and pain preceding their own death, as the findings indicate. This strongly sustains the notion that having a sense of control is vital to mitigate the risk of suffering at their EOL.

This study also highlighted the general lack of awareness amongst the participants about the availability of anticipatory care tools which may be utilised with profit to sustain autonomy. This was evident from their facial expressions and increased level of interest, once the concept of ACP was introduced. Upon deliberating the scope and the applicability of ACP to preserve their autonomy and dignity in their EOL, most respondents expressed an increased level of enthusiasm regarding such an option. This finding echoes those published by Malcomson & Bisbee (2009) and further indicates the need for the availability of such tools to safeguard their well-being till the end. Considering the Maltese context, this expression of surprise amongst the participants might be explained in view of the lack of national EOL policies guiding EOL care in institutions (CDE, 2018), which is seemingly leaving the local older adults blind to exposure to useful tools to maintain control over their EOL.

Concurring with findings from Piers et al. (2013), this study revealed that the main motivators for the uptake of ACP were based on previous experiences of death and dying of loved ones and on their own personal fears, which were further amplified throughout their residence within the institution.

Many study respondents revealed that an ACP could enable them to maintain control over their lives till the end. They responded that with the opportunity to document their values, wishes and preferences via such a tool, their voice could be preserved and still given prominence, in the eventuality, they lose the cognitive capacity for decision-making. Therefore, resonating with findings in Gardner & Kramer (2009) and Sharp et al. (2013), ACP was considered a tool to preserve their preference for control till the end in such a delicate phase and it also serves as an opportunity to address their fear of losing their decision-making capacity in the future.

The opportunity to maintain control over their last period of life was also noted to result in peace of mind for most of the participants, as with the filling out of an ACP, they finally had the opportunity to plan their own future, amidst a healthcare system where the uncertainty of future decline is left unaddressed (CDE, 2018). This advantage in drawing up an ACP was also highlighted by Schubart et al. (2014). In addition, several of the participants in my study, namely John, Jane and Sue, indicated that their peace of mind in drawing up an ACP might also be related to the fact that their family members or dedicated proxy decision-makers would have the opportunity to be aware of their past wishes and preferences, a point highlighted in Levi et al. (2010), which might also transpire into a decrease in possible conflicts in-between family members and with clinicians (Winzelberg et al., 2005).

Moreover, the novel concept of ACP was viewed as a unique opportunity to preserve the participants' autonomy and dignity in the latter stages of life, as it was deemed as their first-ever opportunity to address their fear of suffering preceding their own impending death, which might interfere with their views of a good death. This finding concurs with findings in Htut et al. (2007) and Seymour et al. (2004), as the availability and uptake of ACP were viewed as a shield against futile treatment which might prolong undesired suffering at the EOL. In fact, the introduction of ACP was viewed by most study participants as a facilitator in the achievement of a good and dignified death, as mentioned in Levi et al. (2010), as with such a tool in hand, they were allowed to maintain control till the end, achieve peace of mind and have their voice heard in an environment, where death is medicalised (CDE, 2018) and for the most part, silenced (Osterlind et al., 2016).

A contrasting view on the efficacy and applicability of ACP to guide future care was also revealed in this study by one participant, Paul, based on two factors. ACP was viewed as too redundant to be of use in an uncertain future decline, thus anticipatory decisions regarding health-related matters were not seen as possible to document all possible scenarios given his unforeseeable future. This view was further strengthened given his implicit trust in his family members, as it was indicated that it would be his siblings' responsibility to decide in his best interests, once his decision-making capacity is lost. This could be related to filial piety in Eastern Cultures (Ke et al., 2016), where the responsibility of decision-making falls on the shoulders of the children, rather than on the person receiving care. This could also be understood as the 'deferring approach' mentioned by Chang & Pang (2011), as even though the concept of ACP is clearly understood, decision-making is not avoided, but rather transferred to the trusted family members, based on the value of trust and the unpredictability of future disease prognosis.

The findings in this study also concurred with the findings of Leichtentritt & Rettig (2001), who suggested that EOL decision-making is mediated by individual, relational and socio-cultural perspectives, in which the participants considered both the past (heritage) and future (legacy) time perspectives. This is done by the deliberation of their subjective preference for the quality of care they would like to receive. Jeong et al. (2009) indicated that 'the essence of being', which translated to who the participants were in addition to their past lived experiences, were enhanced through the process of ACP. Therefore, as Leichtentritt & Rettig highlighted, there is a strong connection between the central values of dignity, quality of life and quality of dying, which are seen to be given prominence and centrality in decisions taken at the EOL. Indeed, as the findings of my study revealed, the introduction of ACP does in fact improve the quality of life and care at the EOL (Bischoff et al. 2013) which is then translated into quality dying, as the participants themselves are empowered to voice their preferences on the type of care they would wish to receive before their demise. This may further result in increased satisfaction for the participants themselves and their family members (Detering et al. 2010).

To this end, Dimech et al. (2020) highlighted the major dilemma faced by clinicians and family members at the EOL, namely the conflict between 'prolonging life' versus 'dignity in dying', where the latter was regarded as the preferred choice in sustaining quality of life in the final days. This study consolidates that finding, as the participants themselves, gave their own deliberations against the futility of prolonging life at the end and all were in favour of palliation and comfort, with autonomy and dignity being given prominence, in their ultimate goal of achieving a good death.

5.7 Chapter Conclusion

This study reveals that even though death is a common occurrence in local institutions, discussions concerning such eventuality are lacking, leaving older adults blind to possible means to improve their quality of life at the end and their preference to achieve a quality death. It is clear, that without the introduction of anticipatory care options, such as ACP, older adults do think of various other pathways on how they wish to terminate their own life, which, in their quest to achieve their desirable end-state of a suffering-free death, they end up choosing either immoral or illegal pathways. This results from the lack of proper EOL policies to guide care interventions, as it is evident that two of the major concerns amongst older adults living in institutions are the fear of suffering and pain preceding their own death and the eventuality of losing decision-making capacity in their EOL, in which the participants' voice, till now, was kept silent.

This study further revealed that older adults wish to sustain a sense of control over their EOL, where different variations of attitudes were also highlighted, revealing different meanings of autonomy from the point of view of the older adults. Subsequently, the introduction of ACP as a possible means to preserve their autonomy and dignity till the end was seen as the light at the end of the tunnel, as it was envisaged as a tool of hope, where their fears and concerns could be finally addressed.

The next chapter will summarise the outcomes of the study, whilst also listing down the strengths and limitations of this study. In addition, based on the implication of the findings, recommendations will be put forward for further research and in view of informing new policy strategies aiming to improve practice and further education in this field.

CHAPTER 6

CONCLUSION

6.1 Chapter Introduction

This concluding chapter summarizes the outcomes of the study findings in relation to the research questions underpinning the motivation for this research study. Moreover, an account is given of the strengths and limitations of the study, followed by a set of recommendations to further research in this field, inform policy, improve practice, and further education, based on the findings of this study.

6.2 Overview of the Study Findings

Older adults residing in SVP, apparently view death as a normal phenomenon within their daily lives, both in frequency and proximity, whilst seemingly coming to peace with the fact that the said institution was chosen as their final place where they wish to receive care. This study further shed light on how older adults related to death, mainly as being an opportunity to escape suffering and pain and as the inevitable outcome of life. This appreciation was derived from the meaning associated with their past lived experiences, their present situation, and their concerns about their perceived future state.

Moreover, it was revealed that older adults spoke out in favour of achieving a good and dignified death. Preferences of receiving adequate pain and symptom management, achieving a sense of control and spiritual completion, and the avoidance of the futile prolongation of life, were listed as important factors in achieving their preferred end state of life. To note, when the study participants deliberated about their EOL in a healthcare system which is seemingly silent on the matter, illegal and immoral pathways were considered as means to avoid pain and suffering preceding their own death. This was also expressed as a safeguard in the eventuality that they lose cognitive function to control their final phase of life.

As the findings suggested, older adults shared different attitudes towards decision-making at the EOL, yet the value of autonomy was seen to be subjective and given different meanings within the decision-making process. It was revealed that the process of SDM was given prominence, highlighting the importance of clinicians as technical experts in the field, and where family members are designated as proxy-decision makers in the eventual reality of the possible loss of decision-making capacity. Subsequently, their concern about the possibility of losing decision-making capacity was also highlighted as a pending fear amidst their final days.

The introduction of ACP was seemingly welcomed as a solution to allay their fears, as it was their first-ever opportunity at addressing their concerns and empowered them to maintain control if decision-making capacity was lost. Divergent views emerged regarding ACP, but nonetheless, it was indicative to be a newfound opportunity in their preferences of achieving a good and dignified death and as a possible means to avoid unwanted suffering in the end.

6.3 Strengths and Limitations of the Study

Given the paucity of EOL discussions and lack of related policies in institutions, the opportunity to conduct interviews on this topic was immensely welcomed by the participants, as it was considered their first-ever glimpse of an EOL discussion. Therefore, to my knowledge, these findings are the first-ever representation of how older adults in Maltese institutions relate to death and their subjective attitudes toward decision-making in their EOL. This might hopefully shed light on the unaddressed needs of institutionalized older adults and mobilize resources to provide them with better quality person-centred care, according to their interests.

Moreover, the study was considered a meaningful experience for both the participants and myself, as the level of depth of experiences shared allowed for their views to be heard and interpreted to provide valuable knowledge.

One major limitation noted was that the study was conducted in an environment where anticipatory care options are still lacking, therefore, given the constraints on the interview duration, some of the queries of the study participants might have been left unanswered. In addition, limitations were also noted related to the recruitment process, as within the time frame allotted, only six older adults volunteered to take part in this study, which were subsequently chosen as the participants. This could be attributed to the difficulty in finding mentally preserved participants in an institution, favouring the entry of persons with dementia, and possibly due to the sensitive nature of the topic, which might not be of interest to everyone. Moreover, another limitation could be attributed to the fact that the participants were chosen from only three wards out of a total of forty-six, which might have limited the diversity of experiences lived at the ward level, which could have possibly generated different findings.

Given that the study was conducted during the Covid-19 pandemic, the movement of participants was restricted and unfavoured in view of possibly endangering the participants’ safety. Therefore, after liaising with the Infection Control Nurse, that infection control protocols will be adhered to during data collection, some of the interviews had to be held in the patients’ rooms, rather than in the originally designated office, which would have been more welcoming and private for an interview.

The movement of patients was also restricted in view of certain institutional barriers imposed during the data collection phase. To this end, I liaised with the Chief Nursing Officer, that in case the participants needed to leave their ward for the interview, I had to accompany them to and from the interview site and take full responsibility for their wellbeing throughout the whole process. (*See Methodology Chapter, Section 3.10, for additional limitations*)

6.4 Recommendations for Further Research

The following recommendations are based on the implications of this study and the lacuna in local research as regards the voice of institutionalized older adults on their EOL phase.

1. New qualitative research should focus on the impact of the event of death on the surviving residents in the wards and the psychological and existential implications on their perceived future states.

