The Lived Experiences of Nurses' Encounters with Patients' Deaths in a Palliative Inpatient Setting

Joseph Xuereb

22MSNR28

A dissertation presented to the Faculty of Health Sciences in part-fulfilment of the requirements for the Degree of Master of Science in Nursing at the University of Malta

Department of Nursing

Faculty of Health Science

University of Malta

May 2022

Abstract

Background: Nurses working in an inpatient palliative care unit encounter patient death frequently. Such frequent encounters leave an impact on these nurses and on their nursing practice. However, relatively few studies focus on the impact such frequent encounters have on nurses working in the palliative care unit.

Objectives: The aim of this study was to explore the lived experiences of nurses who encounter patient death in a palliative inpatient setting. The objectives were to explore the perceptions and attitudes of nurses about death, how these nurses experience the death of their patients, identify the coping strategies these nurses utilise, and examine nurses' perception of supportive strategies that could be implemented.

Design: A qualitative phenomenological design using the principles of Interpretative Phenomenological Analysis.

Setting: The palliative care unit of the general oncology hospital in Malta is the setting of this study.

Participants: Five Maltese staff nurses working in the palliative care unit.

Methods: The participants were recruited using purposive sampling. Data was collected through two face-to-face semi-structured interviews with each participant, which were audio recorded. The data was transcribed verbatim and analysis was done using Interpretative Phenomenological Analysis.

Results: Two super-ordinate themes emerged that described the lived experience of the nurses; *Outlook on Death* and *Dealing with Patient Death.*

Conclusion: Nurses working in the palliative care unit perceived death as an inevitable part of life. They described some deaths of their patients as being 'good' or 'bad', and they always aimed to enable a 'good' death for their patients. The nurses were affected by both types of these deaths, and also by the relationship they had with their patients prior to their death. Witnessing patient death also shaped the nurses' perceptions on life and death generally. All participants found their own combination of coping strategies to deal with patient death and find support from their colleagues. Most participants however felt that they could be better supported at work to better deal with patient death, citing training and group activities as methods on how they could be better supported.

Key words: Palliative care, nurses, lived experiences, death, Malta

Dedication

To my loving wife Lauriann

Acknowledgments

I would like to thank all of those who in one way or another contributed to this dissertation.

My thanks and gratitude go towards my academic supervisor, Dr Joanna Depares M.Sc. (Melit.), PhD, and my co-supervisor Mr. Daren Chircop M.Sc. (Melit.) for their time and guidance throughout this project.

Lastly, I would like to express my appreciation towards my wife Lauriann, for her constant support, patience, help, and encouragement throughout this dissertation.

Contents

List of Abbreviations

AXIS Tool	Critical Appraisal Tool for Cross-Sectional Studies
CASP	Critical Appraisal Skills Program
CINHAL	Cumulative Index to Nursing Allied Health Literature
DAP-R	Death Attitude Profile-Revised
EBSCO	Elton B. Stephens Company Database
FATCOD	The Frommelt Attitudes Toward Care of the Dying Scale
FREC	Faculty Research Ethics Committee
IPA	Interpretative Phenomenology Analysis
MeSH	Medical Subject Headings
PEO	Population, Exposure, and Outcome
PRISMA	Preferred Reporting Items for Systematic Reviews
PubMed	Public Medical Literature Analysis and Retrieval System Online
UOM	University of Malta
WHO	World Health Organisation

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Chapter 1: Introduction

1.1 General Introduction

Death is defined as the end-of-life of any living thing (Cambridge Advanced Learner's Dictionary, 2022), and is as much real as is birth, since it is the inevitable end of human life (Ayten et al., 2009). Cancer is the cause of nearly 16% of deaths worldwide (WHO, 2022), which amounts to 10 million deaths each year. Hospital care is required for people suffering from cancer, for both physical care and psychological support. This has led to an increase in demand for palliative care (Dionne-Odom et al., 2015). Palliative care is a treatment that improves the quality of life of people suffering from cancer, a high percentage of whom are at an advanced stage. A palliative approach places a focus on preventing and offering relief to symptoms and suffering, rather than curing the underlying condition. Palliative care also takes into consideration the spiritual and psychosocial aspects of the patients and their families (WHO, 2022). Death is anticipated in a palliative care setting, both by the patient and family members (Iranmanesh et al., 2008). Hence, nurses working in a palliative care setting face death on a daily basis, which generally leads to an assumption that nurses working in this setting are at ease with the acceptance of death (Peters et al., 2013).

1.2 Background of the Study

The work of the nurse, especially in the palliative care setting, reminds nurses of their own mortality due to their confrontation with death (Vachon et al., 2012), which can lead to anxiety in nurses (Lehto & Stein, 2009). In fact, end-of-life care is considered as one of the most stressful parts of being a nurse (Holland & Neimeyer 2005). Indeed, nurses describe the death of a patient, witnessing a patient suffering,

and listening to patients talk about their impending death as stressful aspects of their practice (Burnard et al., 2008), which are all situations that palliative care nurses deal with in their everyday work. Unlike other healthcare professionals who care for ill patients whose conditions often improve, nurses working in a palliative care setting are constantly surrounded with dying patients and the intense emotions of fear and sadness surrounding death, without any possibility of cure (Jocham et al., 2009). Wilson and Kirshbaum (2011) highlighted how the stress that nurses experience on the death of their patients can impact both their nursing care, as well as their relationships with others and other factors outside of their work. Similar findings emerged from a literature review by Peters et al (2013), leading these authors to conclude that it is therefore essential for palliative care nurses to be comfortable with death as this enables them to provide quality palliative care.

1.3 The Local Scenario

Locally, 27% of deaths are attributed to cancer, making it the second leading cause of mortality (OECD/European Observatory on Health Systems and Policies, 2019). In 2020, deaths from cancer in Malta equated to 966 deaths (Sung et al., 2021). The public sector in Malta provides palliative care services mainly for adult oncology patients, while Hospice Malta, a voluntary organisation, provides palliative care services to oncology patients and people with other terminal illnesses (Azzopardi-Muscat et al., 2017). At present, paediatric patients requiring palliative care are cared for in the paediatrics ward of the local oncology hospital (Azzopardi-Muscat et al., 2017). Further to this, Hospice Malta also plans to open the St Michael Inpatient Hospice in the coming years for adult palliative patients (Hospice Malta, 2022).

No published studies on Maltese people's perceptions of death were found; however, an undergraduate dissertation with a phenomenological approach about Maltese people's perception of death was retrieved. The findings show that Maltese people view death as a feared but inevitable part of life and as a mysterious event (Caprio, 2020). One published study (Grech et al., 2018) was found, which looked at Maltese nurses' experiences of encounters with patient death in a haematological setting. The findings showed that the participants felt that they needed more support services to assist them with providing end-of-life care, and the nurses felt distressed when their concerns were not addressed. A postgraduate dissertation (Grima, 2018) was found about Maltese nurses working in a cardiology setting and their encounter with sudden death, which findings found that nurses were shocked but had to carry on with their professional care, and participants described coping strategies that they developed to deal with such deaths. Three undergraduate dissertations (Dimech, 2010; Fenech Adami, 1993; Scalpello Hammett, 2011) were found about Maltese student nurses' experiences of patient death and their perceptions and attitudes towards caring for dying patients. The findings of the these three studies revealed that Maltese student nurses fear death but have a positive attitude towards end-of-life care.

1.4 Rationale of the Study

Numerous studies have explored the lived experiences of nurses caring for the dying patient (Holms et al., 2014; Liu & Chiang, 2017; Limbu & Taylor, 2021; Parola et al., 2018; Rafii et al., 2016). What is limited from the literature is palliative care nurses' lived experience of patient death which they encounter frequently in their everyday working life. Research on palliative care nurses mostly focuses on their

experience of caring for the dying patient (Liu & Chiang, 2017; Parola et al., 2018). There is also research focusing on the experiences of nurses in different settings who experience death, and how this experience affects them (Holms et al., 2014; Limbu & Taylor, 2021; Rafii et al., 2016). Literature also shows that attitudes towards death which are influenced by their experiences impact the end-of-life care that these nurses provide (Blaževičienė et al., 2020; Park & Oh, 2019; Shi et al., 2019). Furthermore, although end-of-life care is considered as one of the most stressful aspects of nursing practice, there is limited literature on how nurses, specifically palliative care nurses, cope with patient death and how these nurses could be supported. Understanding the nurses' lived experiences of encounters with patient death will help in identifying strategies that could support palliative care nurses to cope with the resultant stress which ultimately, will enable them to provide quality end-of-life care.

The opening of the aforementioned St Michael Inpatient Hospice, will lead to an increase in demand for nurses working in an inpatient palliative setting locally. Therefore, this study will provide culturally relevant findings, filling a gap in the literature and furthermore, enabling evidence-based identification of supportive strategies.

The author of this research study had frequently worked in a palliative care setting, while working as a nurse in the nursing relieving pool of an oncology hospital. The author was intrigued with how the nurses managed to work in this ward, where death is usually the only outcome for their patients. From the author's perspective, the nurses working in an inpatient palliative care setting seemed unaffected by patient

death. In this regard, this study will provide a voice for these nurses to share their experiences of frequently witnessing patient death.

1.5 Purpose of this Study

The aim of this research study was to explore the lived experiences of nurses who encounter patient death in a palliative inpatient setting. The research objectives were to:

1. Explore the perceptions and attitudes of nurses about personal and patient death.
2. Explore how nurses experience the death of their patients.
3. Identify coping strategies that nurses utilise when encountering patient death.
4. Examine nurses' perception of supportive strategies that could be implemented.

The research question of this study is: "What is the lived experience of nurses who encounter patient death in a palliative inpatient setting?"

Hermeneutic phenomenology is the guiding philosophy of this study, focusing on the meanings and interpretations of an individual's experiences (Smith et al., 2012). The methodology used for this study is Interpretive Phenomenological Analysis (IPA) as guided by Smith et al. (2012). Data was gathered by conducting semi-structured interviews. Since local studies focusing on the lived experiences of nurses working in a palliative care setting are limited, this study is anticipated to contribute to culturally relevant information about these nurses' experiences and support needs that could guide the development of evidence-based organisational and educational supportive strategies.

1.6 The Dissertation Structure

A brief description of the six chapters that make up this dissertation is presented here. This chapter provided background information on this subject and the purpose of this study. A review and critique of the available literature is presented in Chapter 2. A detailed description of the methodology and method used for this study is presented in Chapter 3, as well as the ethical considerations. Chapter 4 presents the findings of this study, that emerged from the data analysis of the participants' narrations. These findings are then discussed in relation to the extant literature and with reference to transactional theory (Lazarus, 1966) in Chapter 5. The strengths and limitations of this study are also presented in this chapter. The final chapter provides the recommendations for future research, clinical practice, and education.

Chapter 2: Literature Review

2.1 Introduction

This chapter presents a literature review of the experiences of nurses working in a palliative inpatient setting and their encounters with patients' death. The research question and its population, exposure and outcome are presented in the first part of the literature review, which is followed by a detailed description of the search process. Finally, the chapter describes a critical appraisal of the included studies, as well as a brief discussion of the results that will highlight the gaps in literature.

2.2 Inclusion and Exclusion Criteria

The PEO framework (Sackett et al., 2001) was used to formulate the research question of this review and identify the inclusion and exclusion criteria. The aim of this review was to explore the lived experiences of nurses who encounter death working in a palliative inpatient setting. Hence, the research question was: "What are the lived experiences of nurses' encounters with patient deaths in a palliative inpatient setting?". The different components of the PEO framework are illustrated in Table 2.1. The inclusion criteria for the literature search included nurses working in an adult palliative care unit, since participants in the current study cared for adult patients, and studies with their lived experience as an outcome, and encounter with patient death as the exposure. Exclusion criteria included nurses working in any other wards and studies with outcomes not including the nurses' lived experience.

Table 2.1

The Different Components of the PEO Framework

Population	Exposure	Outcome
Nurses working in an adult palliative inpatient setting	Patient death	Lived experience

An exploratory search revealed that studies on the lived experiences of nurses who encounter death whilst working in a palliative care unit are limited. The reserach question for this literature review was amended to "What are the lived experiences of nurses' encounters with patient deaths?" Hence, the population, exposure and outcome of the PEO framework were expanded upon to include more related studies. The outcome component was expanded to include perceptions and attitudes towards death, in addition to lived experience. The exposure was expanded upon to also include end-of -life care, since it is closely linked to attitudes and perceptions about death. The population was expanded to include nurses working in other settings where such nurses encounter patient death and provide end-of-life care. In addition to palliative care, these settings also included: oncology, medical, surgical, and intensive/critical care. Studies including nursing students were excluded. Studies searched for had to be published and peer reviewed. Lastly, articles in languages other than English were excluded due to a lack of translation facilities. Table 2.2 illustrates the inclusion and exclusion criteria.

Table 2.2

Inclusion and Exclusion Criteria

Inclusion Criteria	Exclusion Criteria
Nurses working in settings where nurses both encounter patient death and provide end-of-life care	Nurses working in settings where patient death is not encountered, or where nurses do not provide end-of-life care
Nurses caring for adult pallaitive patients	Nurses caring for paediatric palliative patients
Nurses' lived experiences, attitudes and/or perceptions about death	Nursing students
Peer-reviewed studies	Studies not peer-reviewed and grey literature
Studies in the English language	Studies not in the English language

2.3 Search Method

After developing the inclusion and exclusion criteria, a search strategy was developed, which is described in the following sections.

2.3.1 Search Terms

Different search terms and Medical Subject Headings (MeSH) terms were identified by using a thesaurus and from background reading. Where possible, truncations were utilised to identify alternative terminology with respect to the search terms. These terms are presented in Table 2.3 below, in conjunction with the revised PEO elements.