2. Qualitative research should examine the perceptions and need for palliative care implementation in long-term care facilities from the patient's perspective.

3. Qualitative research should also be aimed towards gathering additional knowledge on the applicability of anticipatory care options like the introduction of ACP in LTC from the patient's perspective.

4. Qualitative research should also focus on the clinician's views on ACP and its appropriate implementation whilst caring for patients in their EOL and as a catalyst for decision-making at the EOL.

5. Qualitative research exploring the staff's attitude on how to encroach and communicate EOL care communication and decision-making to patients and their relatives.

6.5 Recommendations for Policy

With reference to the recommendations for action presented in the NSPAA (2014-2020) to 'maximize autonomy' and 'investing further in EOL care' in LTC (p. 22), as highlighted in the latest revised initiatives in the NSPAA (2023-2030) (p. 69), and in addition to the implications of this study, the following recommendations are suggested.

1. Legislation should be introduced to facilitate decision-making in the EOL to safeguard autonomy and maximize control, regulating concepts such as ACP and AD. This would allow the implementation of frameworks to regulate EOL care in institutions and provide guidance and safeguards to clinicians to provide care according to the patients' wishes and values. The

implementation of this legislation would also pave the way to improve the quality of practice within LTC (Froggatt et al. 2017).

2. Policies should be developed to initiate the implementation of a Palliative Care Approach in LTC and in other environments where death is a common occurrence. At SVP, this could develop into a specialist branch, where Palliative Care Specialists could be involved to provide palliation and comfort to residents and relatives in need. This service could also fill a lacuna in the current healthcare system and alleviate pressure from the ward staff who need to balance their energy in delivering quality care to both the living and the dying, simultaneously.

3. Early identification policies should be developed to identify residents with a limited prognostic trajectory, so care is tailored according to the resident’s actual needs and preferences, with all the other stakeholders involved in the process, based on the GSF-PIG (2022).

4. Policies should be developed to introduce ACP in LTC to create alliances between the person needing care, the family members, and the service providers and as an opportunity to respect the human rights and wishes of older adults. For new admissions, ACP should be offered as part of the admission triage package, where consecutive meetings could be held afterwards, upon their willingness to participate, by adequately and proficiently trained health professionals.

   Policies should also target current residents, where interested residents could also be engaged either in an opportunistic manner or when prognostic trajectories are bleak, by trained professionals with all relevant stakeholders involved.

5. Policies should also be developed when persons with cognitive impairment are admitted to LTC since decision-making for said residents usually falls on the shoulders of their family members/guardians. In such cases, the policy should facilitate and regulate the communication between the family members/guardians and service providers in creating transparency on the general condition of the resident and reach a consensus regarding decisions to be taken in the residents’ best interests.

6. After contacting the Bed Management at SVP (Mr Camilleri, December 2022, personal communication) and the management in a couple's ward at SVP (Mr Bajada, December 2022, personal communication) it was confirmed that there are no written policies regarding the transfer of surviving patients to other wards who lost their spouse or family member.

   As things stand, the bereaving patient is transferred to another ward after the funeral has taken place, therefore the surviving spouse loses his loved one, his living milieu, and his social connections all within a week following this tragic event. Ideally, policies should be introduced to safeguard the well-being of the surviving spouse and allow enough time for bereavement, whilst also respecting the need for other couples to be placed together.

   The policy should allow the bereaving resident to stay in the ward for at least three weeks following the funeral of his spouse, during which the resident is allowed to bereave, rest, and say the final goodbyes. With the help of an agent from Bed Management, the resident is then allowed enough time to choose his preference from the wards available. If two deaths occur simultaneously in a couple's ward, the surviving residents could be offered the opportunity, if they wish, to reside together until relocation, to make space for another couple. In such cases, the bereavement period is doubled, to allow them enough time to make their arrangements and transfers according to their preferences.

6.6 Recommendations for Practice

1. An in-house psychologist service should be introduced so that residents could share their thoughts and emotions with a qualified staff member about concerns regarding their EOL and death, especially when the event of death occurs within the same room and/or ward of the resident. Residents should be allowed to discuss freely their existential thoughts and what meanings they associate with them, within a specialized service which allows them enough time to be heard.

2. Ward staff, especially nurses should encourage willing residents to engage in conversation about their thoughts, expectations, and future concerns when a resident is dying within the same ward or when the event of death occurs. A short memorial service should be carried out monthly in each ward to remember those who died in that ward.

3. Residents should be always at the centre of the decision-making process, thus they should always be informed about any changes in their prognosis and always involved when decisions need to be taken.

4. Meetings should be held regularly between the clinicians, a ward representative, the resident, and the family members so that the goals of care are discussed, and care is tailored according to the resident's wishes, preferences and values, which can take the form of ACP. These meetings must allow enough time for residents to understand the scope of ACP and express their subjective views on this delicate phase and deliberate whom to trust as proxy decision-maker if they wish to do so. Moreover, such meetings could also be set up upon the residents' request in case they wish to change or update their preferences for their future care.

6.7 Recommendations for Education

1. Palliative care training should be provided to all clinical staff working with residents in LTC.

2. Adequate training should be provided to all Allied Health Professionals and Caring staff on how to deal with the sensitivity of the dying phase and the proper communication skills needed with both the residents and their relatives.

3. Educational courses on ACP should be initiated within institutions to spread awareness and inform LTC staff about the tools available to promote the autonomy and dignity of the residents.

4. Specialized Palliative courses could be provided to interested and experienced clinicians, involving special training in conducting ACP, which could translate into additional resources in the form of Advance Care Practitioners.

The main aim of this study was to give voice to the older adults residing in Malta's largest institution and given these findings, one might assume that from within the institutional walls, **silence has been broken.**

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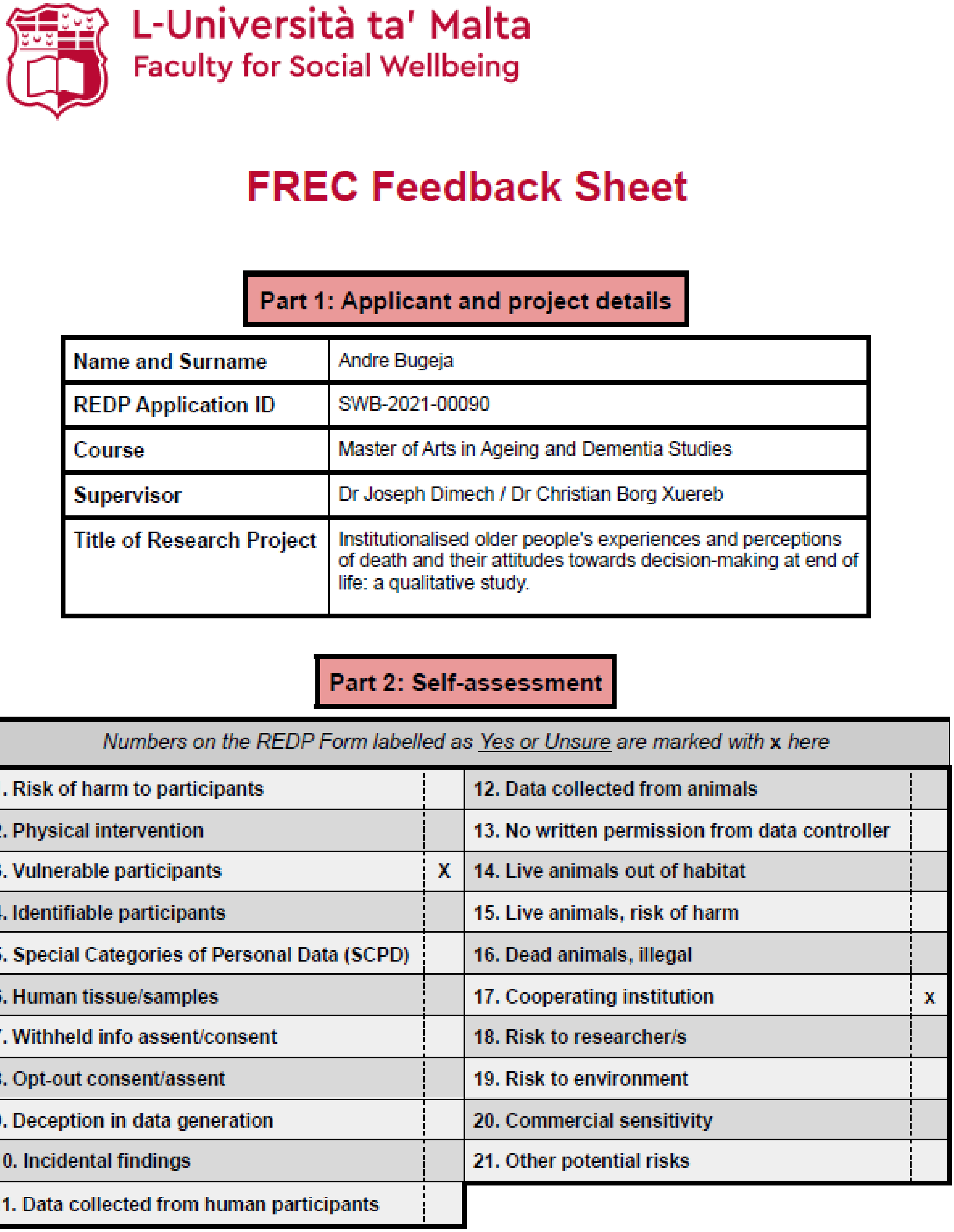
APPENDICES

Appendix 1 – Faculty Research Ethics Committee Approval



L-Università ta' Malta
Faculty for Social Wellbeing

FREC Feedback Sheet

Part 1: Applicant and project details

Name and Surname	Andre Bugeja
REDP Application ID	SWB-2021-00090
Course	Master of Arts in Ageing and Dementia Studies
Supervisor	Dr Joseph Dimech / Dr Christian Borg Xuereb
Title of Research Project	Institutionalised older people's experiences and perceptions of death and their attitudes towards decision-making at end of life: a qualitative study.

Part 2: Self-assessment

Numbers on the REDP Form labelled as Yes or Unsure are marked with **x** *here*

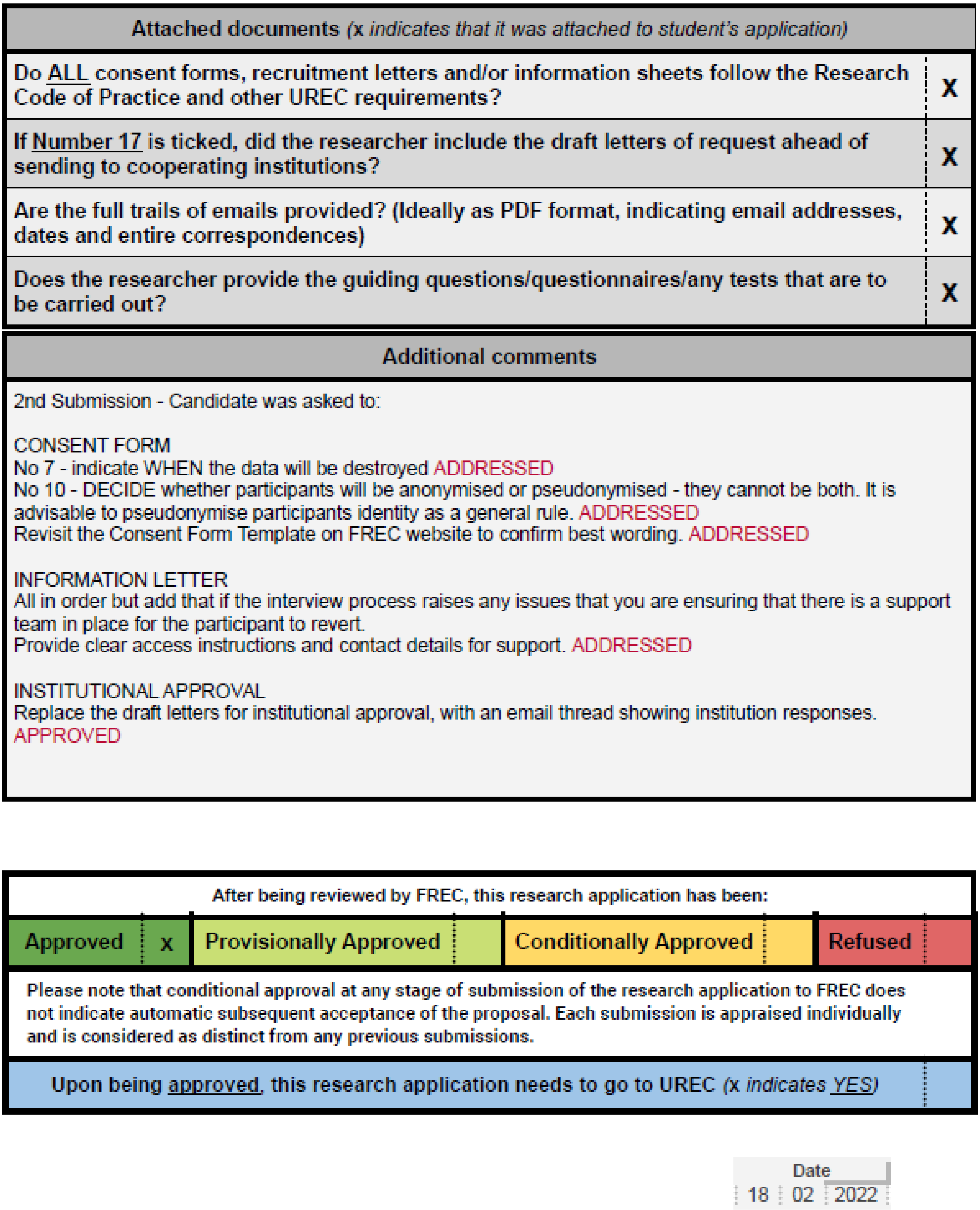
1. Risk of harm to participants		**12. Data collected from animals**	
2. Physical intervention		**13. No written permission from data controller**	
3. Vulnerable participants	X	**14. Live animals out of habitat**	
4. Identifiable participants		**15. Live animals, risk of harm**	
5. Special Categories of Personal Data (SCPD)		**16. Dead animals, illegal**	
6. Human tissue/samples		**17. Cooperating institution**	x
7. Withheld info assent/consent		**18. Risk to researcher/s**	
8. Opt-out consent/assent		**19. Risk to environment**	
9. Deception in data generation		**20. Commercial sensitivity**	
10. Incidental findings		**21. Other potential risks**	
11. Data collected from human participants			

Detailed evaluation

Are more elaborate answers provided for the numbers ticked in the self-assessment checklist? Are the answers of the Research Ethics and Data Protection (REDP) Form following the recommendations provided by the Research Code of Practice and the Research Ethics Review Procedures?

Reviewer's comments

Ticked 3 - resolved
Ticked 17 - resolved



Attached documents *(x indicates that it was attached to student's application)*	
Do ALL consent forms, recruitment letters and/or information sheets follow the Research Code of Practice and other UREC requirements?	**X**
If Number 17 is ticked, did the researcher include the draft letters of request ahead of sending to cooperating institutions?	**X**
Are the full trails of emails provided? (Ideally as PDF format, indicating email addresses, dates and entire correspondences)	**X**
Does the researcher provide the guiding questions/questionnaires/any tests that are to be carried out?	**X**

Additional comments

2nd Submission - Candidate was asked to:

CONSENT FORM
No 7 - indicate WHEN the data will be destroyed ADDRESSED
No 10 - DECIDE whether participants will be anonymised or pseudonymised - they cannot be both. It is advisable to pseudonymise participants identity as a general rule. ADDRESSED
Revisit the Consent Form Template on FREC website to confirm best wording. ADDRESSED

INFORMATION LETTER
All in order but add that if the interview process raises any issues that you are ensuring that there is a support team in place for the participant to revert.
Provide clear access instructions and contact details for support. ADDRESSED

INSTITUTIONAL APPROVAL
Replace the draft letters for institutional approval, with an email thread showing institution responses.
APPROVED

After being reviewed by FREC, this research application has been:

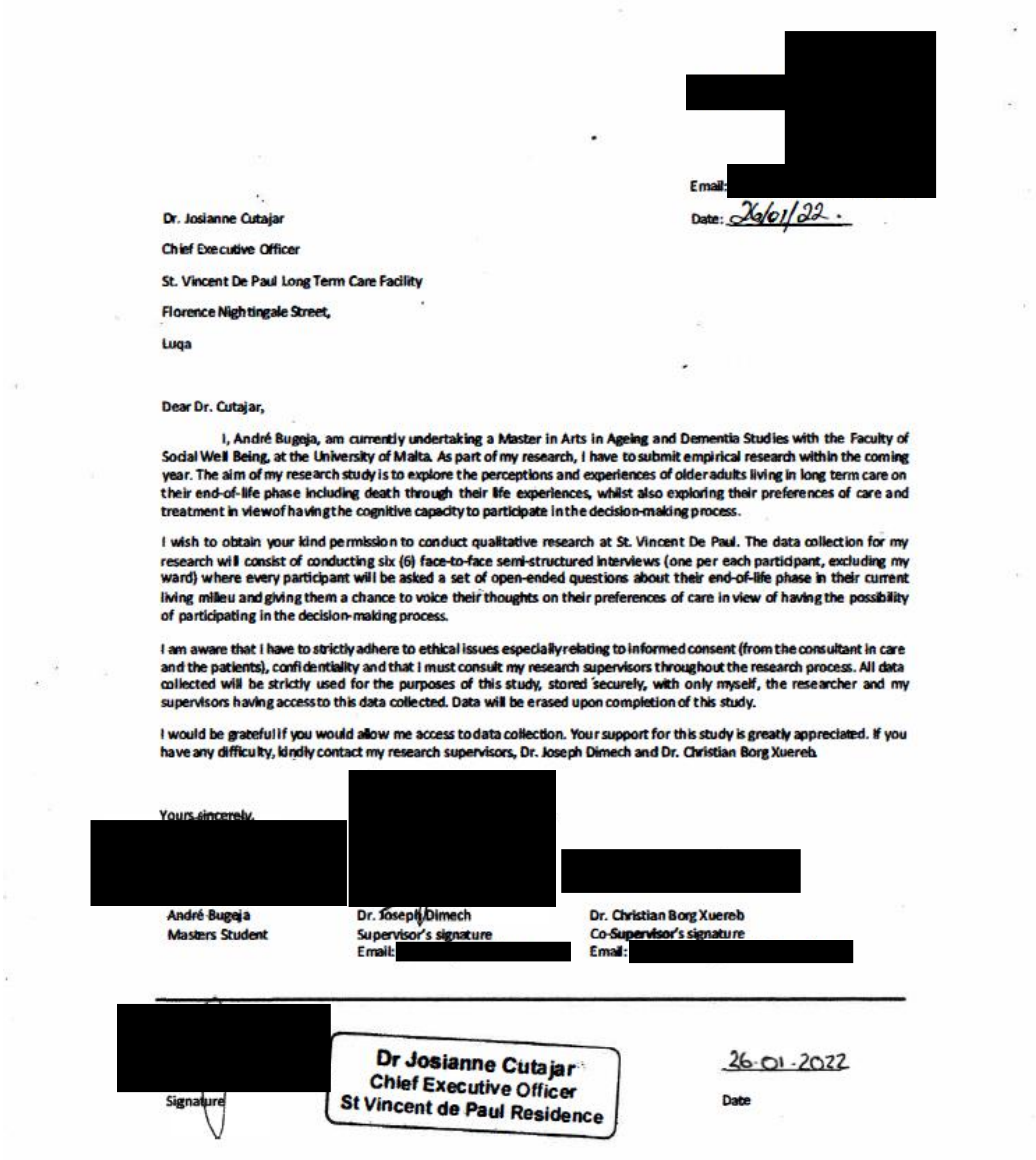
Approved	x	**Provisionally Approved**		**Conditionally Approved**		**Refused**	

Please note that conditional approval at any stage of submission of the research application to FREC does not indicate automatic subsequent acceptance of the proposal. Each submission is appraised individually and is considered as distinct from any previous submissions.

Upon being approved, this research application needs to go to UREC *(x indicates YES)*	

Date
18 02 2022

Appendix 2a - Institutional Access Approval – Chief Executive Officer - SVP-LTC



[redacted]

Email: [redacted]

Date: 26/01/22.

Dr. Josianne Cutajar
Chief Executive Officer
St. Vincent De Paul Long Term Care Facility
Florence Nightingale Street,
Luqa

Dear Dr. Cutajar,

I, André Bugeja, am currently undertaking a Master in Arts in Ageing and Dementia Studies with the Faculty of Social Well Being, at the University of Malta. As part of my research, I have to submit empirical research within the coming year. The aim of my research study is to explore the perceptions and experiences of older adults living in long term care on their end-of-life phase including death through their life experiences, whilst also exploring their preferences of care and treatment in view of having the cognitive capacity to participate in the decision-making process.

I wish to obtain your kind permission to conduct qualitative research at St. Vincent De Paul. The data collection for my research will consist of conducting six (6) face-to-face semi-structured interviews (one per each participant, excluding my ward) where every participant will be asked a set of open-ended questions about their end-of-life phase in their current living milieu and giving them a chance to voice their thoughts on their preferences of care in view of having the possibility of participating in the decision-making process.

I am aware that I have to strictly adhere to ethical issues especially relating to informed consent (from the consultant in care and the patients), confidentiality and that I must consult my research supervisors throughout the research process. All data collected will be strictly used for the purposes of this study, stored securely, with only myself, the researcher and my supervisors having access to this data collected. Data will be erased upon completion of this study.

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 research supervisors, Dr. Joseph Dimech and Dr. Christian Borg Xuereb.