Table 2.3

Terms Mapped to Database Vocabulary

PEO Elements	Search Terms
Population – Nurses	Hospice and Palliative Care Nursing (MeSH), palliative nursing (MESH), hospice nursing (MESH), hospice care (MESH), Oncology Nursing (MeSH), Critical Care Nursing (MeSH), Medical-Surgical Nursing (MeSH), cancer nursing, medical nursing, surgical nursing, general nurses, ITU, CCU
Exposure – Patient death, end-of life care	Death (MeSH), dying, patient death, end-of-life, end-of-life care, end of life, end of life care
Outcome – Lived experience, attitudes and/or perceptions about death	Life experiences (MeSH), personal experience (MESH), Perception (MeSH), Attitude (MeSH), view (MESH), lived experience, belief, outlook

2.3.2 The Search

In order to avoid search bias and to ensure that all relevant studies available are found, several electronic databases were used (Randolph, 2009). Using the University of Malta (UOM) online library, the following databases were searched: PubMed, and Cochrane Library of Systematic Reviews, Medline Complete, PsycINFO, and the Cumulative Index to Nursing Allied Health Literature (CINHAL)

databases which were accessed from the EBSCO host site. In addition, the CINHAL database was also searched since it is a useful database especially for qualitative studies (Chapman, 2009). The language restriction could have led to language bias since results from articles published in other languages would have been overlooked (The Cochrane Collaboration, 2011). The publishing date of the articles had to be between 2012 and 2022, both years included. The rationale behind this date range was to keep an updated and manageable number of studies for the review.

2.3.3 Database Search

After identifying the search terms and any truncations, the former were combined by utilising the Boolean Operators 'AND' and 'OR' to generate the search strategies that would be used for the electronic databases. These Boolean Operators are used to combine or exclude the search terms in a search (Cooper et al., 2018). In addition, phrases were enclosed in quotation marks, so that results with that particular word order would be found. Table 2.4 presents the search strategy of the databases.

Table 2.4

Search Strategy used for Searching the Databases

Search Strategy
((palliative OR hospice* OR Oncology OR "intensive care" OR ITU OR CCU OR "nurs*") AND (Death OR dying OR "patient death" OR "end-of-life care" OR "end of life" OR "end of life care") AND ("Life experiences" OR "personal experience" OR experience* OR "lived experience" OR Attitude OR attitude* OR perception OR perceive* OR perspective* OR view* OR belief OR outlook))

These searches were carried out during the month of March 2022. The number of results found from each database is presented in Table 2.5.

Table 2.5

Results from Databases

Limiters Applied	Database Accessed	Hits
English language, peer-reviewed, Published date: 2012 - 2022	CINHAL (EBSCO)	2,428
	Cochrane Library of Systematic Reviews (EBSCO)	84
	PubMed	2,747
	PsychInfo (EBSCO)	862
	Medline Complete (EBSCO)	3,532

2.3.4 Search Results and Selection

A total of 9,653 records were retrieved from searching the databases. 87 duplicates were removed by using the bibliographic software RefWorks, which left 9,566 records. Through reading the titles and abstracts, 9,504 records were deemed to be irrelevant and hence, removed. This left 62 records, where the full text was read to determine if they were eligible according to the inclusion and exclusion criteria presented in Table 2.2. Out of the remaining 62 records, 54 were removed due to various reasons, namely: (i) 29 articles did not report the outcomes of interest; (ii) 18 articles included nurses who did not provide end-of-life care; (iii) 7 articles did not report findings for palliative, oncology, medical-surgical, or intensive care nurses only. From the review of the references of the remaining articles, one study was found to be relevant but, on reading the full-text, it was deemed irrelevant since the outcomes of interest were not reported. This selection process is summarised in Figure 1 below, which was adopted from Page et al. (2021).

Eight studies were included in this review, of which five are qualitative studies and three are quantitative studies. These studies were conducted in the United States of America (USA) (n=2), Canada, China, South Africa, Portugal, Taiwan, and Turkey. In the next section, a critical appraisal of these qualitative and quantitative studies including ethical considerations is presented.

Figure 2.1

Prisma Flow Diagram (Page et al., 2021)
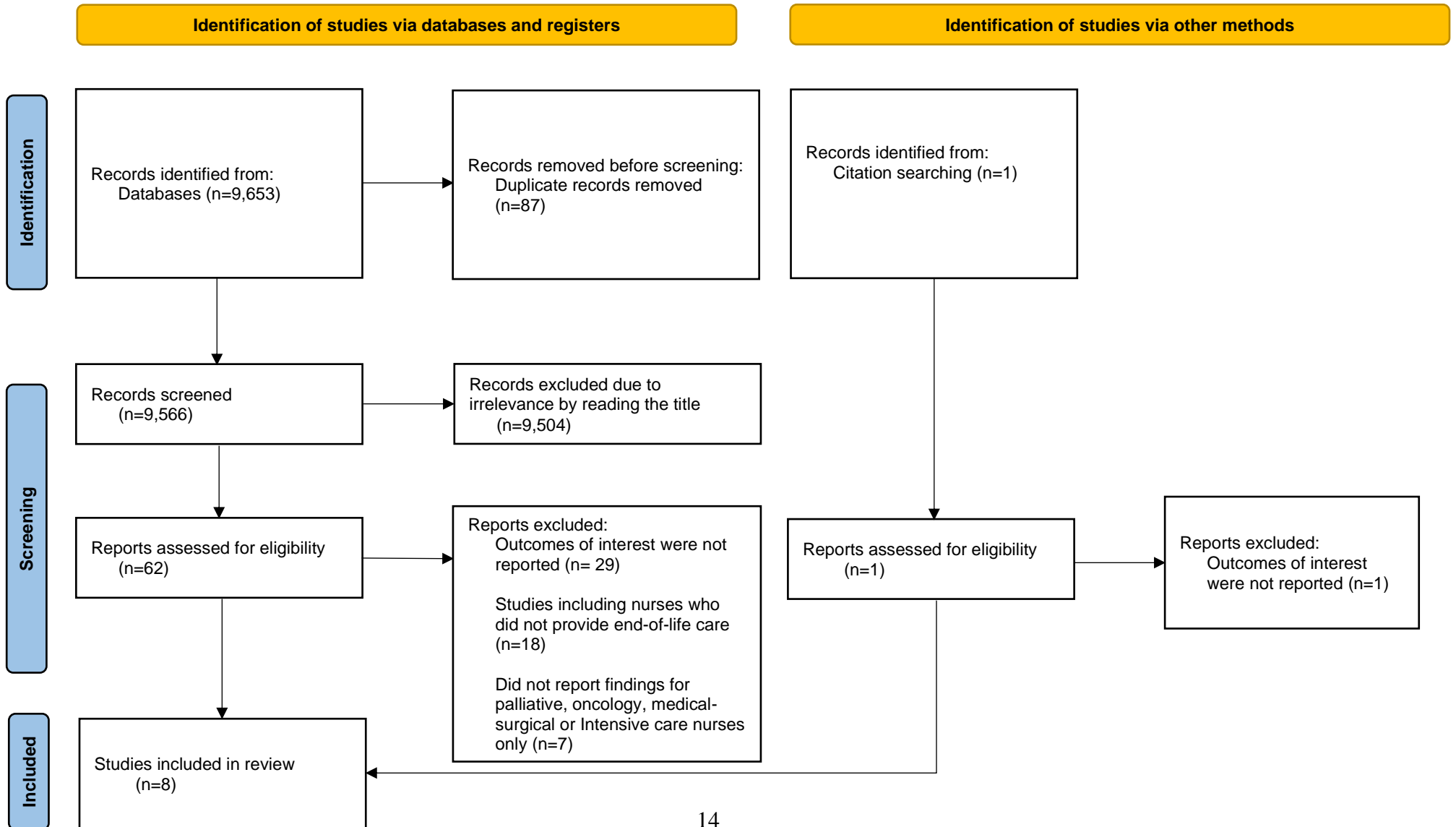
2.4 Critical Appraisal of Qualitative Studies

Critical appraisal enables the assessment of the validity of the methods that a study employs, and the relevance and value of the results for the concerning population (Lincoln & Guba, 2011). For the appraisal of the qualitative studies, the Critical Appraisal Skills Programme (CASP) (2018) qualitative checklist was used (Appendix A). This tool consists of ten questions, of which the first two are screening questions that cover the aim and methodology of the study. The remaining questions cover the research method to evaluate the quality of the research, with questions about sampling, recruitment of participants, research design, data collection, rigour of data analysis, methods, recounting of findings, and ethical issues.

In this section, a critical appraisal of the qualitative research is presented. Table 2.6 presents the characteristics of the qualitative studies included in this literature review. From the five qualitative studies, four had a phenomenological design. Two of these studies utilised descriptive phenomenological analysis, whilst the other two utilised interpretative phenomenological analysis. The other study did not specify a design.

Table 2.6

Qualitative Studies Characteristics

Authors	Title of Study	Country	Sample Size (n=*x*)	Nurse Population	Methodology	Method
Vachon et al. (2012)	Death Confrontation, Spiritual-Existential Experience and Caring Attitudes in Palliative Care Nurses: An Interpretative Phenomenological Analysis	Canada	n=11	Oncology nurses including palliative care nurses	Interpretative Phenomenological Analysis	Semi-structured interviews
Hinderer (2012)	Reactions to Patient Death The Lived Experience of Critical Care Nurses	USA	n=6	Critical Care nurses	Descriptive Phenomenological Analysis	Semi-structured interviews
Naidoo & Sibiya (2014)	Experiences of critical care nurses of death and dying in an intensive care unit: a phenomenological study	South Africa	n=4	Intensive Care nurses	Descriptive Phenomenological Analysis	In-depth interview

Liu & Chiang (2017)	From vulnerability to passion in the end-of-life care: The lived experience of nurses	Taiwan	n=13	Oncology nurses including palliative care nurses	Interpretative Phenomenological Analysis	Focus group
Temelli & Cerit (2021)	Perceptions of Palliative Care Nurses Related to Death and Palliative Care Practices	Turkey	n=23	Palliative care nurses	Not specified	Semi-structured interviews

2.4.1 Introduction

These five studies explored different aspects of patient death and the experiences surrounding it. Vachon et al. (2012) sought to understand how palliative care nurses cope with proximity to death, and what their lived spiritual-existential experience is, and possible links between the two. Hinderer (2012) and Naidoo and Sibiya (2014) focused on critical nurses and their lived experiences of their encounters with patient death and dying, while the study by Liu and Chiang (2017) explored the lived experiences of oncology nurses in the provision of end-of-life care. The qualitative study by Temelli and Cerit (2021) aimed to explore the perceptions of death and of palliative care practices of palliative nurses. Vachon et al. (2012) and Liu and Chiang (2017) chose interpretive phenomenological analysis, whilst Hinderer (2012) and Naidoo and Sibiya (2014) chose descriptive phenomenology, which are appropriate study designs to explore the lived experiences of the participants (Creswell, 2014). The research design of the study by Temelli and Cerit (2021) was not made explicit, and the researchers only stated that the study followed a qualitative design. All studies clearly stated why they used a qualitative methodology, and all studies except Temelli and Cerit (2021) explained and justified their choice of research design, and how they addressed their research question. Choice of designs were appropriate, in relation to the research questions being posed. None of the studies referred to a theoretical framework.

2.4.2 Sampling

All included studies, bar the one by Temelli and Cerit (2021), used purposive sampling to recruit participants which is appropriate to recruit from a population with specific characteristics, who had experienced the phenomena being researched

(Rodriguez & Smith, 2018). In the study by Temelli and Cerit (2021), no indication of the recruitment strategy was mentioned, and the authors of this study only stated that all nurses working in the ward from where the participants were recruited agreed to participate in the study. Sample sizes of these studies were all small, which is appropriate for acquiring an in-depth understanding of the phenomena under study (Gill et al., 2008). No study provided a rationale for these sample sizes. Participation was on a voluntary basis, and the participants were chosen according to eligibility criteria, with the exception of Temelli and Cerit (2021) who did not mention eligibility criteria. Characteristics of the participants were collected and presented in all studies.

2.4.3 Data Collection

Vachon et al. (2012), Hinderer (2012), and Temelli and Cerit (2021) chose semi-structured interviews; Naidoo and Sibiya (2014) chose unstructured interviews as the method for data collection, while Liu and Chiang (2017) chose six reflective group sessions. In view of the studies' objectives to understand the participants' experiences, interviews were deemed as an adequate choice (Gray & Grove, 2018). The choice of focus groups by Liu and Chiang (2017) was also appropriate since group dynamics could help participants express their views in a way that would not occur in one to one interviews (Gray & Grove, 2018).

Vachon et al. (2012), Hinderer (2012), and Temelli and Cerit (2021) used an interview guide, which was only provided by the former, while Naidoo and Sibiya (2014) and Liu and Chiang (2017) started with one initial question and then used

probing to facilitate the conversation and uncover the participants' experiences. All studies recorded these sessions digitally through audio recording.

None of the studies stated if a pilot study was carried out. A pilot study could have given the researcher an opportunity to test the interview guide and practise the interviewing techniques, and make appropriate changes (Majid et al., 2017). Only Hinderer (2012) indicated that data was collected until there was data saturation. Data saturation promotes validity and reliability of the findings (Gray & Grove, 2018). None of the studies mentioned if the researchers were trained in conducting interviews and group sessions. If the researchers were not trained, the data collection may have not been carried out appropriately, leading to unreliable data (Gill et al., 2008).

Vachon et al. (2012) acknowledged the researcher's interpretative input in understanding the participants, and Hinderer (2012) used bracketing to set aside personal opinions prior to starting data collection. This technique is important since it decreases the influence of the preconceptions of the researcher from affecting the research process (Tufford & Newman, 2012). Temelli and Cerit (2021) addressed researcher bias by having the coding done independently by two researchers and an agreement index was used to check for the reliability of the coding, which was measured at 82%, which is above the 70% minimum suggested by Yildirim and Simsek (2016). This minimised having one individual trying to validate a particular theme or not recognise a particular theme (Berg & Lune, 2012). Naidoo and Sibiya (2014) and Liu and Chiang (2017) stated that they followed the four principles of trustworthiness by Lincoln and Guba (1986). No description how this was carried

out was given, so it could not be determined how much the findings of the study were influenced by the researchers themselves. No studies reported any changes being made to their research design throughout the study.

2.4.4 Data Analysis and Findings

Vachon et al.'s (2012) and Liu and Chiang's (2017) data analysis was guided by IPA (Smith et al., 2012), while Hinderer's (2012) data analysis was guided by the Colaizzi's method (Colaizzi, 1978). On the other hand, Naidoo and Sibiya's (2014) data analysis was guided by Giorgi's method (Giorgi, 1985). Temelli and Cerit (2021) analysed the data using content analysis, and a description of the analysis process was provided.