Yours sincerely,

[redacted] [redacted] [redacted]

André Bugeja
Masters Student

Dr. Joseph Dimech
Supervisor's signature
Email: [redacted]

Dr. Christian Borg Xuereb
Co-Supervisor's signature
Email: [redacted]

[redacted]

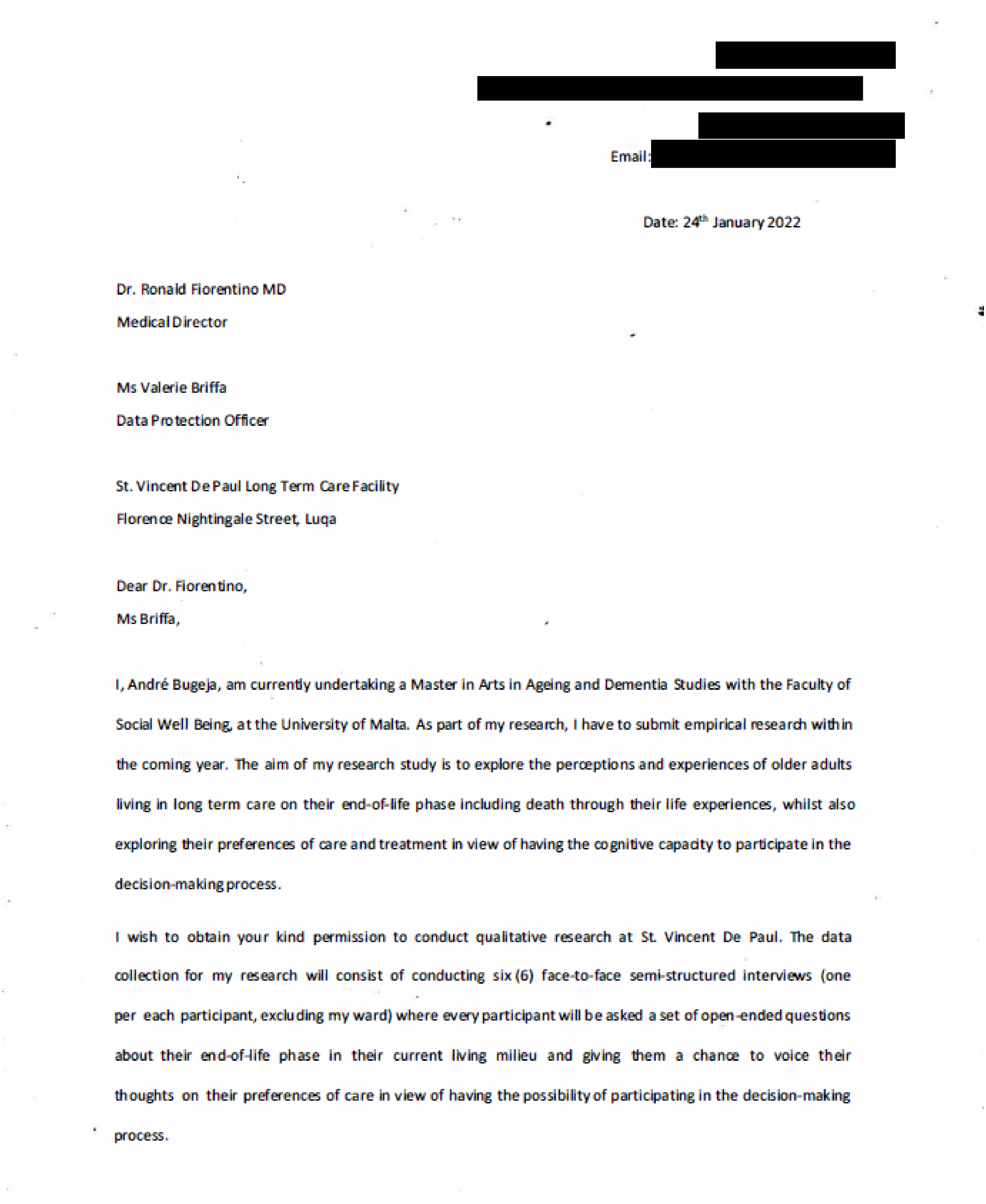
Signature

Dr Josianne Cutajar
Chief Executive Officer
St Vincent de Paul Residence

26-01-2022

Date

Appendix 2b - Institutional Access Approval – Medical Superintendent & Data Protection Officer



[redacted]
Email: [redacted]

Date: 24th January 2022

Dr. Ronald Fiorentino MD
Medical Director

Ms Valerie Briffa
Data Protection Officer

St. Vincent De Paul Long Term Care Facility
Florence Nightingale Street, Luqa

Dear Dr. Fiorentino,
Ms Briffa,

I, André Bugeja, am currently undertaking a Master in Arts in Ageing and Dementia Studies with the Faculty of Social Well Being, at the University of Malta. As part of my research, I have to submit empirical research within the coming year. The aim of my research study is to explore the perceptions and experiences of older adults living in long term care on their end-of-life phase including death through their life experiences, whilst also exploring their preferences of care and treatment in view of having the cognitive capacity to participate in the decision-making process.

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I am aware that I have to strictly adhere to ethical issues especially relating to informed consent (from the consultant in care and the patients), confidentiality and that I must consult my research supervisors throughout the research process. All data collected will be strictly used for the purposes of this study, stored securely, with only myself, the researcher and my supervisors having access to this data collected. Data will be erased upon completion of this study.

In your capacity as Data Protection Officer for SVP-LTC, 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 research supervisors, Dr. Joseph Dimech and Dr. Christian Borg Xuereb.

Yours sincerely,

[redacted]
André Bugeja
Masters Student

[redacted]
Dr. Joseph Dimech
Supervisor's signature
Email: [redacted]

[redacted]
Dr. Christian Borg Xuereb
Co-Supervisor's signature
Email: [redacted]

Approved

[redacted]
Signature - Dr Fiorentino (Med.Dir.)

24/01/2022
Date

DR RONALD FIORENTINO M.D
MEDICAL SUPERINTENDENT

[redacted]
Signature – Ms V Briffa (DPO)

24/01/2022

Appendix 2c - General Data Protection Regulation – SVP-LTC – Permission Form

Permission to conduct research studies within St Vincent de Paul Long-term Care Facility

GENERAL DATA PROTECTION REGULATION

All data for residents or staff at SVP is categorised as "special category personal data" in terms of the General Data Protection Regulation (GDPR) and Data Protection Act (DPA) (Cap. 586). To this effect, access to resident or staff data is subject to compliance with the provisions of the GDPR and DPA as well as other relevant legislation and regulations published from time to time in the Maltese Islands.

The Data Protection Officer may be contacted at St Vincent de Paul Long-term Care Facility, Florence Nightengale Str, Luqa LQA 3301 or on telephone 22912286 or by e-mail dpo-svp@gov.mt

---

Declaration on Access to Resident or Staff Data

I hereby declare that:

- I will respect the confidentiality and privacy of any personal data or information that I will come across during my research study at SVP and will in no circumstance disclose any such information to third parties not directly involved in my research study;
- All references to personal data will be omitted unless an informed consent is specifically obtained from the person identified in the research study:
- Documentation collected is explicitly used for the purpose of this research study and any material which would be superfluous will be adequately destroyed;
- Written consent will be obtained from the data subject or their legal guardians prior to enrolling the residents in the research and or for any filming, recordings and photographs taken.
- Participation in the research being conducted should be at the discretion of the individual and they can refuse any participation whatsoever if they wish;
- Respect, dignity and the privacy of the residents will be preserved at all times;
- The integrity and privacy of the SVP residence will be safeguarded;
- I am aware of the provisions of the GDPR and other regulations in force in the Maltese Islands and will abide by all SVP Residence regulations.

Name of Research Study Institutionalised Older People's Experiences & Perceptions of Death...

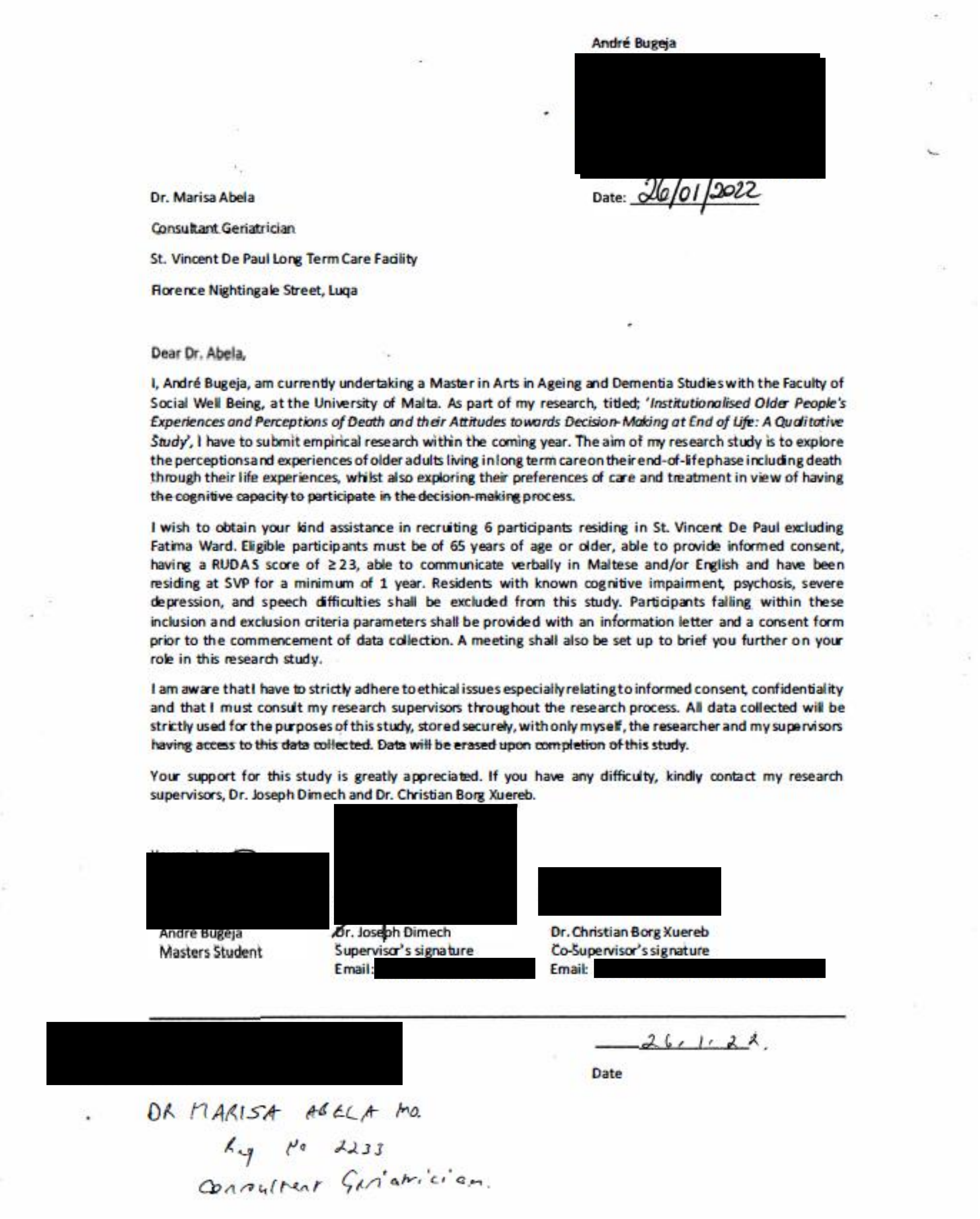
Full Name of Researcher André Bu[illegible].