All studies provided a section detailing the analysis process, which included transcription of the recordings collected, and how literature was used to discuss their findings. Vachon et al. (2012) and Liu and Chiang (2017) carried out reflexivity during data analysis, which was important since it guided the reader to better understand the research process and how the researchers reached their conclusions (Braun & Clarke, 2019). Vachon et al. (2012), Hinderer (2012) and Liu and Chiang (2017) validated the findings with the participants, while the former also validated the findings with other researchers. Liu and Chiang (2017) also mentioned that the analysis was peer reviewed by colleagues to notice if any potential bias may have affected the analysis (Gill et al., 2008). Both these types of validation promote validity of the findings (Gray & Grove, 2018).

Although different approaches were used, the findings were presented in a similar manner, by presenting the super-ordinate themes and themes together with direct quotes from the transcripts. Vachon et al. (2012) identified seven themes, Hinderer (2012) identified four themes, Naidoo and Sibiya (2014) identified five themes, whilst Liu and Chiang (2017) and Temelli and Cerit (2021) identified three themes. In all studies, the findings were then discussed in relation to the research question.

2.4.5 Discussion

All studies discussed the findings in relation to the available literature and provided recommendations for further research and study limitations. Due to the lack of a pilot interview, these studies lacked reliability (Gill et al., 2008). Only Naidoo and Sibiya (2014) provided an in-depth description of how the results from the study could be implemented into education, institutional management and practice, and to develop policy. While Temelli and Cerit (2021) provided suggestions for education and nurses training, no suggestions for future research were provided by this study.

2.5 Cross-Sectional Studies

This section presents the critical appraisal of the quantitative studies included in this review, which were all cross-sectional studies. For the appraisal of the quantitative studies, the AXIS critical appraisal tool was used (Downes et al., 2016) (Appendix B). This is a tool designed to appraise cross-sectional designs. Table 2.7 presents the characteristics of the cross-sectional studies that are included in this literature review.

Table 2.7

Cross-Sectional Studies Characteristics

Authors	Title of study	Country	Sample Size (n=x)	Nurse population	Methodology	Method
Gama et al. (2012)	Factors influencing nurses' attitudes toward death	Portugal	n=360	Nurses from three general hospitals	Cross-sectional	Sociodemographic and professional questionnaire (QSDE), Death Attitude Profile-Revised (DAP-R), Adult Attachment Scale (AAS
Guo and Zheng (2019)	Assessing oncology nurses' attitudes towards death and the prevalence of burnout: A cross-sectional study	China	n=279	Oncology nurses including palliative care nurses	Cross-sectional	Death Attitudes Profile Scale and the Maslach Burnout Inventory

Barnett et al. (2020)	Death Attitudes, Palliative Care Self-efficacy, and Attitudes Toward Care of the Dying Among Hospice Nurses	USA	n=90	Hospice centres, hospitals, nursing homes, and other long-term care facilities	Cross-sectional	The Death Attitude Profile—Revised (DAP-R), The Frommelt Attitudes Toward Care of the Dying Scale, The Palliative Care Self-Efficacy Scale

2.5.1 Introduction

Through the use of cross-sectional studies, risk factors and outcomes can be analysed. Further to this, cross-sectional studies are deemed as practical, since they involve the gathering of data at a single point in time (Polit & Beck, 2010). Gama et al. (2012) aimed to identify nurses' attitudes towards death, and the training, professional, and sociodemographic factors that affect these attitudes. The aim of Guo and Zheng (2019) was to examine the occurrence and severity of burnout in Chinese oncology nurses and examine its relationship with death attitudes. Barnett et al. (2020) examined the relationship between hospice nurses' death attitudes, palliative care self-efficacy and attitudes towards end-of-life care. All studies addressed clear research questions and objectives. A cross-sectional study was appropriate for all studies since the design is useful to give a description of a population and test for any relationships (Leeuw et al., 2009).

2.5.2 Methodology and Sampling

Guo and Zheng (2019) recruited from one oncology hospital, while Gama et al. (2012) recruited participants from three general hospitals, and Barnett et al. (2020) recruited from hospice centres, hospitals, nursing homes, and other long-term care facilities in one metropolitan area, making the sample more representative of the population being studied and enabling broader conclusions to be made (Polit & Beck, 2010). The target population was clearly defined in all three studies, but only Guo and Zheng (2019) carried out a power calculation for sample size and presented the methods used for this calculation. The sample size for the study by Guo and Zheng (2019) was in accordance with the calculated required sample size, hence reducing the possibility for type II and type I errors (Gray & Grove, 2018). Type II

error is when any significant results are not detected, even when they exist, and type I is when significant conclusions are drawn, when they do not really exist (Gray & Grove, 2018). For the other two studies, type I and type II errors may have been an issue due to a lack of a power calculation (Gray & Grove, 2018).

Guo and Zheng (2019) and Barnett et al. (2020) used convenience sampling, which could lead to biases given that participants are included in the study by coincidently being in the right place at the right time (Gray & Grove, 2018). Gama et al. (2012) used purposive sampling to select their participants. This method is vulnerable to errors in judgment from the researchers, and hence it is prone to bias and has low level of reliability (Gray & Grove, 2018). None of the studies took measures to address non-responders, which could have led to non-response bias which is when the characteristics or responses of the non-responders differ significantly from the responders (Cheung et al., 2017). All three studies presented their eligibility criteria for the studies in a clear manner.

2.5.3 Data Analysis and Results

The instruments used by the three studies had all been previously tested and demonstrated as reliable. All studies stated that the p-value was set at $p<0.05$ and only Guo and Zheng (2019) stated that the confidence interval was set at 95%. This p-value was set at an appropriate level to reduce the possibility of a type I error (Greenland et al., 2016). By not providing a confidence interval, the relevance of the results and their level of representation of the population could not be determined (Greenland et al., 2016). Only Barnett et al. (2020) did not provide a description of how the statistical tests were used in the data analysis. The three studies provided

results that were adequately described and presented both in text and graphical form. The Cronbach alpha coefficient was used by all studies to determine reliability, with all studies reporting Cronbach's values of $\alpha > 0.80$, which indicates reliability (Gray & Grove, 2018). The three studies presented the results for all of the mentioned tests in the method, and a detailed discussion of all of the included results was presented by all studies.

2.5.4 Discussion

All studies mentioned their limitations, particularly the lack of generality of their results. Further to this, Barnett et al. (2020) mentioned that, due to the study design, conclusions about causality and directionality of the results could not be drawn. This applied to the three studies since cross-sectional designs only collect data at one point in time, and hence changes in the phenomena being studied could not be determined in these studies (Gray & Grove, 2018). All studies collected demographic characteristics of the participants, which included characteristics that could be considered as confounding factors, such as marital status, religious belief, education, years of working experience, and frequency of end-of-life care. All studies mentioned that these characteristics were controlled statistically to reduce their effect on the findings (Gray & Grove, 2018). Other external confounding factors that could not be measured or controlled could have affected the findings of all studies (Gray & Grove, 2018).

2.6 Ethical Considerations

Ethics concerns the way participants are treated by the researchers during a study. The latter are responsible for ensuring that the participants do not undergo any mental, physical, or emotional harm (World Medical Association, 2013). All appraised studies obtained ethical approval from their respective board, however, not all studies mentioned that informed consent was obtained from the participants. Only Liu and Chiang (2017), Temelli and Cerit (2021), and Barnett et al. (2020) claim to have acquired informed consent. The risks and benefits of the study were only explained by Naidoo and Sibiya (2014). On the other hand, Temelli and Cerit (2021) explained that participants could leave at any time or stop the interview recording at any time. No study explained if they provided information about the researchers' and participants' roles during the study, or the right to refuse without consequences.

Only Hinderer (2012) mentioned where most of the data was collected. This might have impacted the results of the other studies since it is not clear how comfortable the participants were during data collection, resulting in possible bias (Gray & Grove, 2018). None of the qualitative studies provided details as to how they safeguarded confidentiality, and whether the collected data was destroyed upon completion of the studies, and accordingly, there is a possibility that, after the publication of results, participants were unprotected from any damage, albeit psychological and physical damage.

2.7 Summary of Findings

Table 2.8 presents the main findings of each of the qualitative studies. In Table 2.9, quantitative studies results are presented by presenting the scores for each subscale of the "The Death Attitude Profile - Revised (DAP-R)" and the "The Death Attitude Profile" (Chinese version). The former is a Likert scale ranging from one to seven, whereby one is *strongly disagree*, seven is *strongly agree*, and four is *neutral*. The latter is the Chinese version of the scale, having a five point Likert scale where one is *strongly agree*, five is *strongly disagree*, and three is *neutral*. Only these findings from the quantitative studies were included since only the results from these subscales are relevant for the current literature review.

Table 2.8

Summarised Findings of Qualitative Studies

Research Study	Main Findings
Vachon et al. (2012)	Witnessing death could make nurses more aware of death. Witnessing death also changes how nurses live their everyday life to a more meaningful one.
Hinderer (2012)	Nurses accept death as inevitable part of life, but still are emotionally negatively affected. Nurses described how they emotionally distance themselves and became hardened over time to not be affected by death. This distancing though was not always possible with all patients.
Naidoo and Sibiya (2014)	Critical care nurses need support systems to help them cope with the emotional toll that patient death has on them. This support helps both the nurses' emotional wellbeing and also assists nurses to provide end-of-life care.
Liu and Chiang (2017)	Caring for dying patients offer nurses an opportunity to reflect on their own selves and help them improve themselves. Their experience of providing end-of-life care also helps them to provide better care for their patients, since the nurses start to empathise more with the patients.
Temelli and Cerit (2021)	Nurses view death as natural but sometimes scary. They also viewed death as a means of ending the suffering for the patients. Nurses also felt bad when younger patients died, or patients were suffering.

Table 2.9

Summarised Findings of Quantitative Studies According to Each Subscale Score of the DAP-R and DAP (Chinese Version)

Research Study	Gama et al. (2012)	Guo and Zheng (2019)	Barnett et al. (2020)
Subscale and Subscale range	1 – Strongly agree 4 – Neutral 7 – Strongly disagree	1 – Strongly agree 3 – Neutral 5 – Strongly disagree	1 – Strongly agree 4 – Neutral 7 – Strongly disagree
Fear of death – negative thoughts and feelings about death (Wong et al., 1994)	M = 4.16	M=2.78, SD 0.69	M = 2.61, SD = 1.10
Death avoidance – avoidance of thoughts of death as much as possible (Wong et al., 1994)	M = 3.64	M=2.97, SD 0.77	M = 2.70, SD = 1.22
Neutral acceptance – death is neither welcomed nor feared (Wong et al., 1994)	M = 5.35	M=3.91, SD 0.65	M = 5.89, SD = 1.48
Approach acceptance – death is viewed as a passageway to happy afterlife (Wong et al., 1994)	M = 3.74	M=2.77, SD 0.66	M = 4.23, SD = 1.35
Escape acceptance – death is viewed as an escape from a painful existence. (Wong et al., 1994)	M = 3.5	M=2.72, SD 0.78	M = 5.54, SD = 0.28

Note: M, mean score; SD, standard deviation. Gama et al. (2012) did not provide the standard deviation for the mean scores.

The findings of both qualitative and quantitative described how nurses perceived death as being inevitable and meaningful. The findings also described how patient death affected nurses emotionally. In turn, nurses described what coping strategies they utilise to cope with the emotional effect patient death has on them. The relevant results for this literature review from the three quantitative studies addressed the nurses' perception of death and thus, their results could be combined with the findings from the qualitative studies. The qualitative studies presented the findings in themes and subthemes, which were elaborated upon through further discussion and excerpts from the interviews. For the purpose of the present literature review, the findings from these studies were grouped together and coded from which, three themes emerged:

- Meaning of death

- Emotional reaction to death

- Coping with death

The findings from the studies are discussed according to each theme in the next section.

2.7.1 Meaning of Death

Nearly all studies described the perception of death of the nurses. These perceptions are described in this theme.

Encountering death made nurses reflect on the definition of death and what it means to them. Vachon et al. (2012) and Temelli and Cerit (2021) found that nurses described death as the end-of-life and something that is natural. The fact that death is

in turn inevitable provided comfort for nurses (Hinderer, 2012; Naidoo & Sibiya, 2014). Further to this, according to Hinderer (2012), the nurses' acceptance of the inevitability of death allows them to care for dying patients. Moreover, death was more accepted by the nurses when they had provided the best possible care. Vachon et al. (2012) and Temelli and Cerit (2021) also found that nurses saw death as a transition and path to the afterlife. This is also confirmed by Barnett et al. (2020), where nurses agreed with statements that described death as a passageway to a happy afterlife. Hinderer (2012) revealed that nurses also saw death as a sign that the purpose of the person in life was complete.

Temelli and Cerit (2021) also found that nurses saw death both as the end of pain, and also as sometimes being difficult and scary. Vachon et al. (2012) described how for some nurses, death was a mystery or did not have a meaning or serve a purpose. This theme presented how the findings from these studies described the perception of death of the nurses. They perceive death as the natural and inevitable end-of-life, while it also can mark the end of pain and a transition to the afterlife.

2.7.2 Emotional Reaction to Death

The findings of the eight studies showed that caring for dying patients and encountering patient death causes nurses to experience several emotions and feelings, which are described in this theme. Encountering death makes nurses reflect on their own lives and inevitable death (Hinderer, 2012). In addition, Vachon et al. (2012) highlighted that death made nurses appreciate their lives more and in turn, elevate their life by making it more meaningful.

Gama et al. (2012), Guo and Zheng (2019), and Barnett et al. (2020) found that nurses encountering death had lower scores in the death avoidance subscale, meaning that they did not avoid thoughts about death. According to Liu and Chiang (2017), caring for dying patients helped nurses prepare for their own death by becoming more confident in facing their personal death.

In contrast, some nurses showed ambivalence towards their own death, by showing anxiety when talking about their own death, but stating that it did not affect them (Vachon et al., 2012). This is backed up by the findings of Gama et al. (2012), Guo and Zheng (2019), and Barnett et al. (2020), who from the neutral acceptance subscale found that nurses do neither fear nor look forward to death.

Patient suffering was highlighted as the most difficult aspect that the nurses in Vachon et al.'s (2012) study faced when caring for patients who are dying. This was due to the fact that nurses ended up feeling negative emotions from witnessing suffering, such as helplessness and guilt, since they could not provide comfort to the suffering patient (Hinderer, 2012). Vachon et al. (2012) also found that nurses felt powerless and frustrated when they were not able to relieve suffering. Vachon et al. (2012) highlighted that nurses attempt to counteract the suffering by looking at it in a positive way or by focusing on other positive aspects. Accordingly, nurses described deaths as 'positive', when death marked the end of suffering (Hinderer, 2012).

'Horrible' deaths were described as when the patient was suffering, and in such cases, nurses described that they felt distress and discomfort (Hinderer, 2012; Liu & Chiang, 2017).

Hinderer (2012) described how the family members of the patients affected the nurses, particularly in stressful situations where the relatives were unable to accept that death is imminent or when the relatives unnecessarily delay death by continuing futile treatment. This also affects how nurses cope with death, which will be mentioned further on. Knowing that the patient was going to die also caused stress to some nurses due to the anticipation of death (Hinderer, 2012).

Nurses also described that having patients stay for a long time in the ward and forming a strong relationship with patients caused such deaths to affect them more (Hinderer, 2012; Liu & Chiang, 2017). Hinderer (2012) also revealed that nurses found that some deaths were unforgettable due to these strong relationships. As will be discussed in the next theme, this goes contrary to what the nurses described as trying to emotionally distance themselves from the death in order to not let death affect them. Sometimes nurses found that they had to delay their emotional reactions till after work because of their duties at work. This contrasts to the coping strategy adopted by nurses who 'leave work at work', which will be discussed further on. Naidoo and Sibiya (2014) and Temelli and Cerit (2021) also highlighted that nurses found deaths of young patients more difficult and made the situation more emotional since they felt sorry for them.

These findings described how exposure to death made nurses more aware of death and their life, and how sometimes nurses felt negative emotions when faced with patient death.

2.7.3 Coping with Death

The review of these studies also highlighted how the nurses cope with patient death. Vachon et al. (2012) found that nurses use mechanisms to not have their work life affect their personal life, such as by trying to separate work from personal life. As described previously by Hinderer (2012), nurses are not always successful in doing this, since in some instances they have to delay their emotional reaction until after work.

Hinderer (2012) and Naidoo and Sibiya (2014) revealed that nurses often seek support from their work colleagues to help each other cope with stressful experiences.

As also mentioned before, Hinderer (2012) found that relatives influence the ability of nurses to cope. Nurses describe that when family members handle the death of their relative well, the nurses cope better. On the other hand, when relatives handle the situation badly, nurses often feel uncomfortable in the situation and do not cope well.

The first theme discussed how nurses stated that they accepted patient death when they had given the best possible care. In contrast, Hinderer (2012) revealed that, with time, nurses learn to distance themselves emotionally from death, and become less emotionally invested in the death experience. As described in the previous theme, this distancing was also not always achieved, since the nurses described how, in some instances, they formed bonds with certain patients and were emotionally affected negatively by their death.

In the study by Hinderer (2012), the nurses described how, with time, they became '*hardened*' and started setting up a '*wall*' when experiencing death. This led to the nurses describing themselves as becoming more comfortable when providing end-of-life care, and feeling less overwhelmed, which helped them cope better.

This theme presented the coping strategies that the studies' findings described. Nurses in these studies cope by finding support from their colleagues, and by emotionally distancing themselves from patient death. Nurses also described that with experience they also found that they could cope better.

2.7.4 Summary of Findings and Identified Gaps in Knowledge

In summary, the findings of this literature review highlighted how nurses who encounter patient death react to death and how they handle it. Throughout their work, nurses experience stressful episodes and uncomfortable situations relating to patient death. They describe how patient death can be different, the different emotions evoked by such deaths, and how witnessing death helps them reflect on the meaning of death, including their own. In turn, the research also highlighted how nurses find ways how to cope with patient death, in order to continue working in their ward and care for dying patients.

This review highlighted that there is still a lack of research about nurses working in a palliative care unit and their lived experiences related to death. Due to witnessing death on a more regular basis than in other wards, these nurses may have a different experience than other nurses relating to death and its effects. Therefore, it is imperative that further research is conducted on this population.

Although the questionnaires used in the quantitative studies offers data that can be compared and contrasted, it is not ideal to explore the experiences of nurses, since it is difficult to convey the emotions and feelings of the participants (Kothari, 2013). In contrast due to their nature, it is challenging to generalise findings from qualitative research, and hence findings from the qualitative studies might not apply locally (Grove et al., 2015).

Local research in this area does not seem to be present, and accordingly, the present study aims to address these identified gaps in knowledge.

2.8 Conclusion

Research about the experiences of nurses when encountering death is important, to understand these nurses and in turn provide them with support that they require. This review identified current literature on this topics, and also identified current gaps in knowledge. In this regard, this study aims to address the gaps identified by this literature review. In the next chapter, a detailed account of the methods used in this study is presented.

Chapter 3: Research Methodology

3.1 Introduction

This chapter provides a clear trail of the methods, providing rationale for each decision taken, while adhering to the theoretical foundations of Interpretative Phenomenological Analysis (IPA) (Kallet, 2004). In this chapter, a description of the research methods and the research question of this study will be presented. This chapter first explains the reasons why IPA was chosen as the methodology to guide this study and describes the methods and processes of participant selection, data collection, and data analysis. In addition, this chapter discusses the ethical issues faced, and how these were addressed to improve the rigour of this study.

3.2 Research Question, Aims, Objectives

The aim of this study was to explore the lived experiences of nurses who encounter patient death in a palliative inpatient setting. The objectives of the study were to:

1. Explore the perceptions and attitudes of nurses, about patient death and their own death.

2. Explore how nurses experience the death of their patients.

3. Identify coping strategies that nurses utilise when encountering patient death.

4. Examine nurses' perception of current supportive strategies, and what further supportive strategies could be implemented.

The research question of this study is: "What is the lived experience of nurses who encounter patient death in a palliative inpatient setting?"

3.2.1 Operational Definitions

Operational definitions of terms are important to clarify the keywords of the research question (Brent et al., 2016). For this research question, the two terms 'experience' and 'patient death' were identified as keywords. For the purpose of this study, 'experience' is defined as the understanding and perceptions of the nurses working in a palliative inpatient setting (Given, 2008). 'Patient death', for the purpose of this study, is defined as the final hours before death and the moment of death itself.

3.3 Research Design

This section describes the research design chosen, and the rationale underlying this choice. The appropriate research design guides the study on the method, time, and location of the data collection and its analysis (Parahoo, 2014). In addition, the research design provides the direction that the research should follow as established by its objectives (Creswell, 2014).

The research approach for this study was chosen according to the philosophical underpinnings about reality, epistemology, and methodology (Creswell, 2014). On one hand, qualitative methodology aims to understand the meanings that participants derive from their environment, and how these affect their behaviour. In contrast, quantitative methodology has the purpose of seeking one true reality (Polit & Hungler, 2010).

The aim of this study was to explore the experiences of nurses working in a palliative inpatient setting and their encounters with patient death. For this reason, the deductive and hypothesis-driven methodology of quantitative approaches was

deemed inappropriate, since the collected data would not provide a complete insight

of the nurses' experiences, feelings, and behaviours (Biggerstaff & Thompson,

2008).

Epistemology is the study of the scope, origin, and nature of knowledge (Creswell,

2014). A qualitative approach permitted the research to be based in a hermeneutic

epistemological perspective. Such a perspective recognises the power of words and

the immersion of experiences in language itself (Denzin & Lincoln, 2011).

Therefore, a qualitative design is able to facilitate the study of different viewpoints

of this lived experience through the collection of applicable knowledge (Berg &

Lune, 2012).

Furthermore, qualitative research encompasses multiple fields as its research

traditions, namely anthropology, psychology, sociology, and philosophy (Corbin &

Strauss, 2008). The methodological approaches linked with these fields are

phenomenology, narrative, grounded theory, and ethnography. According to Finlay

(2009), phenomenology encompasses both a philosophy and an array of research

approaches. These approaches may be hermeneutic, that is, trying to understand the

phenomenon by learning about lived experiences of the subjects being studied, or

descriptive, that is, the aim being only to describe the phenomena under

investigation. The epistemology of phenomenology is based on Heideggerian

hermeneutics and Husserlian phenomenology. This approach directs the researcher

on how to investigate the data to obtain a better understanding of the individuals'

perceptions, subjective feelings, and experiences, while also guiding the researcher

on how individuals define the world in familiar situations (Larkin et al., 2006). IPA

was chosen because it gains access to the nurses' lived experiences through interviews, enabling the researcher to gain access to the nurses' experiences and their understating of these experiences. Since the researcher has prior experience of working in a palliative inpatient setting, it is extremely difficult to remove all preconceptions. Hence IPA was also chosen since it accepts the researcher's preconceptions as a way to access the participants' experiences, through interpretative activity (Smith et al., 2012). The following section describes the theoretical underpinnings of IPA.

3.4 Theoretical Underpinnings of IPA

The theoretical underpinnings of IPA, namely phenomenology, hermeneutics and idiography, are described in the following sections. IPA was utilised as the methodology for this study since it helps the researcher delve into the experiences of palliative care nurses and the meaning that they give to these experiences (Smith et al., 2012).This methodology helps participants describe these experiences, by providing them with a space where these accounts of such experiences can be revealed, while uncovering their outlook within the context of their worlds (Larkin et al., 2006). Concepts based on hermeneutics and phenomenology are included in IPA, resulting in an interpretive and descriptive method (Todres & Holloway, 2010). The choice of this methodology allows the researcher to describe the life experiences and phenomenon being studied through phenomenological reflection and writing and at the same time, the researcher becomes part of the interpretative process by playing an active part in the research process (Todres & Holloway, 2010). In the following section, the philosophical underpinnings of IPA – descriptive, hermeneutics and idiography – are described.

3.4.1 Descriptive Phenomenology

Phenomenology originating from Husserl (Smith et al., 2012) theoretically informs IPA. Husserl attempted to build a philosophical perspective of consciousness, which was further developed upon by Merlaeau-Ponty and Heidegger (Shinebourne, 2011). In accordance with an IPA approach, the researcher utilised this philosophical view to understand the nurses' lived experiences of encounters with patient death, and how they made sense of these experiences (Smith, 2004). Husserl's consideration of the 'life world' of a person facilitated the ability to examine these everyday life experiences. The principal belief of such a consideration is the core of the experience, and the ways in which the perception of every experience is subject to a reflection, resulting in a conscious effort and understanding (Biggerstaff & Thompson, 2008). Therefore, IPA is related to phenomenology because it allows the participants to recount their experiences from their own perspectives.

Bracketing is a technique used by the researcher to put any preconceptions or assumptions aside and focuses solely on the phenomena being studied (Larkin, Watts, & Clifton, 2006). Husserlian's phenomenology emphasises bracketing, but IPA acknowledges that this is impossible to achieve. As mentioned briefly in the rationale of why IPA was chosen for this study, IPA views these preconceptions as valuable for the researcher to have a better understanding of the participants' experiences. Hence, the researcher has to become aware of his/her preconceptions through reflexivity and how these preconceptions may influence the research process (Smith et al., 2012).

3.4.2 Hermeneutics

The aim of IPA is not to simply describe the experiences of individuals, but also to explain the underlying and hidden meaning behind their lived experiences (Shinebourne, 2011). For this reason, IPA is tied to hermeneutics. As described by Smith et al. (2012), hermeneutics is the "*theory of interpretation*" (p. 21), which stresses the importance of the role of both the researcher and participant during the research process. Hermeneutic philosophy emphasises the significance of acquiring an understanding of the individuals' experiences and the subjective meanings given to interactions between the individuals and their environment (Todres & Holloway, 2010).

In contrast with Husserl, Heidegger emphasises that an element of personal commitment is always present; a factor which stems from simply living in the world (Smith, 2004). For this reason, the researcher needs to think reflexively and critically as to how preconceptions will affect the research process (Todres & Holloway, 2010). This 'double hermeneutics' – as this dual process is referred to – can be described as the "*the researcher is trying to make sense of the participants trying to make sense of their personal or social world*" (Smith, 2004, p.40). The researcher in the current study sought to make sense of the experiences of the nurses working in an inpatient palliative care setting who encounter patient death, while being mindful of the influence of his preconceived perceptions.

3.4.3 Idiography

Idiography is concerned with particular people in particular contexts. Samples in IPA are hence purposively chosen, and with a small number of participants (Smith et al.,

2012). The aim is not to produce great amounts of data, but to collect data which permits an in-depth analysis (Smith, 2004). The analysis in idiography starts with a thorough examination of every case, followed by a thoughtful analysis of differences and similarities among the participants (Chapman & Smith, 2002). This method enables the creation of detailed accounts of the reflections and meanings of every shared experience (Clarke, 2009). This approach helps to uncover emerging patterns within the cases, while uncovering the specific details of each particular case (Smith et al., 2012). These theoretical foundations that IPA draws upon, provided the framework for the current study, as explained in the following sections.

3.5 Method

This section describes each of the phases of the research process that were carried out in the present study and the rationale underlying the choices made.

3.5.1 Target Population

Participants in IPA are deemed as experts in the subject being researched (Reid et al., 2005) and as such, the participants should be chosen subject to the valuable and specific information needed on the phenomenon being studied, in order to gain a detailed description of this phenomenon (Walsh & Downe, 2006). Purposive sampling was therefore considered as the most suitable, since participants are chosen due to the specific characteristics that allow for a detailed study of the lived experience (Shinebourne, 2011). These characteristics are referred to as the eligibility criteria, which are discussed below.

Participants had to be nurses currently working in the palliative care at the local oncology centre, with more than six months' experience in an inpatient palliative

care setting. Registered nurses who during the time of the study were (i) working in the relieving pool at the local oncology centre and (ii) used to work in a palliative care setting in the past were both excluded since they could draw upon experiences of death in other units rather than their experiences within a palliative care unit. This would have possibly created an interpretative problem during the data analysis phase due to a variation in the lived experience (Smith et al., 2012).

At the time that the present study was conducted, the charge nurses did not have the same patient contact as staff nurses because of the nature of their roles and were therefore excluded due to the same reason as stated above.