Signature [redacted]

ID / Passport Number

Disclaimer: Pursuant to the General Data Protection Regulation (EU) 2016/679 (GDPR) and the Data Protection Act (Cap. 586) we have a legal duty to respect and protect any personal information we collect from you and we will abide by such duty. We take all safeguards necessary to prevent unauthorised access and we do not pass on your details collected from you as a visitor and/or user to any third party unless you give us consent to do so or as authorised by law

Appendix 3 - Gatekeeper Information and Recruitment Form



André Bugeja
[redacted]
Date: 26/01/2022

Dr. Marisa Abela

Consultant Geriatrician

St. Vincent De Paul Long Term Care Facility

Florence Nightingale Street, Luqa

Dear Dr. Abela,

I, André Bugeja, am currently undertaking a Master in Arts in Ageing and Dementia Studies with the Faculty of Social Well Being, at the University of Malta. As part of my research, titled; '*Institutionalised Older People's Experiences and Perceptions of Death and their Attitudes towards Decision-Making at End of Life: A Qualitative Study*', I have to submit empirical research within the coming year. The aim of my research study is to explore the perceptions and experiences of older adults living in long term care on their end-of-life phase including death through their life experiences, whilst also exploring their preferences of care and treatment in view of having the cognitive capacity to participate in the decision-making process.

I wish to obtain your kind assistance in recruiting 6 participants residing in St. Vincent De Paul excluding Fatima Ward. Eligible participants must be of 65 years of age or older, able to provide informed consent, having a RUDAS score of ≥23, able to communicate verbally in Maltese and/or English and have been residing at SVP for a minimum of 1 year. Residents with known cognitive impairment, psychosis, severe depression, and speech difficulties shall be excluded from this study. Participants falling within these inclusion and exclusion criteria parameters shall be provided with an information letter and a consent form prior to the commencement of data collection. A meeting shall also be set up to brief you further on your role in this research study.

I am aware that I have to strictly adhere to ethical issues especially relating to informed consent, confidentiality and that I must consult my research supervisors throughout the research process. All data collected will be strictly used for the purposes of this study, stored securely, with only myself, the researcher and my supervisors having access to this data collected. Data will be erased upon completion of this study.

Your support for this study is greatly appreciated. If you have any difficulty, kindly contact my research supervisors, Dr. Joseph Dimech and Dr. Christian Borg Xuereb.

[redacted] [redacted] [redacted]

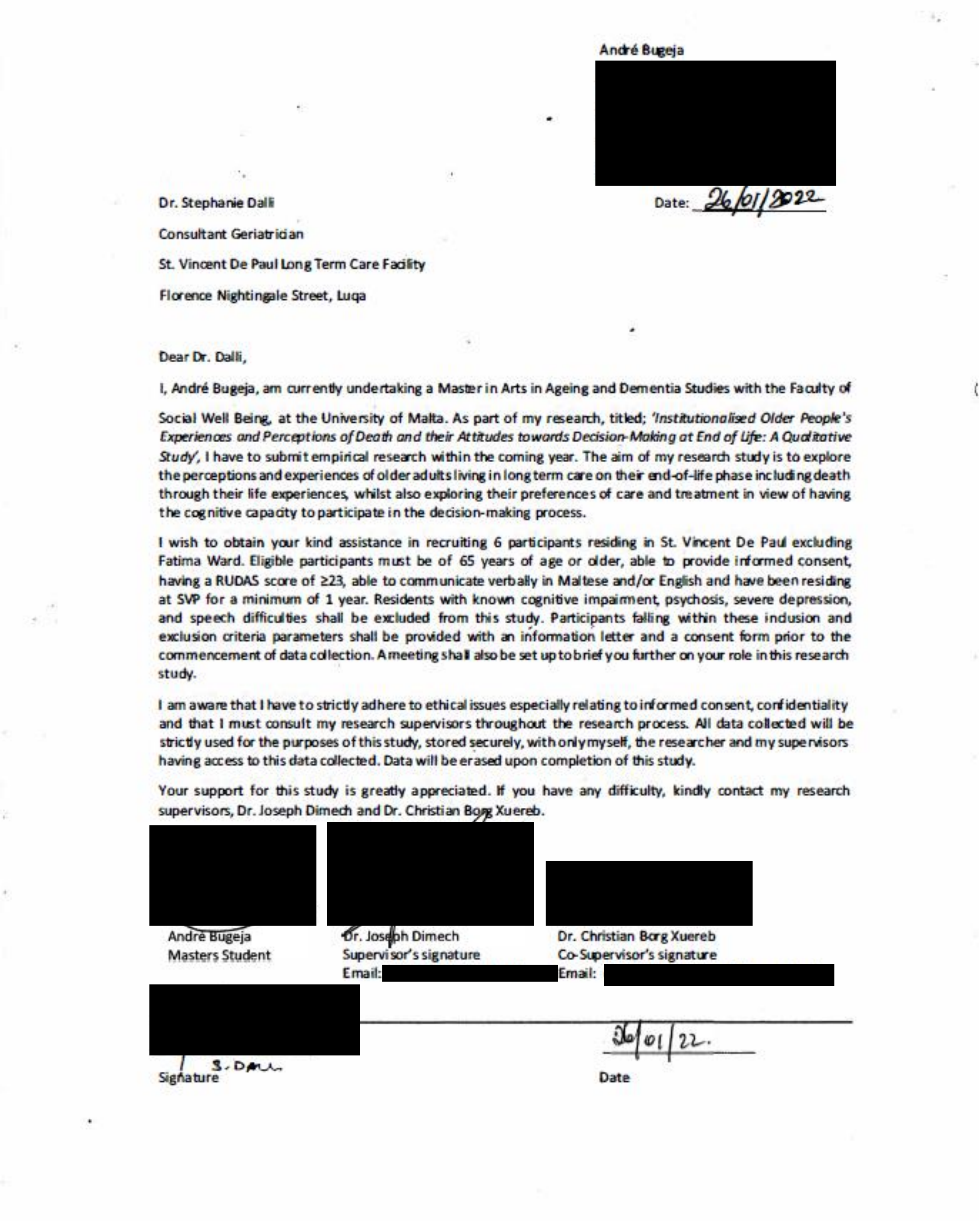
André Bugeja Masters Student	Dr. Joseph Dimech Supervisor's signature Email: [redacted]	Dr. Christian Borg Xuereb Co-Supervisor's signature Email: [redacted]

[redacted]

26.1.22.

Date

DR MARISA ABELA MD.
Reg No 2233
Consultant Geriatrician.



André Bugeja

[redacted]

Date: 26/01/2022

Dr. Stephanie Dalli

Consultant Geriatrician

St. Vincent De Paul Long Term Care Facility

Florence Nightingale Street, Luqa

Dear Dr. Dalli,

I, André Bugeja, am currently undertaking a Master in Arts in Ageing and Dementia Studies with the Faculty of Social Well Being, at the University of Malta. As part of my research, titled; *'Institutionalised Older People's Experiences and Perceptions of Death and their Attitudes towards Decision-Making at End of Life: A Qualitative Study'*, I have to submit empirical research within the coming year. The aim of my research study is to explore the perceptions and experiences of older adults living in long term care on their end-of-life phase including death through their life experiences, whilst also exploring their preferences of care and treatment in view of having the cognitive capacity to participate in the decision-making process.

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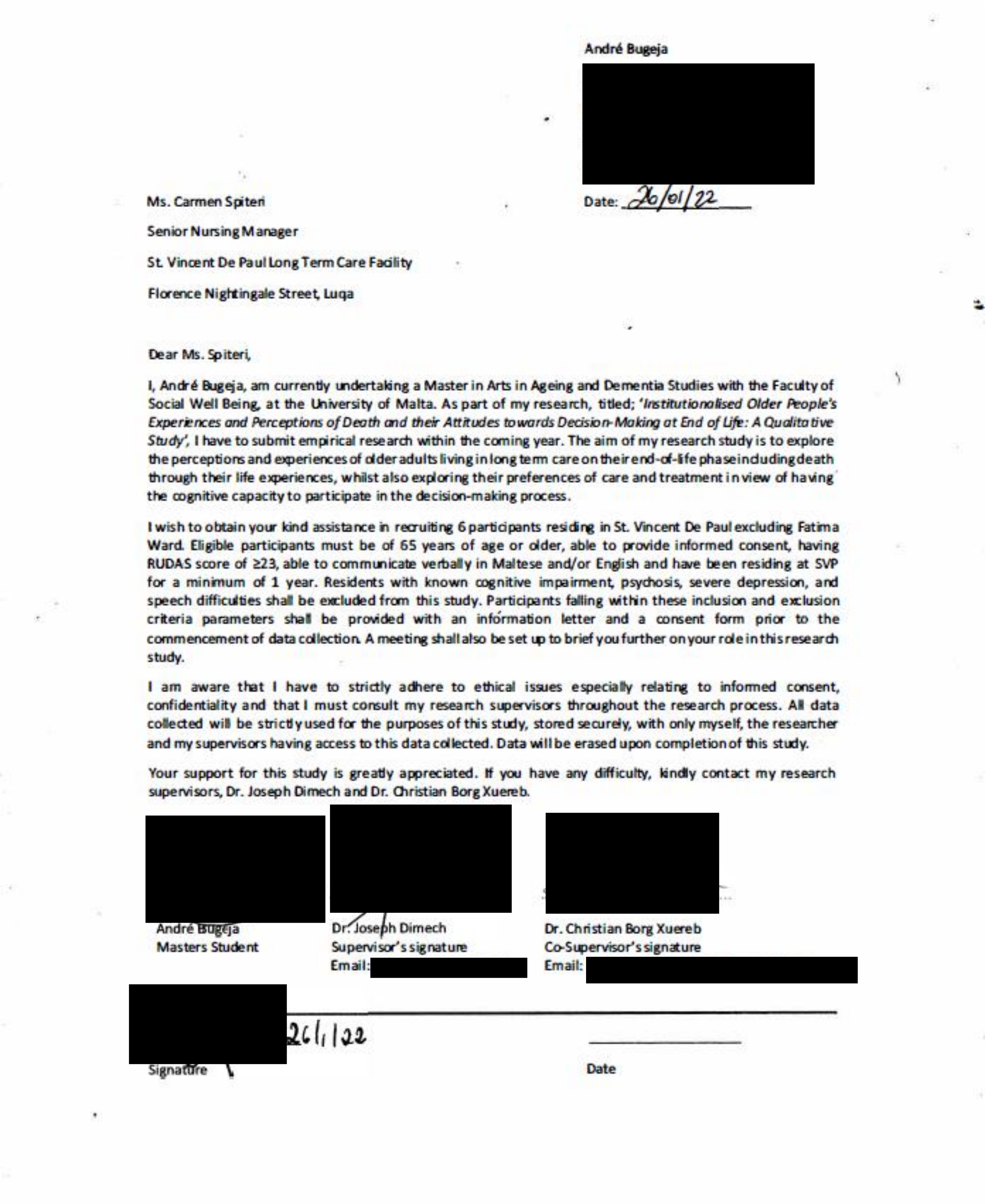
Your support for this study is greatly appreciated. If you have any difficulty, kindly contact my research supervisors, Dr. Joseph Dimech and Dr. Christian Borg Xuereb.