3.5.2 Sampling and Recruitment Process

Sampling is used to study the characteristics of a population by studying a small selection from the same population (Corbin & Strauss, 2008). As previously mentioned, small sample sizes are recommended for IPA studies since the primary concern of IPA is the detailed analysis of each case (Smith et al, 2012). Smith et al. (2012) recommends a sample size between three and six participants, since this size is enough to produce an adequate amount of data, while still developing enough arguments related to the similarities and differences between the participants. In view of this and the decision to carry out repeat interviews, a sample of five participants was deemed adequate for the present study.

These five participants were recruited through an intermediary, according to the inclusion and exclusion criteria described above. The intermediary was one of the charge nurses of the palliative care unit at the local oncology centre at the time of the

study. Information on this study was provided to the intermediary (Appendix C), who then approached prospective participants and provided them with an information letter, containing details of the study and what their participation entailed (Appendix D). This method helped the participants to understand the purpose, risks, and benefits of the proposed research, and to decide on whether they will participate or not, without any coercion (Childress, 2017). Interested individuals were requested to give their contact details to the intermediary, with permission for these to be passed on to the researcher. The participants who chose to participate were contacted by phone by the researcher to set up a meeting to discuss the research study.

During this initial meeting, the research study was explained in detail by the researcher, and adequate time was allocated for any queries and to answer any questions that they had. If the individuals agreed to participate, a date for the interview was set up and a consent form was provided for them to review (Appendix E). Before the first interview, the researcher again provided a description of the study, and if the participant once again agreed to participate, the signed consent form was collected and the interview was started. For the second interview, the researcher contacted the consenting participants by phone to set up a date for the second interview. Prior to the commencement of the second interview, the researcher again sought verbal consent from the participants.

3.5.3 Methods of Data Collection

The method used for data collection is described in this section. For data collection, two, face-to-face semi-structured interviews were carried out. Semi-structured

interviews using an interview guide (Smith, 2004), were chosen since they allowed the researcher to gain an account of the participants' lived experiences (Smith, 2008) while providing flexibility and generating richer information (Smith, 2004). Semi-structured interviews were chosen over focus groups, since it is harder to retain confidentiality when carrying out a focus group (Leung & Savithiri, 2009). Semi-structured interviews were also chosen over structured interviews since, even though an interview schedule is used in semi-structured interviews, the researcher lets the participant, rather than the schedule, guide the interview (Smith, 2008). By guiding the conversation, the participants were at ease to talk about their experiences and reflections in a way that was comfortable to them (Smith, 2008). Face-to-face interviews were chosen, since it provided the opportunity for the researcher to note down in a notebook any non-verbal communication beyond the verbal interaction during the interview, in view that significant hidden meanings can be communicated in such a manner (Smith et al, 2012).

A month after the first interview, a second semi-structured interview was carried out as a follow-up. The rationale behind the second interview was to discuss certain points that were raised in the first interview that required further exploration (Flowers, 2008).

The interviews took place in a location and time selected by the participants. This provided the participants with ease of mind while recounting their experiences and additionally ensuring that the data was collected at a suitable place and time for them (Biggerstaff & Thompson, 2008). Following consent being obtained, audio-recording was used in each interview, to ensure that the participants' responses could

be recalled accurately. According to Smith (2008), there is a risk of losing some of the significant aspects of the lived experiences when attempting to write everything down. The durations of the first interviews were between forty-five minutes and seventy-five minutes, while the second interviews lasted between fifteen and thirty minutes.

3.6 Interview Schedule

The interview schedule is used to facilitate the conversation with the participants, which then leads to them giving an account of the experience being studied (Smith et al., 2012). The interview schedule was developed after doing a brief literature review, and discussions with experts in the field. The interview schedule (Appendix F) consisted of seven open ended questions that covered issues relating to the research question. The interview schedule was piloted, as will be explained further below. The first question asked the participants about their general experience working in a palliative care setting, with the aim of allowing the participants to start talking about their work and put the participants at ease, as suggested by Smith et al. (2012). The following questions covered the objectives of the research study, as outlined above, covering the (i) perceptions of patient death, (ii) coping strategies, and (iii) supportive strategies available to them. These questions were complemented with 'probes' such as "*Can you give me an example of a particular experience*", and 'prompts'. The probes were utilised to encourage the participants to expand further when recounting their lived experience (Leech, 2002). The prompts aided the flow of the interview, by adding certain important factors that needed to be tackled (Leech, 2002). For each of the second interviews, the researcher opted not to utilise an

interview guide, since data from the first interviews guided the discussion in the follow-up interviews.

While both Maltese and English are official languages in Malta, an interview guide was prepared in English, since English is a requirement to work as a professional nurse in Malta. Nevertheless, the participants were left to conduct the interview in the language of their choosing so that they would feel more comfortable expressing themselves (Gerrish & Lacey, 2010). All participants answered in Maltese, and the transcriptions of the audio recording were done verbatim in Maltese.

3.6.1 Pilot Interview

To assess the feasibility and suitability of the interview schedule, a pilot interview was done (Malmqvist et al., 2019). The nurse who participated in this pilot interview was selected according to the inclusion and exclusion criteria described above. Written consent was also obtained from this participant prior to participation. Being a novice researcher, this pilot interview allowed the researcher to establish the estimated time that the interview requires (Malmqvist et al., 2019).

The objective of this pilot interview was to refine the interview schedule. However, no changes to the schedule were deemed necessary and therefore, with the participant's consent, the data from the pilot interview was included in the analysis and findings.

3.7 Data Analysis

The following section describes how the data collected from the interviews was analysed. The data gathered from the semi-structured interviews was transcribed verbatim. Analysis was done in Maltese and the emergent themes and any excerpts were then translated and written in English by the researcher. The researcher listened to the audio recording several times to become more immersed and familiar with the data (Gerrish & Lacey, 2010). The data from the first and second interviews were collated and analysed collectively. For analysing the data collected, Smith et al. (2012) presents a six step systematic process that is based on thematic analysis. This process is conducted with an approach of willingness and openness towards the data collected, to unearth the meanings ascribed to the experience of the participants. A description of the six steps as applied in the present study follows below:

Step 1: Reading and Re-Reading

The audio recordings were listened to while reading the transcripts, to understand better the participants' stories. In the margins, emotions and any significant comments by the participants were noted, since these are crucial when it comes to interpreting the data (Smith et al., 2012).

Step 2: Initial Noting

Certain statements deemed as significant were highlighted, and exploratory comments were noted on the transcripts in Maltese (Smith et al., 2012). As suggested by Smith et al. (2012), these included (i) descriptive comments that described what the participant was saying, (ii) conceptual comments that included interrogative comments and described the conceptual meaning of the transcript, and

(iii) linguistic comments that showed how the participants used language, noting

repetitions, metaphors, and pauses. An example of each type of exploratory comment

from the transcript of this research study is presented in Table 3.1.

Table 3.10

Example of Exploratory Comments as Suggested by Smith et al. (2012)

Type of Comments	Example
Descriptive comments	*"I walk … go into nature, because there you only think about your basic needs, like drinking, eating, and not falling [while walking]." (Jasmine, I1, p. 6, lines 32-33)* - Walking is a coping strategy for her.
Conceptual comments	*"I walk … to go into nature, because there you only think about your basic needs, like drinking, eating, and not falling [while walking]." (Jasmine, I1, p. 6, lines 32-33)* - She goes for walks to forget and not think about what happened at work by only focusing on other things, such as not falling over while hiking.
Linguistic comments	*"the death of a human being is the same as the death of a tree – the tree ends there." (Jasmine, I1, p. 16, line 9-11)* - Jasmine uses a simile to liken the death of a human to a death of a tree to explain that for her death has no meaning and it is the end of a person.

Step 3: Developing Emergent Themes

These exploratory comments were then used to identify developing themes. This involved grouping similar data, to form sub-themes. Patterns between these sub-themes were grouped together to produce themes (Smith et al., 2012).

Step 4: Searching for Connections Across Emerging Themes

In this step, connections across the themes were identified to create super-ordinate themes. To identify between super-ordinate themes, differences and commonalities of the themes were explored. Some themes were removed, since they did not fit the evolving structure or lacked strong evidence (Smith et al., 2012).

Step 5: Moving to the Next Case

Since multiple cases were involved in this study, this step tackles the analysis of the next case and repeats steps one through four. During this step, the researcher tried to bracket any arising ideas from the previous transcript and for each subsequent case, as guided by the ideographic theory (Smith et al., 2012).

Step 6: Looking for Patterns Across Cases

Once analysis of all transcripts was done, all the themes and super-ordinate themes from all the cases were revised and a table of all the super-ordinate themes was created (Smith et al., 2012).

Whilst analysing the data, an inductive approach was taken to allow themes and patterns to arise from the data collected, and not from previous theories (Bendassolli, 2013). From these themes, a narrative account was created. This aided the researcher

to differentiate between themes and identify certain issues associated with each theme (Corbin & Strauss, 2008).

3.8 Ethical Considerations

The following section describes the ethical considerations of the present study. Ethical approval for this study was attained from the Faculty Research Ethics Committee (FREC) (Appendix G). In addition, permission was also obtained from the oncology hospital Clinical Chairperson, Chief Nursing Officer, Human Resources officer, Chief Executive Officer and from the hospital's Data Protection Office, and from the charge nurse of the palliative ward from where the nurses were recruited (Appendix H). Once such approvals were obtained, the process of data collection commenced.

3.8.1 Recruitment of Participants

Due to its nature, qualitative research requires the researcher to accept full responsibility to ensure that the participants' perceptions and subjective realities are safeguarded (Komesaroff et al., 2001). The researcher made sure that that the participants' autonomy, the confidentiality of their personal information, and the ethical principles of non-maleficence, informed consent and beneficence were protected (Kapp, 2006). In addition, the researcher was obliged to protect the participants' right to full disclosure, and to protect them from harm (Newington & Metcalfe, 2014). Participation in this study was voluntary. The participants were recruited from the palliative care ward at the local oncology hospital where the researcher had some work experience in, prior to the commencement of this study and therefore, to reduce the risk of coercion of prospective participants, an

intermediary was responsible for approaching potential participants and inviting them to participate. Moreover, no information about any nurses who declined to participate in the study was disclosed to the researcher.

3.8.2 Informed Consent

The researcher obtained consent from the eligible nurses by seeking both verbal and written confirmation (Appendix E). The researcher provided the participants with verbal and written relevant information, including the purpose and nature of the study, their expected duration of participation in the study, and a description of how the data would be collected. The participants were also informed of any possible discomforts or risks they could encounter during the study, as well as the steps taken to minimise or prevent such discomforts or risks. Moreover, further information was provided on how confidentiality will be maintained and who has access to the research data (refer to the participation information letter in Appendix D).

Additionally, the researcher provided the participants with his and the research supervisors contact details, in the event that any queries arose or further information was required. Furthermore, it was reiterated that participation was voluntary, and withdrawal was possible at any stage of the study without any repercussions (Parahoo, 2014). With these implemented strategies, the rights of full disclosure and self-determination were respected (Rebar & Macnee, 2010).

Informed consent is expected before the commencement of research involving humans (Musmade et al., 2013). The researcher allowed the participants sufficient

time prior to the signing of the consent form to ponder about their participation, and make sure that all their questions were answered (Musmade et al., 2013).

3.8.3 Minimisation of Harm

Due to the nature of the topic being discussed and the possible recounting of painful experiences, there was the possibility that the participants might experience emotional distress or discomfort (Braun & Clarke, 2006). To mitigate any harm, optional professional counselling was offered to the participants free of charge (Appendix I). Details were provided in this regard in both the information letter and consent form.

3.8.4 Confidentiality

Since the participants in this study were recruited from the only palliative care ward in Malta, descriptions given by the participants and any information given about their characteristics could have very easily made the nurses identifiable to other nurses working in the same unit and the same hospital. Strict measures were taken to protect the participants' identity, particularly by assigning codes to the transcripts to ensure confidentiality (Rebar & Macnee, 2010). The codes that link the data to the identity of the participant were stored securely and separately from the data, in an encrypted file, on the researcher's password protected computer. This data alongside all transcripts and audio recordings will be erased upon completion of this study, or at any prior stage if requested by a participant (Burns & Groove, 2009). The location where the interviews was carried out was chosen by the participants, so that they felt secure and comfortable, and free from disturbances. Finally, care was taken to ensure that no identifiable details were included in the completed dissertation.

3.8.5 Roles and Boundaries

Researchers have to distinguish between their role of researcher and their professional role when carrying out research (Grove et al., 2015). Since the researcher had worked with most of the participants, effort was made for the researcher to be viewed in the role of a researcher and not that of a colleague. This was done by the researcher by clearly stating his position as a researcher when first meeting with the prospective participants. As suggested by Smith et al. (2012), during the interview the researcher also took a neutral stance, and did not agree or disagree with the participants, even when the participants asked for the researcher's opinion, on topics that the researcher was familiar with, due to his past work experience in the same palliative ward.

Following data collection, data analysis was carried out. The following section describes how this was carried out.

3.9 Assessing Trustworthiness in IPA Designs

Smith et al. (2012) argue that qualitative research cannot be assessed with the same criteria as that of quantitative studies. Most guidelines for quantitative research are not effective in assessing qualitative research, and these can lead to skimming over the studies, and not really delving into and understanding the small details in the work (Smith et al., 2012). The guideline (Yardley, 2000) suggested by Smith et al. (2012), and the one referred to in this study, provides a broad assessment of the qualitative research, regardless of the theoretical underpinnings of the study (Smith et al., 2012).

3.9.1 Sensitivity to Context

Yardley (2000) states that the theory chosen and any findings from previous research using similar methodologies, should be made clear in the research study. This method established how findings from previous research differed and related. In the present study, this is illustrated in the discussion of the results in Chapter 5. The researcher showed 'sensitivity' towards the socio-cultural setting of the study, which refers to socio-economical, historical, and ideological influences on the beliefs of both the researcher and the participant. Sensitivity was also shown towards the theoretical aspects of the study, as described previously. These elements were exhibited throughout the study: the ideographic nature of the methodology; the recruitment of the participants; the interviews of the subjects; and the analysis where verbatim extracts were generated. Relative identities and common beliefs were actively raised by the researcher during the interview. Hence, sensitivity to dialogue context and linguistics were crucial for interpreting the meaning of the collected data (Yardley, 2000).