[redacted]	[redacted]	[redacted]
André Bugeja Masters Student	Dr. Joseph Dimech Supervisor's signature Email: [redacted]	Dr. Christian Borg Xuereb Co-Supervisor's signature Email: [redacted]

[redacted]

S. DALLI
Signature

26/01/22.
Date



André Bugeja
[redacted]
Date: 26/01/22

Ms. Carmen Spiteri
Senior Nursing Manager
St. Vincent De Paul Long Term Care Facility
Florence Nightingale Street, Luqa

Dear Ms. Spiteri,

I, André Bugeja, am currently undertaking a Master in Arts in Ageing and Dementia Studies with the Faculty of Social Well Being, at the University of Malta. As part of my research, titled; '*Institutionalised Older People's Experiences and Perceptions of Death and their Attitudes towards Decision-Making at End of Life: A Qualitative Study*', I have to submit empirical research within the coming year. The aim of my research study is to explore the perceptions and experiences of older adults living in long term care on their end-of-life phase including death through their life experiences, whilst also exploring their preferences of care and treatment in view of having the cognitive capacity to participate in the decision-making process.

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Your support for this study is greatly appreciated. If you have any difficulty, kindly contact my research supervisors, Dr. Joseph Dimech and Dr. Christian Borg Xuereb.

[redacted]
André Bugeja
Masters Student

[redacted]
Dr. Joseph Dimech
Supervisor's signature
Email: [redacted]

[redacted]
Dr. Christian Borg Xuereb
Co-Supervisor's signature
Email: [redacted]

[redacted] 26/1/22
Signature

Date

Appendix 4a - Patient information and Recruitment Sheet – English Version

4th December 2021

Information letter

Dear Sir/Madam,

My name is André Bugeja and I am a student at the University of Malta, presently reading for a Masters in Ageing and Dementia Studies. I am presently conducting a research study for my dissertation titled, '**Institutionalised Older People's Experiences and Perceptions of Death and their Attitudes Towards Decision-Making at End of Life: A Qualitative Study'.** This is being supervised by Dr. Joseph Dimech and co-supervised by Dr. Christian Borg Xuereb. This letter is an invitation to participate in this study. Below you will find information about the study and about what your involvement would entail, should you decide to take part.

The aim of my study is to explore the perceptions and experiences of institutionalized older people on death and dying and what are the meanings associated to them throughout their life experience. Furthermore, this study will also explore the preferences for care at end of life and attitudes towards decision-making in view of possible cognitive impairment. Your participation in this study would help contribute to a better understanding of the meaning and values older people residing in institutions associate to death and gather further knowledge on the preferences of care chosen at end of life if tools such as Advance Care Planning and/or Advance Directives would be available. Any data collected from this research will be used solely for purposes of this study.

Should you choose to participate, you will be asked to take part in an interview where I will ask you several questions regarding your perceptions and experiences of end of life and death whilst residing in an institution and your preferences for care at end of life if you had the possibility to elicit these preferences in your current healthcare plan. The interview will last around 60 minutes and it will be audio recorded for data analysis purposes.

Data collected will be treated confidentially and pseudonyms will be used when transcripts of data will be utilized for the research purposes. I, as the researcher and my supervisors will be the only individuals having visibility and access to this data.

Participation in this study is entirely voluntary; in other words, you are free to accept or refuse to participate, without needing to give a reason. You are also free to withdraw from the study at any time, without needing to provide any explanation and without any negative repercussions for you. Should you choose to withdraw, any data collected from your interview will be deleted.

If you choose to participate, please note that there are no direct benefits to you, but the results of this study will aid in the implementation of policies in such area in the future. Your participation does not entail any known or anticipated risks.

If, in any case, your participation in this study will lead you to experience any distress or discomfort, support will be provided by Prof David Mamo's psychiatric firm at SVP grounds, where free debriefing sessions will be provided. Prof David Mamo is already made aware of this study, and if support is needed, you can either contact the ward medical officer for your referral or myself, as the researcher, on [redacted].

Please also note that, as a participant, you have the right under the General Data Protection Regulation (GDPR) and national legislation to access, rectify and where applicable ask for the data concerning you to be erased. All data collected will be deleted after the completion of this study.

A copy of this information sheet is being provided for you to keep and for future reference.

Thank you for your time and consideration. Should you have any questions or concerns, please do not hesitate to contact me by e-mail on [redacted]; you can also contact my supervisors over the phone: [redacted] and [redacted] or via email: [redacted] and [redacted] respectively.

Sincerely,

[redacted]

Researcher

André Bugeja
Email: [redacted]

[redacted]

Supervisor

Dr. Joseph Dimech MD, PhD, M Ger, DGM
Consultant Geriatrician
Associate Dean
Queen Mary University London. Malta
Email: [redacted]
Contact: [redacted]

[redacted]

Co-supervisor

Dr. Christian Borg Xuereb, PhD, MSc Health Psychology, BPsy (Hons)
Head, Department of Gerontology and Dementia Studies
Registered Health, Academic & Research Psychologist (MPPB130)
Email: [redacted]
Contact: [redacted]

Appendix 4b - Patient Information and Recruitment Sheet – Maltese Version

5 ta’ Diċembru 2021

Ittra ta’ tagħrif

Għażiż/a Sinjur/a,

Jiena André Bugeja, student fl-Università ta’ Malta, u bħalissa qiegħed insegwi Masters fl-Anzjanita’ u d-Dimenzja. Ir-riċerka għad-dissertazzjoni tiegħi jisimha: **Institutionalised Older People's Experiences and Perceptions of Death and their Attitudes towards Decision-Making at End of Life: A Qualitative Study.** It-tuturi tiegħi huma Dr. Joseph Dimech u Dr. Christian Borg Xuereb. B’din l-ittra nixtieq nistiednek tipparteċipa fir-riċerka. Hawn taħt issib aktar informazzjoni fuq l-istudju li qed nagħmel u fuq xi jkun l-involviment tiegħek jekk tiddeċiedi li tieħu sehem.

L-għan tal-istudju hu li nesplora l-esperjenzi u l-perċezzjonijiet tar-residenti fi ħdan instituzzjonijiet għall-anzjani fuq il-kunċett tal-mewt waqt li fl-istess ħin nesplora ukoll l-atitudni ta l-istess residenti rigward id-deċiżjonijiet li jittieħdu fi tmiem il ħajja fuq preferenzi ta’ kura. Sehmek jgħin biex ikun hawn iżjed għarfien dwar kif residenti fi ħdan instituzzjonijiet ta’ l-anzjani jesperjenzaw tmiem il’ ħajja u il-perċezzjoni tagħhom dwar il-mewt. Permezz ta’ dan l-istudju, ser tingħata ukoll l’opportunita’ lir-residenti sabiex jesprimu l-preferenzi tagħhom dwar deċiżjonijiet li jittieħdu fi’ tmiem il-ħajja, fl-eventwalita’ li jitilifu il-kapaċita’ mentali li jieħdu decizjoni awtonoma. L-informazzjoni kollha li tinġabar fir-riċerka tintuża biss għall-fini ta’ dan l-istudju.

Jekk taqbel li tipparteċipa, tintalab li tieħu sehem f’intervista, fejn se tiġi mistoqsiji/a ammont ta mistoqsijiet rigward is-suġġetti li għadna kif semmejna. L-intervista ser iddum għal-tul ta’ madwar 60 minuta u ser isseħħ f’ ambjent kalm u komdu għalik, bla ebda distrazzjonijiet. L-intervista se tiġi irrekordjata bl-awdjo sabiex inkun nista’ nikteb it-transkrizzjonijiet għal-fini ta’ l-analiżi ta l-informazzjoni.

L-informazzjoni miġbura ser tibqa kunfidenzjali waqt il-proċess kollu u spunti li jittieħdu mit-transkrizzjonijiet biex nippreżenta ir-riżultati ta l-istudju, ser ikunu ikkodifikati u miżmuma anonimi. L-informazzjoni miġbura se tkun tista tigi aċċessata minni bħala r-riċerkatur u mis-superviżuri tiegħi biss.

Il-parteċipazzjoni tiegħek f’dan l-istudju tkun għal kollox volontarja; fi kliem ieħor, inti liberu/a li taċċetta jew tirrifjuta li tieħu sehem, mingħajr ma tagħti raġuni. Inti wkoll liberu/a li twaqqaf il-parteċipazzjoni tiegħek fl-istudju meta tixtieq, mingħajr ma jkollok tagħti spjegazzjoni u mingħajr ebda riperkussjoni. Jekk tagħżel li ma tkomplix tipparteċipa, l-informazzjoni li tkun laħqet ittieħdet fl-intervista miegħek titħassar.

Jekk tagħżel li tipparteċipa, jekk jogħġbok innota li m’hemm l-ebda benefiċċju dirett għalik, iżda ir-riżultati ta’ dan l-istudju jistgħu jikkontribwixxu għal-ħolqien u implimentazzjoni ta’ prattiċi u miżuri ġodda fir-rigward ta’ tmiem il-ħajja, fil-futur. Il-parteċipazzjoni tiegħek ma fiha l-ebda riskju magħruf jew mistenni.

F’każ li l-parteċipazzjoni tiegħek f’dan l-istudju iwasslek biex tesperjenza xi skumdita’ ta’ kwalunkwe tip, servizz ta’ sapport se jkun imniegħed minn Prof David Mamo, f’San Vinċenz stess, fejn sessjonijiet ta’ tagħrif u diskussjonijiet se jingħataw b’xejn. Prof David Mamo diġa mgħarraf b’dan l-istudju, u f’kaz li jkollok bzonn dan is-servizz, mitlub titkellem mat-tobba tas-sala tiegħek jew tikkuntattja lili, bħala ricerkatur, fuq [redacted], sabiex tkun tista tigi irreferut/a.

Bħala parteċipant/a, għandek id-dritt, skont ir-Regolament Ġenerali dwar il-Protezzjoni tad-Data (GDPR) u l-leġiżlazzjoni nazzjonali, li taċċessa, tikkoreġi u fejn hu applikabbli, titlob li l-informazzjoni li tikkonċernak titħassar. L-informazzjoni kollha li tinġabar fl-istudju se tithassar meta jitlesta l-istudju.

Qed ngħaddilek kopja ta’ din l-ittra biex iżżommha bħala referenza.

Grazzi tal-ħin u l-kunsiderazzjoni tiegħek.

Jekk ikollok xi mistoqsija, tiddejjaqx tikkuntattjani fuq [redacted]; tista' tikkuntattja wkoll lit-tuturi tiegħi fuq: [redacted] u [redacted] jew elettronikament fuq: [redacted] jew [redacted] rispettivament.

Tislijiet,

[redacted]

Riċerkatur

André Bugeja

[redacted]

[redacted]

Superviżur

Dr. Joseph Dimech MD, PhD, M Ger, DGM

Consultant Geriatrician

Associate Dean

Queen Mary University London. Malta

Email: [redacted]

Contact: [redacted]

[redacted]

Ko-Superviżur

Dr. Christian Borg Xuereb, PhD, MSc Health Psychology, BPsy (Hons)

Head, Department of Gerontology and Dementia Studies

Registered Health, Academic & Research Psychologist (MPPB130)

Email: [redacted]

Contact: [redacted]

Appendix 5a - Patient Consent Form – English Version

Participant’s Consent Form

Institutionalised Older People's Experiences and Perceptions of Death and their Attitudes towards Decision-Making at End of Life: A Qualitative Study.

I, the undersigned, give my consent to take part in the study conducted by Mr. André Bugeja. This consent form specifies the terms of my participation in this research study.

1. I have been given written and/or verbal information about the purpose of the study; I have had the opportunity to ask questions and any questions that I had were answered fully and to my satisfaction.
2. I also understand that I am free to accept to participate, or to refuse or stop participation at any time without giving any reason and without any penalty. Should I choose to participate, I may choose to decline to answer any questions asked. In the event that I choose to withdraw from the study, any data collected from me will be erased.
3. I understand that I have been invited to participate in an interview in which the researcher will ask a set of questions as guided by an interview schedule to explore my perceptions and experiences on death and dying and my preferences for care in my end of life. I am aware that the interview will take approximately 60 minutes. I understand that the interview is to be conducted in a place and at a time that is convenient for me.
4. I understand that my participation does not entail any known or anticipated risks.
5. I understand that there are no direct benefits to me from participating in this study, but the results of this research study might aid in the implementation of future policies.
6. I understand that, under the General Data Protection Regulation (GDPR) and national legislation, I have the right to access, rectify, and where applicable, ask for the data concerning me to be erased.
7. I understand that all data collected will be erased on completion of the study by the end of December 2023.
8. I have been provided with a copy of the information letter and understand that I will also be given a copy of this consent form.
9. I am aware that, if I give my consent, this interview will be audio recorded and converted to text as it has been recorded (transcribed).
10. I am aware that, if I give my consent, extracts from my interview may be reproduced in these outputs, using a pseudonym [a made-up name or code – e.g. respondent A].

I have read and understood the above statements and agree to participate in this study.

Name of participant: ______________________________________

Signature: ______________________________________

Date: _______________________________________

[redacted]
____
Researcher

André Bugeja

[redacted]

[redacted]
____
Supervisor

Dr. Joseph Dimech MD, PhD, M Ger, DGM
Consultant Geriatrician
Associate Dean
Queen Mary University London. Malta
Email: [redacted]
Contact: [redacted]

[redacted]
____
Co-Supervisor

Dr. Christian Borg Xuereb, PhD, MSc Health Psychology, BPsy (Hons)
Head, Department of Gerontology and Dementia Studies
Registered Health, Academic & Research Psychologist (MPPB130)
Senior Lecturer
Email: [redacted]
Contact: [redacted]

Appendix 5b - Patient Consent Form – Maltese Version

Formola tal-Kunsens tal-Parteċipant/a

Institutionalised Older People's Experiences and Perceptions of Death and their Attitudes towards Decision-Making at End of Life: A Qualitative Study.

Jiena, hawn taħt iffirmat/a, nagħti l-kunsens tiegħi li nieħu sehem fl-istudju ta' Mr. André Bugeja. Din il-formola tal-kunsens tispjega t-termini tas-sehem tiegħi f'din ir-riċerka.

1. Ingħatajt l-informazzjoni bil-miktub u/jew bil-fomm dwar l-iskop tar-riċerka; kelli l-opportunità nagħmel il-mistoqsijiet, u kull mistoqsija ngħatajt tweġiba għaliha b'mod sħiħ u sodisfaċenti.
2. Nifhem ukoll li jiena liberu/a li naċċetta li nieħu sehem, jew li nirrifjuta, jew li nwaqqaf ilparteċipazzjoni tiegħi meta nixtieq mingħajr ma nagħti spjegazzjoni jew mingħajr ma niġi penalizzat/a. Jekk nagħżel li nipparteċipa, jaf niddeċiedi li ma nweġibx kull mistoqsija li ssirli. F'każ li nagħżel li ma nkomplix nieħu sehem fl-istudju, l-informazzjoni miġbura mingħandi se titħassar.
3. Nifhem li ġejt mistieden/mistiedna nipparteċipa f'intervista u l-persuna li qed tagħmel ir-riċerka se ssaqsini xi mistoqsijiet biex tesplora l-esperjenzi u l-perċezzjonijiet ta' residenti fi ħdan istituzzjonijiet għall-anzjani dwar il-mewt u il-preferenzi rigward deċizjonijiet li jittieħdu fi tmiem il-ħajja. Jiena konxju/a li l-intervista se ddum bejn wieħed u ieħor 60 minuta. Nifhem li l-intervista se ssir f'post u f'ħin li huma komdi għalija.
4. Nifhem li l-parteċipazzjoni tiegħi ma fiha l-ebda riskju.
5. Nifhem li bil-parteċipazzjoni tiegħi f'dan l-istudju, m'hemm l-ebda benefiċċju dirett għalija, iżda ir-riżultati ta' dan l-istudju jistgħu jassisstu fil-ħolqien u implimentazzjoni ta' miżuri ġodda f'dan ir-rigward fil-futur.
6. Nifhem li, skont ir-Regolament Ġenerali dwar il-Protezzjoni tad-Data (GDPR) u l-leġiżlazzjoni nazzjonali, għandi dritt naċċessa, nikkoreġi u, fejn hu applikabbli, nitlob li l-informazzjoni li tikkonċernani titħassar.
7. Nifhem li l-informazzjoni kollha miġbura se titħassar meta jintemm l-istudju, sa Diċembru, 2023.
8. Ingħatajt kopja tal-ittra ta' tagħrif biex inżommha u nifhem li se ningħata wkoll kopja ta' din il-formola tal-kunsens. Qrajt u fhimt l-istqarrijiet t'hawn fuq, u naqbel li nipparteċipa f'dan l-istudju.
9. Konxju/a li, jekk nagħti l-kunsens tiegħi, l-intervista se tkun irrekordjata bl-awdjo u maqluba fi kliem, kif irrekordjat/a (traskrizzjoni).
10. Konxju/a li, jekk nagħti l-kunsens tiegħi, siltiet mill-intervista tiegħi jistgħu jiġu riprodotti bl-użu ta' psewdonimu [isem ivvintat jew kodiċi - eż. parteċipant A].

Isem il-parteċipant/a: ___________________________________
Firma: ___________________________________
Data: ___________________________________

[redacted]

Ricerkatur

André Bugeja
andre.bugeja.10@um.edu.mt

[redacted]

Superviżur

Dr. Joseph Dimech MD, PhD, M Ger, DGM
Consultant Geriatrician
Associate Dean
Queen Mary University London. Malta
Email: [redacted]
Contact: [redacted]

[redacted]

Ko-Superviżur

Dr. Christian Borg Xuereb, PhD, MSc Health Psychology, BPsy (Hons)
Head, Department of Gerontology and Dementia Studies
Registered Health, Academic & Research Psychologist (MPPB130)
Email: [redacted]
Contact: [redacted]

Appendix 6a - Support Services Letter – English Version

Support Services for Participants

Name of student researcher: **André Bugeja**

Course: **Master of Arts in Ageing and Dementia Studies**

Student researcher's contact email: [redacted]

Student researcher's contact number: [redacted]

Name of research supervisor: **Dr. Joseph Dimech**

Research supervisor's contact email: [redacted]

Research supervisor's contact number: [redacted]

Name of research co-supervisor: **Dr. Christian Borg Xuereb**

Research co-supervisor's contact email: [redacted]

Research co-supervisor's contact number: [redacted]

Title of Research Study: **Institutionalised Older People's Experiences and Perceptions of Death and their Attitudes towards Decision-Making at End of Life: A Qualitative Study.**

Dear Participant,

I would like to take this opportunity to thank you for your participation in this study. I appreciate your involvement and cooperation throughout this entire process.

I would like to remind you that the aim of this study is to explore the perceptions and experiences of older adults residing in institutions on end-of-life, including death and dying and to gather information on the preferences of care at end-of-life in view of the absence of policies safeguarding autonomy and dignity in this phase of life.

This study was not anticipated to cause distress and the interview questions were formatted in as sensitive a manner as possible; however if your participation has led you to experience any dis-tress or discomfort for whatever reason, then you can either inform me or the medical officer in your ward that you wish to speak to Prof. David Mamo (Psychiatrist), where free debriefing sessions will be provided.

If you require any additional information or wish to report any concerns about this study, please do not hesitate to contact both myself, on [redacted] or my research supervisor on [redacted] or [redacted].

Kind regards,

[redacted]

Appendix 6b - Support Services Letter – Maltese Version

Servizzi ta' Support għall-Parteċipanti

Isem tal-istudent ricerkatur: André Bugeja

Kors: Master of Arts in Ageing and Dementia Studies

L-imejl tal-istudent ricerkatur: [redacted]

Nru tat-telefon tal-istudent ricerkatur: [redacted]

Isem ta' min jissorvelja r-ricerka: Dr. Joseph Dimech u Dr. Christian Borg Xuereb

L-imejl ta' min jissorvelja r-ricerka: [redacted]

Nru tat-telefon ta' min jissorvelja r-ricerka: [redacted]

Titlu ta' l-Istudju-Ricerka: Institutionalised Older People's Experiences and Perceptions of Death and their Attitudes towards Decision-Making at End of Life: A Qualitative Study.

Għażiż Parteċipant/a,

Nixtieq nieħu din l-opportunità biex nirringrazzjak tal-parteċipazzjoni tiegħek f'dan l-istudju. Napprezza l-involviment u l-kooperazzjoni tiegħek matul dan il-proċess kollu.

Nixtieq infakrek l-għan ta' dan l-istudju hu li nesplora l-esperjenzi u l-perċezzjonijiet tar-residenti fi ħdan instituzzjonijiet għall-anzjani fuq il-kunċett tal-mewt waqt li fl-istess ħin nesplora ukoll l-atitudni ta l-istess residenti rigward id-deċiżjonijiet li jittieħdu fi tmiem il ħajja fuq preferenzi ta' kura.