3.9.2 Commitment and Rigor

'Commitment' refers to the long term engagement with the topic (Yardley, 2000) and should be exhibited by the researcher in relation to the topic being researched, as well as commitment towards the ability in the research methodology and immersion in the data (Yardley, 2000). In the current study, commitment was exhibited by comprehensively describing and providing the rationale behind each decision taken throughout the research process. The comprehensiveness of data collection and analysis demonstrated 'rigour'. The researcher also conducted in-depth analysis of the data rather than just surface level analysis (Smith et al., 2012).

3.9.3 Transparency and Coherence

'Transparency' refers to the study's clear description of all steps of the research process (Yardley, 2000), and during the present study, this was done through detailed accounts of the participant selection, interview guide, and interviews, as well as during the process of data analysis. In the current study, the steps of the latter were recorded in tables illustrating the themes. During the analysis process, annotated transcripts were shown.

'Coherence' relates to the association of the research question, the philosophical perspectives, the data analysis, and the investigation (Yardley, 2000). As outlined in the above sections, the present study was guided by the philosophical principles of IPA, and coherence was accomplished accordingly.

3.9.4 Impact and Importance

According to Yardley (2000), regardless of its comprehensiveness, a study aims to add new important knowledge and thus have an 'impact'. 'Importance' refers to the extent that the method directs the research to make the said 'impact' (Yardley, 2000). The findings of this research study aim to address the present gaps in knowledge, as were mentioned in the previous chapters.

3.10 Reflexivity

According to Smith et al. (2012), it is difficult for a researcher to put aside their preconceptions and belief throughout the research process. For this reason, measures need to be taken to minimise the chance that the researcher's preconceptions and beliefs influence the research process and to highlight instances where this has

occurred. Such measures increase the trustworthiness of the analysis. To identity these perspectives and personal experiences, the researcher utilised reflexivity (Finlay, 2009). Lack of reflexivity in a study leads to the findings being motivated by the experiences and preconceptions of the researcher (Dowling, 2006).

Reflexivity does not eliminate bias, but rather helps the researcher to become aware of it and be mindful of their thoughts while interpreting the data (Finlay, 2009). Having previously worked as a reliever in the palliative care unit, I had assumptions on how nurses working in a palliative care setting react to death compared to other nurses working in other oncology wards and who may also experience patient death. In my opinion, nurses working in the palliative ward, did not seem to be affected by patient death, since I saw that they treated patient death just like any other part of their nursing care. Although I questioned the psychological effect that encountering patient death with such frequency had on these nurses, I never felt that the nurses in the palliative ward worried about this impact. From my perspective, the nurses at the palliative ward did not differ from the other nurses in other wards that I worked in, in the way they went on with their day and cared for patients, even though their work included encountering frequent patient death. As stated in the first chapter, although there appears to be a general assumption that palliative nurses are unaffected by the frequent encounters with death, I could not envisage how this was so, which is why I wanted to explore this phenomenom. Therefore, although I had some experience working with nurses in the palliative care unit prior to the commencement of this present study, I am aware that my perception of these nurses was that patient death had no effect on the nurses working in the palliative care ward.

Throughout the current study, I made use of a reflexive journal with the aim to identify my beliefs and presumptions. Reflexivity allowed the researcher to become aware of these issues mentioned, that might also have affected the interview and data analysis (Finlay, 2009). As noted down in my reflexive journal and as presented in the excerpt below, I felt anxious since I was worried that the participant might not talk during the interview. I was also concerned about my competence in carrying out the interview. Even though I researched on how to properly conduct an interview, this was still the first interview that I had ever conducted, and thus I could only guess on how it would pan out. At the same time I was excited, since the interview's success meant the start of data collection for this research study:

> *"It is the day of the first interview. I am excited, and anxious on how the interview will pan out. Will the participant talk? Will any useful information be collected? ... Am I able to conduct the interview? Will I be able to keep the participant talking? ... Even though I have read and researched on how to properly conduct this interview, I can never be prepared enough before experiencing the first one."*

After the first interview going better than expected, I gained confidence for the second one. Notwithstanding, there was still an element of concern that the first interview was an anomaly and the second interview would not be as successful:

> *"Feeling more confident before the second interview since the first interview went well, and much better than I expected. Still excited and anxious since it is still my second ever interview, and there is a fear that this second interview will not go as well as the first one."*

For the subsequent interviews, I was more prepared and felt more confident; I did my utmost to go into each interview clear-headed and aimed to bracket what was said in preceding interviews. However, I was surprised and frustrated when Erika started to answer some questions with statements such as *"I cannot think of anything"* (Erika, I1, p.4, line 24) or giving short answers, despite the probing, whereas other participants gave longer responses. On listening to the interview multiple times and analysing the transcript, I concluded that I might have been overconfident going into this interview, since the interviews before Erika's went better than I expected. I noticed that, for example, I did not provide Erika with enough time to think on how to answer, probably due to my frustration that the interview was not going well. The second interview with Erika provided me with an opportunity to approach the interview better and learn from the mistakes of the first interview. This was another advantage of carrying out the follow up interviews.

3.11 Conclusion

By letting the aim of this research study guide the choice of methodology, the most adequate methodology to answer the research question and reach the aims and objectives as set out in this chapter, was IPA. Accordingly, this chapter described the rationale behind the choice of methodology and the theoretical underpinnings of IPA. A description of the method of the research study was explained in detail. The ethical issues tackled, and actions taken so that the findings are trustworthy were also described. In the next chapter, the findings from the interview transcripts are presented.

Chapter 4: Results

4.1 Introduction

This chapter presents the findings which were derived from nurses working in a palliative care setting and related to their lived experiences encountering death. In this chapter there will be no reference to the extant literature, as recommended by Smith et al. (2012). Emergent themes were produced from the data analysis, and these will be presented within themes and super-ordinate themes, relevant to the research question of this study.

To illustrate how these themes were identified, excerpts from the interview transcripts are presented throughout the chapter, as suggested by Smith et al. (2012). These excerpts are enclosed within quotation marks and italicised. As described in Chapter 3, two interviews were held with each participant. For ease of reference, I1 refers to excerpts taken from the first interview, while I2 refers to excerpts taken from the second interview.

All interviews were carried out in the participants' native language, that is, Maltese. The original excerpts in Maltese are written down verbatim, then translated in English. Accordingly, the excerpts are presented in both Maltese and English. An ellipsis has been inserted in lieu of parts of the excerpts, specifically for editorial reasons. To enhance the coherence of certain excerpts, additional text which was not part of the original transcript was inserted, using square brackets.

The five participants were chosen from the oncology centre in Malta and, given the small number of nurses on the palliative care unit, no details will be provided on

their demography in order to safeguard confidentiality. Furthermore, each participant was allocated a pseudonym: Erika, Daniella, George, Jasmine, and Lukas.

During data analysis, narrations of the participants' experiences seemed to relate to their personal views of death and their responses to witnessing these deaths. This led to the development of two super-ordinate themes namely: '*Outlook on Death*' and '*Dealing with Patient Death*'.

Table 4.1 below shows theses super-ordinate themes, the themes, and the sub-themes, which emerged from the data analysis and which explain the lived experiences of nurses who encounter death in a palliative care setting. Thematic excerpts are also presented in the second column to better illustrate the superordinate themes.

Table 11

Super-Ordinate Themes and Themes that Emerged from Data Analysis of the Transcripts

Super-Ordinate Theme: <u>Outlook on Death</u>	
Themes and Sub-Themes	**Thematic Excerpts**
1. Defining death a) Death as part of the journey of life b) Death as a relief of suffering c) Views on own death	*"it is part of life. Whoever is born has to go. Whether you accept it or not, you still have to experience it".*

Themes and Sub-Themes	Thematic Excerpts
2. Contrasting patient deaths a) Aiming for a 'good' death b) Defining a 'bad' death	*"That's our aim, to give them a peaceful death as much as possible, because truth be said, no death is nice, but there is a big difference between someone who dies in delirium and restlessness … and someone who dies with a certain calmness".*
3. Death leaves a mark a) Nurse patient relationship b) Change of perspective	*"[Death] changes your perspective on life."*

Super-Ordinate Theme: <u>**Dealing with Patient Death**</u>	
Themes and Sub-Themes	**Thematic Excerpts**
1. Coping with patient death a) Coping strategies b) Support from colleagues	*"you always have to keep that barrier, if not, you won't survive"* *"we support each other"*
2. The need for support a) Services available b) Group activities	*"For example, I feel the need for group sessions with a psychologist."*

The following sections further describe the two super-ordinate themes and their

respective themes, starting with the super-ordinate theme *'Outlook on Death'*.

4.2 Outlook on Death

The super-ordinate theme 'outlook on death' describes how the participants define death, and how they perceive patient death as well as their own death. They explain how working in a palliative care setting has shaped their understanding and meaning of death. This super-ordinate theme also describes the diverse circumstances that impact the participants response to death, and how these experiences of patient deaths have shaped their perception of death.

4.2.1 Defining Death

This theme is represented by the sub-themes 'death as part of the journey of life', 'death as relief of suffering', and 'views on own death'. It presents how participants described death and their feelings towards patient death and their own death. The nurses' definition of death and their own death has been shaped by their experiences of patient death, which will be referred to in the theme 'Death leaves a mark'.

Death as Part of the Journey of Life

The sub-theme 'death as part of the journey of life' presents how the participants described death. Most of the participants view life as a journey and as such, it has a beginning and an end, and for them, death marks the end of this journey, making it an integrated part of the experience of life:

"Jiena nemmen li dak li jibda jrid jispiċċa. Jien narah ħajjitna passaġġ, it starts and it ends, u l-mewt hija parti mill-ħajja. Ma jistax ikollok mewt jekk ma jkollokx ħajja."
(Jasmine, I1, p.12, line 14-16)

"I believe that whatever begins has to end. I see our lives as a path, it starts and it ends, and death is a part of life. You cannot have death without life."

"Għandek il-vjaġġ tiegħek [tal-ħajja] għalhekk tagħmel li tista' f'ħajtek"
(George, I1, p. 11, line 3)

"You have your journey [of life] and hence you try to make the most out of it"

One of the participants additionally stated that regardless of whether one comes to term with his or her death, there is no escaping death, since it is an inevitable part of life, and everyone will experience it:

"hija parti mill-ħajja. Kull min twieled irid imur. Taccetahiex jew le, in a way xorta ħa tgħaddi minnha"
(Lukas, I1, p. 5, lines 10-11)

"it is part of life. Whoever is born has to die. Whether you accept it or not, you still have to pass through it"

Some participants also stated that for them, death had no particular meaning. George described how for him death is *"[il-mewt] the end. Spiċċajt."* (George, I1, p. 11, line 3) *"[death] is the end. You're no more"*. Jasmine said that human death is no different from any other death in nature, describing how once someone dies, it is the end for them:

"Jiena nemmen li aħna parti min-natura, … mewt il-bniedem bħal qisu meta mietet siġra – is-siġra … tieqaf hemm" (Jasmine, I1, p. 16, line 9-11)	*"I believe that we are a part of nature, … the death of a human being is the same as the death of a tree – the tree … ends there."*

This sub-theme presented how participants described death, as signalling the end-of-life, and as something that is inevitable, and that for some it had no particular meaning.

Death as a Relief of Suffering

The sub-theme 'death as a relief of suffering' presents how, when discussing patient death, most of the participants stated that they viewed patient death as an end to suffering. Nearly all of the participants said that in some situations, death was the only way that the patient could escape from the suffering, especially in cases where everything would have already been done to help the patient feel comfortable. Erika also states that in her ward, death is seen as a relief since the nurses working there witness a lot of suffering at the end-of-life:

"Aħna għalina l-mewt hija xi ħaġa li teħles, li ma tkomplix tbati … Għax naraw ħafna suffering hawnhekk." (Erika, I1, p. 3, lines 8-9)	*"For us, death is something that relieves, you don't suffer anymore … Because we see a lot of suffering here."*

"aħjar hekk għax straħ ... Pazjent qed ibati ... hemm limitu ta' kemm tissetiljah" (George, I1, p. 11, lines 5-7)	*"it's better like this because he is relieved ... a patient who is suffering ... there is a limit to the extent to which you can make him comfortable."*

For George, this relief demonstrates a somewhat positive aspect of death, since death would be the only means to end suffering:

"x'ħin taraha li l-pazjenta ħallietna, taraha straħet, tibda tara l-pożittiv, in inverted commas, fil-mewt." (George, I1, p. 11, lines 25-27)	*"when you see that the patient has passed away, you see that she has been relieved, you see the positives in inverted commas, in death."*

According to Daniella, death also brings relief to the formal and informal carers, and relatives of the patient, since all of them feel helpless when the patient is suffering, particulary when all means to get the patient comfortable have been exhausted:

"in-nies miġburin madwaru … jibdew   *"people are gathered around him …*

iħossuhom helpless, … jibdew jgħidu   *they start feeling helpless … they start*

lilna [biex intaffulu l-uġigħ], … imma   *to ask us [to relieve his pain]… but*

ma tistax tagħmel il-mirakli. [Meta   *you cannot perform miracles … [when*

jmut l-pazjent] jistrieħu huma [il-   *the patient dies] the patient is*

pazjent] u jistrieħu r-relatives u   *relieved, the relatives are relieved,*

jistrieħ kulhadd." (Daniella, I1, p. 4,   *and everyone is relieved."*

lines 36-43)

This sub-theme described how the participants sometimes view death as the only means of relief from pain and suffering. They also said that this relief of suffering can bring out a positive aspect of death, and also provides relief for relatives and the healthcare professionals caring for the patient.

Views on Own Death

The sub-theme 'views on own death' describes how all participants said that they viewed their own death. As mentioned before, these perceptions have been influenced by witnessing their patients' deaths. This effect will be discussed in the theme 'death leaves a mark'. When talking about their own death, most participants expressed that they do not fear it. Lukas further stated that he can joke about his death, since he accepts that it is inevitable:

"Tiegħi personali onestament ma naħsibx li jbeżżagħni" (Daniella, I1, p. 3, lines 41-42).

"Honestly, I don't think that my own death scares me".

"Jiena personalment niċċajta fuqha [il-mewta tiegħi]. Mhix ħaġa sabiħa, imma għalija nnifsi, x'ħin jgħaddi l-ħin, jgħajjatli u mmur. Hija xi ħaġa li nsemmiha u mhix xi ħaġa li ħa tbeżżagħni daqshekk." (Lukas, I1, p. 5, lines 8-10)

"Personally, I joke about it [my death]. It's not a nice thing, but for me personally, when it's time, He calls me and I leave. It's something that I talk about and it's not something that scares me that much."