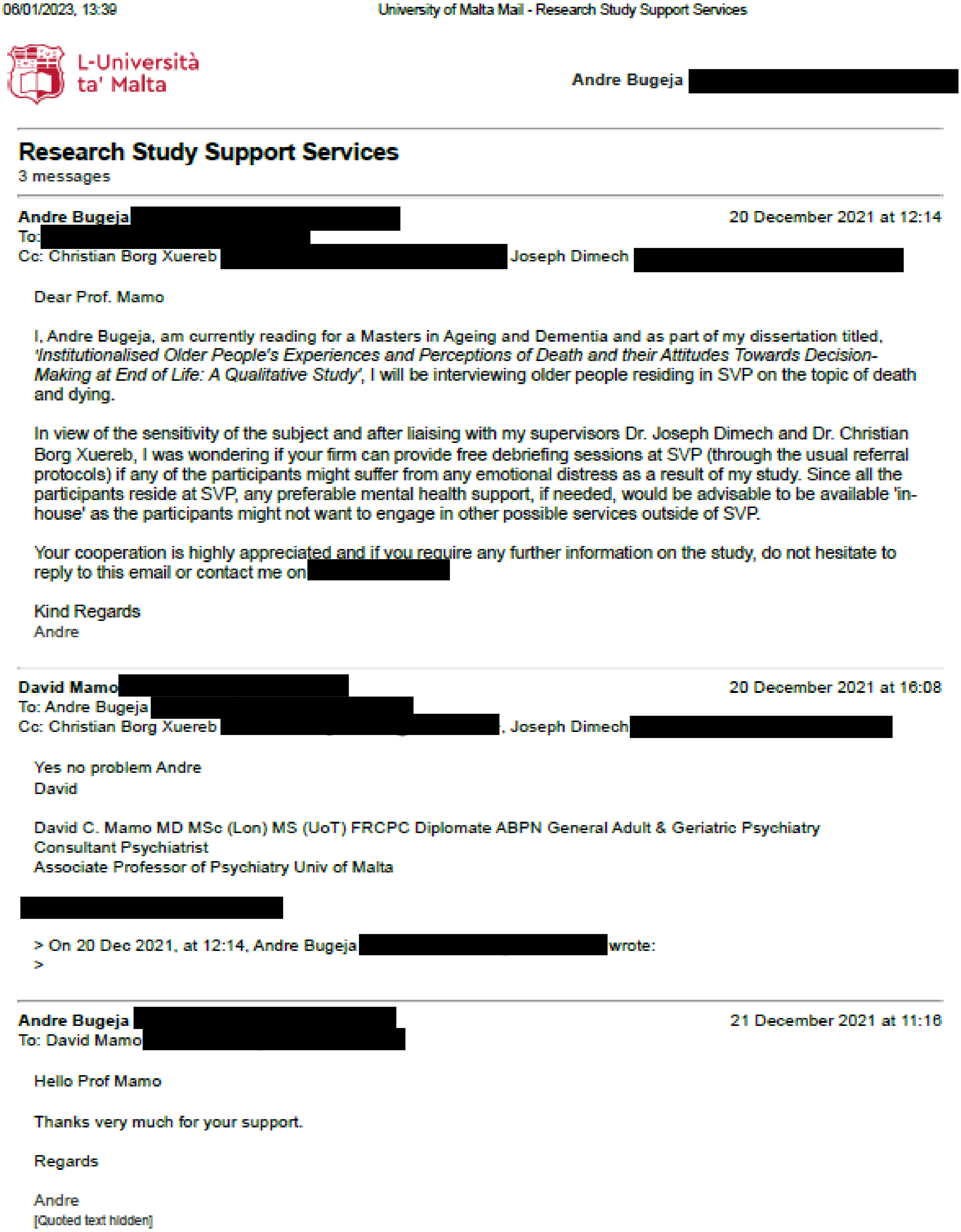
Dan l-istudju ma kienx antiċipat li jikkawża diffikultà u l-mistoqsijiet tal-intervista ġew ifformattjati bl-iktar mod sensittiv possibbli; madankollu jekk id-diskussjoni wasslitek biex tesperjenza kwalunkwe tbatija jew skumdità għal kwalunkwe raġuni, tista tikkuntattja lili jew lit-tabib tas-sala biex nirreferuk għand Prof David Mamo, fejn se jiġu offruti sessjonijiet b'xejn fejn tkun tista tesprimi il-ħsibijiet tiegħek.

Jekk teħtieġ xi informazzjoni addizzjonali jew tixtieq tirrapporta kwalunkwe tħassib dwar dan l-istudju, jekk jogħġbok toqgħodx lura milli tikkuntattja kemm jien stess, fuq [redacted], jew is-superviżuri tar-riċerka tiegħi fuq [redacted] jew [redacted].

B'xewqat tajba,

[redacted]

Appendix 6c - Support Services Engagement



08/01/2023, 13:39 University of Malta Mail - Research Study Support Services

L-Università ta' Malta

Andre Bugeja [redacted]

Research Study Support Services

3 messages

Andre Bugeja [redacted] 20 December 2021 at 12:14
To: [redacted]
Cc: Christian Borg Xuereb [redacted] Joseph Dimech [redacted]

Dear Prof. Mamo

I, Andre Bugeja, am currently reading for a Masters in Ageing and Dementia and as part of my dissertation titled, *'Institutionalised Older People's Experiences and Perceptions of Death and their Attitudes Towards Decision-Making at End of Life: A Qualitative Study'*, I will be interviewing older people residing in SVP on the topic of death and dying.

In view of the sensitivity of the subject and after liaising with my supervisors Dr. Joseph Dimech and Dr. Christian Borg Xuereb, I was wondering if your firm can provide free debriefing sessions at SVP (through the usual referral protocols) if any of the participants might suffer from any emotional distress as a result of my study. Since all the participants reside at SVP, any preferable mental health support, if needed, would be advisable to be available 'in-house' as the participants might not want to engage in other possible services outside of SVP.

Your cooperation is highly appreciated and if you require any further information on the study, do not hesitate to reply to this email or contact me on [redacted]

Kind Regards
Andre

David Mamo [redacted] 20 December 2021 at 16:08
To: Andre Bugeja [redacted]
Cc: Christian Borg Xuereb [redacted], Joseph Dimech [redacted]

Yes no problem Andre
David

David C. Mamo MD MSc (Lon) MS (UoT) FRCPC Diplomate ABPN General Adult & Geriatric Psychiatry
Consultant Psychiatrist
Associate Professor of Psychiatry Univ of Malta

[redacted]

> On 20 Dec 2021, at 12:14, Andre Bugeja [redacted] wrote:
>

Andre Bugeja [redacted] 21 December 2021 at 11:16
To: David Mamo [redacted]

Hello Prof Mamo

Thanks very much for your support.

Regards

Andre
[Quoted text hidden]

Appendix 7a - Interview Schedule – English Version

Interview Schedule **[AUDIO RECORDED]**

1. Can you tell me something about yourself?
2. Can you tell me about your experience of living in a long-term care facility?
3. What is your experience with death in your ward?
4. What happens when another resident in your ward dies?
   a. Prompt: how do you feel? Why?
5. From your experience, how do staff interact with people at their end of life?
6. From your experiences, do you get the opportunity to talk and reflect on your emotions and wishes about death and end of life (EOL)?
7. Do your values and beliefs affect how you look at the care you wish for yourself for your EOL? How come?
8. What does EOL care mean to you?
   a. Prompt: People usually worry that EOL represents pain and suffering, what are your thoughts about this?
   b. Prompt: Do you worry about death?
9. Have any of the ward staff, ever initiated any conversations or given you any information regarding what you are suffering from?
   a. What support would you think you would need as you approach you EOL?
10. What are your experiences on decision making with regards to your health in general so far?
11. What are your thoughts with regards to decision making on EOL?
    a. Prompt: would you prefer to know more about the prognosis?
    b. Prompt: Would you want to be involved in the decision-making process?
    c. Prompt: Would you prefer that the doctor/family to take decisions?
    d. Prompt: With whom would you be the most comfortable with to share these preferences? Why?
12. Would you be willing to document your EOL preferences on a specific document, so that people caring for you, would be aware of your preferences?
    a. Prompt: What do you think are the challenges in achieving this?

Appendix 7b - Interview Schedule – Maltese Version

Interview Schedule – Maltese Version **[AUDIO RECORDED]**

1. Tista tgħidli xi ħaga fuqek inniffsek?
2. Tista tiddiskrivi l-esperjenza tiegħek bħala resident/a li qed tgħix ġo San Vinċenz?
3. X'inhi l-esperjenza tiegħek mal-mewt, fil-ward tiegħek?
4. X'jigri meta tmut persuna oħra fil-ward tiegħek?
    a. Kif tħossok? Għaliex?
5. Mill-esperjenza tiegħek, kif igibu ruħhom l-impjegati ma' residenti li qiegħdin fl-aħħar ta' ħajjithom?
6. Mill-esperjenzi tiegħek, ikollok opportunitajiet biex titkellem u tirrifletti fuq l-emozzjonijiet u x-xewqat tiegħek dwar il-mewt u l-aħħar tal-ħajja?
7. Taħseb li l-valuri u t-twemmin tiegħek jaffetwaw kif inti tħares lejn il-kura li tippreferi għalik fl-aħħar tal-ħajja? Għalfejn?
8. Xi tfisser għalik il-kura fl-aħħar tal-ħajja?
    a. Ħafna jinkwetaw li tmiem il-ħajja, li din iġġib fuqhom uġiegħ u tbatija, x'taħseb dwarha?
    b. Tinkwieta fuq il-mewt?
9. Ġieli kien hemm xi impjegati fil-ward li bdew konverzazzjonijiet jew provdulek xi informazzjoni dwar dak li qed tbgħati minnu?
10. X'inhuma l-esperjenzi tiegħek dwar it-teħid ta' deċizjonijiet rigward saħħtek ingenerali, s'issa?
11. X'inhuma il-ħsibijiet tiegħek fir-rigward ta' deċizjonijiet li jittieħdu fi tmiem il-ħajja?
    a. Tkun tixtieq taf iktar dwar il-kundizjonijiet mediċi tiegħek?
    b. Tkun tixtieq tigi involut fil-proċess meta jittieħdu id-decizjonijiet?
    c. Tkun tixtieq li it-tabib/qraba tiegħek jiehdu id-deċizjonijiet għalik?
    d. Ma' min tħossok l-iktar komdu/a taqsam dawn il-preferenzi? Għalfejn?
12. Tkun lest li tnizzel ix-xewqat tiegħek dwar x'tixtieq fl-aħħar ta' ħajtek fuq dokument apposta sabiex dak li tixtieq ikun magħruf minn tal-familja/ minn min jieħu ħsiebek?
    a. X'taħseb li huma id-diffikultajiet biex dan iseħħ?