While not fearing his own death, given the fact that he accepted its inevitability, George added that he still does not look forward to it:

"mhux ħa ngħidlek I'm looking forward għaliha [l-mewta tiegħi] għax inkun qed nigdeb. Fuqi personali ma tbeżżagħnix għax nemmen li xorta rridu mmutu" (George, I1, p. 10, lines 25-27)

"I won't say that I'm looking forward to it [my own death], because I would be lying. My own death doesn't scare me because I believe that we have to die anyway."

He further explains how this outlook is due to the fact that he does not want to leave his wife alone when he dies. This sentiment is shared by other participants, who expressed that although they do not fear their own death, they are worried about the people they would leave behind:

"ma nixtieqx nimmaġina l-mara tiegħi waħedha, għax naf x'jiġri kieku – allaħares issemmilha dan is-suġġett għax tiġġennen." (George, I1, p. 10, lines 32-33)

"I don't want to imagine my wife alone, because I know what would happen in that case – God forbid I mention this subject because she would lose her mind."

Jasmine also states that, although she witnesses patients who are her age, or even younger, dying, she still views her death as being some time away:

"Tipo għalija s'issa għadha lura [l-mewta tiegħi] – hekk naraha jien … allavolja hawnhekk naraw ħafna nies żgħar imutu, xorta qisek tħossha li dik mhux se tiġri lilek, ħa tiġri lil ħaddieħor" (Jasmine, I1, p. 15-16, lines 30-2)

"It's like, for me, it's still a long way off [my death] – that's how I see it … although we do see a lot of young people dying here, I still feel like it will not happen to me, it will happen to someone else."

In this sub-theme, participants described how that although they do not look forward to their own death, they do not fear it, and is seen as something still some time away. They also expressed how they worry about the people that they would leave behind when they die.

In summary, all of the participants have a similar outlook on death: it marks the end of the journey which is life, and for some patients that they care for, can be the only means for relief of suffering. Looking towards their own death, participants viewed death as inescapable, and while it is something that they do not look forward to, they attest that it is not something that they are scared of.

4.2.2 Contrasting Patient Deaths

This theme is represented by the sub-themes 'aiming for a good death' and 'defining a bad death' and describes how participants distinguished some patient deaths witnessed in their work in the palliative care setting and divided them into two distinct types, namely a 'good' death and a 'bad' death. They further elaborated on how each type of death affects them.

Aiming for a 'Good' Death

This sub-theme presents how participants described some patient deaths as 'good' deaths, and how these affect them. Participants expressed that in their encounters with dying patients, they aim for what they describe as a 'good death'. Although a lot of the participants admit that death is never a good experience, they described why a death can be called 'good'. Erika defines this by comparing two different deaths, where one can be seen as a 'good' death, which she aims to achieve for her

patients and the other as a 'bad' death, which will be discussed further in the sub-theme 'defining a bad death':

"Aħna dik l-aim tagħna, li kemm jista'   *"That's our aim, to give them a*

jkun ikollhom mewta peaceful, għax   *peaceful death as much as possible,*

fil-verita' l-ebda mewta m'hi sabiħa,   *because truth be said, no death is nice,*

pero hemm qabża kbira bejn xi ħadd li   *but there is a big difference between*

jmut f'delirju u restlessness … u xi   *someone who dies in delirium and*

ħadd li jmut b'ċertu kalma, ssetiljat"   *restlessness … and someone who dies*

(Erika, I2, p. 2, lines 4-7)   *with a certain calmness".*

"mhux ħa ngħid li l-mewt tajjeb ta' –   *"I won't say that death is good – but*

imma jista' jkun mewt fil-paċi"   *there can be a peaceful death".*

(Daniella, I1, p. 4, lines 9-11)

When explaining what constitutes a 'good' death, almost all participants mentioned situations in which the patient is pain and symptom-free and is surrounded by relatives:

"importanti li dak li jkun ma jkunx   *"it's important that the patient is not*

muġugħ u jkun komdu, u jekk jista'   *in pain and is comfortable, and if*

jkun fl-aħħar żminijiet ta' ħajtu jkun   *possible, in the last moments of his*

imdawwar b'niesu biex iħossu komdu   *life, he's surrounded by his relatives*

wkoll" (Lukas, I1, p. 2, lines 27-29)   *so that he feels comfortable as well".*

"good death hija meta tara l-patient imdawwar bil-familjari tiegħu, ikun pain free u mingħajr sintomi, u kalm u trankwill." (Jasmine, I2, p. 4, lines 21-24)

"a good death is when you see the patient surrounded by his relatives, he's pain free and without symptoms, and calm, and tranquil."

For Jasmine, a 'good' death, which she always tries to achieve, also means having all of the patient's relationships closed off positevly, as well as resolving any conflicts or problems in life prior to death:

"dejjem jien nipprova nimmira għal good death [għal pazjent], jiġifieri għalija good death [għal pazjent] ... qiegħed trankwill f'ħajtek, qisek għalaqt l-istejjer b'mod tajjeb mal-persuni li tħobb, pruvajt tirranġa fejn kellek it-taħwid." (Jasmine, I1, p.13, lines 5-8)

"I always try to aim for a good death [for the patient], so for me a good death [for the patient] ... there is tranquillity in your life, one has achieved a sense of closure with their loved ones, and tried to fix any troubles that one might had."

A number of the participants further expanded upon the importance of the patient's mental well-being in order for them to have a 'good' death. This includes having their wishes and dreams fulfilled prior to their death, whenever possible, such as attending a wedding, as illustrated in the following excerpts:

"Taf li ħa jmut, imma tinduna li dan at least miet kuntent. Ija, at least ix-xewqa li kellu jagħmel qatagħha u jkun aktar rrassenja ruhu. Jgħid ok ha mmut, imma li xtaqt nagħmel għamiltu" (Lukas, I1, p. 7, lines 13-16)

"You know that he's going to die, but you appreciate that at least he died happy. At least his wish would be fulfilled and he is better prepared. He accepts that he is going to die, and whatever his wishes were, they were fulfilled."

"Ġieli jkun xi tieġ – jgħidlek ġej it-tieġ f'Mejju tat-tifel u jixtieq li jkun preżenti" (Jasmine, I2, p. 2, lines 29-32)

"Sometimes it's a wedding – he tells you that his son's wedding is in May and he hopes to attend."

Additionally, Lukas asserted that taking care of the patient's mental aspect also involves helping the patient accept that they still can have some quality of life, despite the poor prognosis:

"Lilu ukoll serraħtlu moħħu u beda jaċċetta l-fatt li għandu li għandu imma ma spiċċatx id-dinja" (Lukas, I1, p. 7, lines 1-2)

"Once you reassure and comfort him, and he starts accepting his situation, he accepts that it is not the end of the world for him"

When describing a 'good' death, Erika described a feeling of calmness during such a death. Since the patient is calm, it is easier for the relatives to accept the patient's prognosis. However, in a situation where the patient is restless, as will be described in the following sub-theme "Defining a bad death", the relatives become stressed and find it harder to accept that the patient will die in such a manner:

"Meta tkun [mewta tajba] ... anke aħna nħossuna aħjar, għax il-proċess ikun iktar kalm ... anke [l-qraba] jaċċettawha aħjar meta huma jaraw il-pazjent li jkun kalm. ... xi ħadd qisu qed jissielet ... hemmhekk mod ieħor – huma [il-qraba] ha jkunu stressjati u ma jaċċettawhiex daqshekk malajr."
(Erika, I2, p. 2, lines 15-18)

"When it's [a good death] ... even we feel better, because the process is calmer ... even [the relatives] accept it easier when they see that the patient is calm. ... someone who is still fighting ... that's different – they're [the relatives] stressed and they don't accept death that easily."

This may be a reason why the participants always aim for a 'good death', since they would want to avoid such situations for themselves, for the patients, as well as for their relatives. When talking about a 'good' death, Daniella explained how this feeling of calmness, can also bring positive aspects from death, such as bringing family members closer together through a negative event.

"ikun hemm għaqda ġieli bejn il-
familja. Fil-verita' apparti li [l-mewt]
hu xi ħaġa ħażina, fl-istess ħin ġieli
tara n-nies magħqudin flimkien"
(Daniella, I1, p. 4, lines 14-15)

"sometimes there is a sense of
togetherness between families. In
reality, although death is not a good
thing, at the same time, it brings
people together".

In contrast to feeling blamed, and feeling helpless during a 'bad' death, as will be mentioned in the sub-theme 'defining a bad death', Daniella also described how this closeness of the relatives in a 'good' death sadness her. She states how she feels pity for the mourning relatives surrounding the dead patient:

"taffetwak ... għax tgħid kemm huma
miġburin, magħqudin. U kważi kważi
... jaqbdek dieqa ... għax tibda tgħid,
titħassarhom." (Daniella, I1, p. 5,
lines 6-8)

"it affects you ... because you realise
how close they are. And even ... you
feel sadness ... because you pity
them."

This sub-theme described how participants described a 'good' death as being pain and symptom free, calm, and having relatives surrounding the patient. They described how a 'good' death brings families closer, and a participant described how she feels pity for the family. They described how a 'good' death also involves that the psychological aspect of a patient is also taken care of. Most participants described the importance of a 'good' death for them because it reduces their own feelings of helplessness, despite the pity that one feels for the family's impending loss.

Defining a 'Bad' Death

This sub-theme presents how, in contrast to a 'good' death, participants described how what they perceived as a 'bad' death resulted in feelings of uneasiness and stress. Such deaths included patients that had relationship conflicts or other issues in their lives, which they were unable to resolve prior to their death. This, in turn, could lead to a patient dying alone without the company of any relatives. A few participants felt strongly about such instances; they admitted that they would not be able to leave a pet dying alone, let alone a human being, and thus, it affects them negatively when witnessing the death of a patient who is alone:

"il-Maltin nħobbu ngħidu anqas kelb ma trid tara hekk, u veru. Għax illum jekk ikollok annimal tidħol miegħu, żżommu, aħseb u ara bniedem." (George, I1, p. 14, lines 9-11)

"Us Maltese, we have a saying, that you wouldn't even want to see a dog like that, and it's true. Because today, if you have an animal you go in with him to hold him, let alone a person."

" għax jien għidt jekk ikun qed imutli l-kelb anqas inħallih waħdu – aħseb u ara din, umana" (Jasmine, I1, p. 14, lines 17-19)

"Because I said that even if my dog was dying, I wouldn't leave him alone – let alone a human being".

George and Jasmine both experienced, and were affected negatively by such deaths, since they felt pity for them. They described how they felt the need to keep the patient company until their death, as dying alone is contrary to their idea of a 'good' death, which, as previously mentioned, they claimed to always aim to achieve.

"ġieli ... ikollna pazjenti li r-relatives sfortunatament ma kinux close mal-pazjent. Kerha ux. Xi ħaġa kerha. Fil-fatt ġieli kellna pazjenti li kellna noqgħodu aħna ħdejhom ... titħassarhom" (George, I1, p. 14, lines 4-7)

"sometimes ... we have patients whose relatives unfortunately were not close to the patient. It's not nice. In fact, we had patients where we had to stay next to them ... you pity them".

"niftakar ddeċidejna neħduha in turns biex din ma toqgħodx waħedha. Ikollha lil xi ħadd magħha. U dik ħassejtha eh ... Dik kont ħadtha ħażin niftakar." (Jasmine, I1, p.14, lines 16-22)

"I remember that we decided to take it in turns to stay with her so she's not alone. So she could have someone next to her. And I felt that ... I remember that it had affected me badly."

Most participants described patients who do not achieve a 'good' death as being "*not settled*" and "*restless*" when dying. As some participants explained, this is what they describe as terminal restlessness:

"il-patient ikun restless, dik li ngħidulha terminal restlessness" (Jasmine I2, p. 4, lines 17-18)

"The patient would be restless, what we refer to it as terminal restlessness"

Daniella explained how the environment around such a patient death is. She described how these situations can lead to the patient's relatives surrounding the

patient to feel helpless. This helplessness turns into anger which is projected on the nurses by blaming the nurses for the condition the patient is in. Though as Daniella describes, the nurses feel just as helpless in such a situation, since there would not be much they could do. Evidently, as stated by Daniella, it is less than an ideal situation to witness or be involved in:

"ikollok il-pazjent ma jkunx settled … n-nies li jkunu ħdejh … tant ikun hemm hassle li anke ġieli neħlu aħna [mar-relatives]. U l-anger kollha li jkollhom jiżvugaw magħna. … in-nies miġburin madwaru … jibdew iħossuhom helpless, … aħna min-naħa l-oħra tipprova kemm tista' imma ma tistax tagħmel il-mirakli. Li kważi kważi tibda tħossok helpless inti wkoll. Għalina bħala xogħol, hija stressful għalina ukoll. … Mhix xi ħaġa sabiħa li tara." (Daniella, I1, p. 4, lines 21-44)

"you have a patient who is not settled … the relatives surrounding him … there's so much hassle that sometimes we get the blame [from the relatives]. And they let out all of their anger on us … the people around him … start feeling helpless, … and we, on the other hand, do our utmost but we can't do miracles. You start feeling helpless as well. It's stressful for us as well … it's not a nice thing to see."

As Jasmine explains, no amount of medicine can help these patients, since their pain might not be physical but emotional:

"Meta jkun emotional pain tista' tagħti miljun morfina, imma it won't work. Il-patient ħa jibqagħlek restless." (Jasmine, I2, p. 5, lines 5-7)	*"When there is emotional pain, you can give a million morphines, but they won't work. The patient will remain restless."*

Jasmine further explained that this emotional pain can be a reason to why a patient does not die a 'good death' and dies restless. According to Jasmine, this emotional pain can stem from personal issues or conflicts that were left unsolved by the patients, and hence they can never find peace with themselves prior to their death. Jasmine also states that she is affected by such patients since she pities them:

"Tant ikollhom griefex u inkwiet, li tgħid dan mhux se jmut sew ... dan titħassru, għax mhux se jagħlaqha sew l-istorja. Ħa jitlaq imħawwad, u hekk ikun." (Jasmine, I1, p.13, lines 11-14)	*"They have so much hassle and trouble, that you recognise that he won't die a good death ... you pity him, because he won't achieve closure. He will pass away troubled, and that's what ends up happening".*

This sub-theme presented how the participants described a 'bad' death, which was described as patients dying alone, without relatives next to them, and when patients die while being restless, which according to some participants, can be caused by

emotional pain. Participants also described how the environment surrounding such deaths is not ideal to witness or be involved in.

To summarise, participants described what a 'good' death means for them and how this is something that they always aim to achieve. A 'good' death involves the patient being symptom-free, surrounded by relatives, and having any personal issues/wishes settled. On the other hand, participants described the negative effects of a less-than-ideal death, where the patients are restless or alone.

4.2.3 Death Leaves a Mark

This theme presents how the participants described what factors made some patient deaths affect them negatively, and how witnessing patient deaths while working in the palliative care setting has changed the participants' perspective both on life and death. These will be presented through two sub-themes namely 'nurse patient relationship' and 'change of perspective'.

Nurse-Patient Relationship

This sub-theme describes how most participants stated that their relationship with the patient was a determining factor on how they reacted to a patient's death. The other factors will be discussed in the other sub-themes of this theme. Having the patient stay as inpatient in the ward for months was one way that the participants built a relationship with the patient. George further explained why he builds this relationship with such patients, stating that he starts to feel more at ease around such patients, and hence feels more comfortable talking to them:

"mal-pazjenti li jdumu tibni relazzjoni" (Lukas, I1, p. 4, lines 10-11).	*"you build a relationship, with the patients that spend a long time in the ward"*
"Ikollna pazjenti li sfortunatament idumu xhur hawnhekk ... tidrah pazjent, anke kif titkellem miegħu tkun iktar komdu" (George, I1, p. 4, lines 32-34)	*"we have patients that unfortunately spend months here ... you get used to the patient, you feel more at ease talking to him"*

For some participants, the deaths of these long-term patients affected them negatively, even though as Erika mentioned she tries to keep boundaries. These boundaries will be referred to in the theme 'coping with patient death', where most participants described forming a 'shell' to protect them from the emotional burden of witnessing patient death, which is not always successful such as in situations as described below:

"Inti kemm jista' jkun iżżomm boundaries, pero ċertu pazjenti, speċjalment dawk li jkunu damu aktar, qisek tħossha naqra, mhux se ngħidlek ma tħossiex." (Erika, I1, p. 1, lines 23-24)	*"You try as much as possible to keep boundaries, but certain patients, especially those who spend a longer time here, you feel more emotional, I have to admit."*

George even described how when such long-term patients die, all the staff in the ward is affected by their death, stating that *"is-sitwazzjoni fis-sala tkun naqra down, kulħadd" (George, I1, p. 4, lines 29-30) "the atmosphere and everyone in the ward is down"*.

Jasmine also expressed this sense of lack of closure when long-term patients die, specifically when she is off duty, since she feels that she would not have had the opportunity to say her goodbyes to the patient. Lukas stated that these types of long-term patient deaths can affect him negatively, since he feels that there is a lack of closure when the patient dies:

"pazjenti li jdumu ... Once li jmutu ... ir-relazzjoni spiċċajtha – mingħajr closure" (Lukas, I1, p. 4, lines 10-12)

"long-term patients ... When they die ... the relationship ends – without closure".

"Ġieli tkun ilek pereżempju ħames xhur tieħu ħsieb patient, imbagħad tmutlek fl-off jew fir-rest u l-off. Qisek lilek ma ttikx cans tgħidilha goodbye ... ma tkunx għalaqtha l-istorja" (Jasmine, I1, p. 6, lines 14-15)

"Sometimes you spend, for example, five months taking care of a patient, and he dies during your off day, or your rest day. This way, you don't have time to say goodbye ... you don't close off that story."

Participants described that another way they built relationships with patients was by building more rapport with particular patients than others. Jasmine explained that

some patients have certain traits in their character, that she cannot put a finger on, that results in a bond being formed with these particular patients, to the extent that she cries when these patients die. For George, the fact that some patients have a greater impact on him, is a part of being a nurse:

"Issa bħala patient ġieli jkun hemm dak il-patient li jolqtok. Ġieli jkun hemm xi ħaġa fihom il-patients li qisek tmisslek qalbek – ġieli bkejt meta miet xi patient qed tifhem. Ikollhom dik ix-xi ħaġa li lilek qisek jagħmluk close magħhom" (Jasmine, I1, p. 3, lines 12-15)	*"There is sometimes a patient that sticks with you. Sometimes there is something about the patients – I sometimes cry when a patient dies. They have that something that makes you feel close with them".*
"hi l-esperjenza tan-nurse imbagħad. Li ċertu pazjenti jolqtuk iktar minn oħrajn." (George, I1, p. 9, lines 5-6)	*"it's part of being a nurse. You feel attached to certain patients more than others."*

Daniella explained that patients with whom she had a good relationship with, even to the extent of forming a bond with said patient, she described their death as difficult for her. As Jasmine said, these deaths are so difficult that she ended up crying when such patients died, regardless of whether it was a 'good' or 'bad death:

"Lili personali taffetwani skond anke l-bond in a way li tkun qisek bnejt bejn il-patient u r-relatives. Irrelevanti kif tkun il-mewta tagħhom. ... imma meta tkun ħadt grazzja magħhom, in a way hemm ġieli tkun iebsa." (Daniella, I1, p. 5, lines 14-20)

"For me personally, it affects me, depending on the bond which you have built with the patient and the relatives, regardless of the manner in which they die. ... but when you're closer with the patients, sometimes their death is difficult."

A characteristic that drew participants closer to a patient was the patient being of a young age, being similar or younger than that of the participants. As expressed by the participants, the deaths of these young patients affected them negatively because they could relate better to these patients, and it was easier for the participants to see themselves in the patient's situation and empathise with them:

"ġieli jkun hemm każijiet [li taffetwani], speċjalment meta jkunu għadhom żgħar – żgħar as in tamparna ... jista jkun li forsi ... qisni nirrelata magħhom." (Daniella, I1, p. 1, lines 38-42)

"sometimes there are cases [which affect me], especially when they're still young – young as in our age ... maybe ... I might relate to them."

"Naħseb li ta' xi ħadd żgħir iktar inħossha għax qisek tissimilarizza magħhom. Tipo tara lilek innifsek fihom speċi ta" (Erika, I1, p. 2, lines 1-2)

"I think that the death of a young person affects me more because you empathise with them. It's like you see yourself in them".

In contrast, there are certain patient characteristics that, instead of drawing the nurse closer to the patient, the patient distances themselves from the nurse, resulting in a lack of relationship between the nurse and the patient. Jasmine described a patient that never responded to Jasmine's or other nurses' attempts at conversing with her, nor ever opening up to the nurses about her feelings. Such a patient was an 'unknown' person for Jasmine when she died, and Jasmine stated that her death did not affect her negatively:

"[pazjenta magħluqa] qisek once li titlaq, qisek tibda tgħid bilkemm nafha lil dil-patient … ma tantx tkiddek daqshekk il-mewt tagħhom."
(Jasmine, I1, p. 6, lines 5-8)

"[a closed off patient] once she's gone, you realise that you don't even know her … their death doesn't affect you that much."

The participants said that when there was no relationship between them and the patient, the patient's death did not affect them as this was seen as part of their daily work. This happened when the nurse did not have enough time to build any rapport with the patient, so no relationship was built. This results when the patient's death

occurs on the first day during which the nurse has been taking care of the patient, or when the nurse had not taken care of the patient.

"Meta ġieli tidħol għan-night u [l-pazjent] jkun daħal filgħodu, u jmutlek bil-lejl il-patient, dak qisek aqas tħoss xejn inti, għax anqas tkun ilħaqt bnejt relazzjoni magħhom" (Jasmine, I1, p. 3, lines 28-29)

"Sometimes when you come in for your night shift and the patient was admitted in the morning, and the patient dies during the night, you are not affected that much, because you don't have enough time to build a relationship with them".

"pazjent li bilkemm ġieli kien ikun tiegħek, jew anqas naf kif ikun wiċċu, bil-Malti tkun just another one."
(Daniella, I1, p. 5, lines 27-28)

"a patient that is seldom your patient, or you don't even know his face, it will just be another death."

The sub-theme 'nurse-patient relationship' presented what participants said about their relationships with their patients, and how their death affected them. Most participants formed relationships with patients that (i) stayed in their ward for months, (ii) had certain characteristics, and (iii) were of younger age. As stated by the participants, the deaths of the patients with whom they had formed relationships, had affected them negatively.

Change of Perspective

The sub-theme 'change of perspective' describes the ways in which the participants' outlook on life and their definition of death as mentioned previously in the sub-theme 'views on own death', were influenced by witnessing patient death. Witnessing death also affected the participants in their personal lives, as it changed their general outlook on both life and death. Participants expressed that they now appreciate their life and their families more, especially parents who are older in age:

"tapprezza iktar il-ħajja, tapprezza aktar il-ġenituri tiegħek" (George, I1, p. 12, lines 3-4)

"you appreciate life more, you appreciate your parents more".

Jasmine explained how witnessing patient death made her appreciate how precious time is. For this reason, she visits her parents more than her siblings do, given that she is more aware of their death due to witnessing it during her work:

"tibda tagħti priorita' lill-familja ... il-ġenituri tiegħi anzjani, la naf li ħa jmutu, tipo kull off immur għandhom. Ninnota minn ħuti, jersqu f'xi okkażjoni, f'xi birthday jew Father's Day. Qishom m'għandhomx dak l-insight kif għandi jien fuq il-mewt." (Jasmine, I1, p. 15, lines 9-13)

"you start prioritising your family ... my parents are elderly, since I know that they will eventually die, I visit them during every off day. I notice that my siblings only visit them during some occasions, birthdays or father's day. It's like they don't have that insight that I have on death."

Most of the participants stated that witnessing death changed their outlook on life and how they approach it. Patient deaths seemed to have changed the participants orientation to the present rather than the future. When talking about how their perspective on life changed, the participants stated that they started to appreciate life more, to enjoy the moment, and not to worry as much about the future, since death can happen to anyone at any time.

"ma tafx x'jista jiġrilek fil-ħajja. Allura tipprova you live in the now kemm jista' jkun u ma tantx tara lejn il-futur … għax ma tafx x'se jiġri 'l quddiem." (Erika, I1, p. 3, lines 22-24)	*"you don't know what can happen in your life. So you try to live in the now as much as possible, and don't look too much to the future … because you don't know what's going to happen."*
"Ma tista' tieħu xejn for granted. F'sekonda jista' jinbidel kollox. M'hawn xejn garantit, jiena nista' ġejt hawn, u ma nerġax nidhol lura d-dar. Qabel tkun happy go lucky, qatt ma tirrejalizza" (Jasmine, I2, p. 8, lines 17-22)	*"You can't take anything for granted. Everything can change within a second. There is nothing guaranteed, I came here today, and something can happen and I won't go home again. Before, you're happy go lucky, you don't realise such things."*

"li tarah ta' spiss [il-mewt]… iktar iġibek qisu taf kif kemm aħna m'aħna xejn, kemm aħna bħal ħaddiehor" (Daniella, I1, p. 3, lines 35-37)

"you see it [death] frequently… you become more aware that we're nothing, we're the same as everyone else."

Witnessing death also had a negative effect on the participants' outlook on life. Lukas described that life is unfair, since it can be taken away at any time, and any sacrifices made for the future would have been in vain:

"Jiena kemm-il darba għidtha kemm hi tan-nejk il-ħajja … xi ħadd li għadu kemm beda l-pensjoni, tgħid … għamilt ħajtek taħdem, wasalt biex tgawdi l-ħajja, qabdek li qabdek u bqajt sejjer … Mela wasalt biex nirtira, qtajt id-dejn kollu li għandi, għidt ħa ngawdi naqra l-ħajja u nispiċċa." (Lukas, I1, p. 2, lines 13-17)

"I frequently like to say that life is a joke … someone who has just retired … you say to yourself, you spent your life working, and reached the point where you can enjoy life, you get diagnosed and you're gone just like that … So you retire, paid off all your debts, so you can enjoy life, and then you're gone."

Some participants described how witnessing patient death regularly forces them to think more about death than before they worked within the palliative care setting, whereby there would be no reason to think about death, since they did not face it:

"Mhux ħa ngħidlek li ma kontx naħseb fuqu [il-mewt]. Ma jkollokx għalfejn toqgħod taħseb fuqu taf kif."	*"I won't say that I didn't think about it [death]. You didn't have to think about it, you know."*
(Daniella, I1, p. 4, lines 6-8)	

As described by Lukas, witnessing death can also lead to changing the perspective on death, in a way that death is not perceived as something huge and scary anymore; it becomes part of his work routine, as significant as other nursing care practices. This will be described further in the sub-theme 'coping strategies' where participants describe how they get used to witnessing death:

"Il-fatt li tara, f'ġimgħa, on average, jmutu ħamsa min-nies, ma tistax tibqa' tara l-mewt bħala xi ħaġa kbira u tal-biża. Għar-raġuni li tmiss magħha kuljum." (Lukas, I1, p. 5, lines 16-18)	*"the fact that in a week, on average, five people die, you can't keep viewing death as something big and scary, for the reason that you come in contact with it everyday"*

A few of the participants also described how witnessing death has affected the way they talk about death. Daniella explained how a person from the general population would be shocked about how the nurses talk about death between themselves. Jasmine adds that the nurses and staff at the palliative care unit develop a kind of black humour, which only makes sense between themselves and not for the general population. This is also a way for them to cope with patient death as will be discussed in the sub-theme 'coping strategies':

"jiena nara kif nitkellmu aħna bejnietna hawnhekk. Li kieku xi ħadd minn barra ikollu jismagħna nitkellmu, jgħidu; dawn bis-serjeta'?" (Daniella, I1, p. 5, lines 33-35)

"I sometimes look at how we speak between ourselves. If an outsider listened to our conversations, they would not believe what they're hearing."

"you develop ukoll a different sense of humour – black humour – li nies ta' barra minn hawn mhux se jifhmuh, imma aħna li naħdmu hawn jagħmel ħafna sens" (Jasmine, I2, p. 7, lines 11-15)

"you develop also a sense of humour – black humour – that people who do not work here would not understand, but for us, who work here, it makes a lot of sense."

Jasmine also described how witnessing death has influenced her day-to-day conversations, in a way that she does not notice. It seems that she is not aware that she talks about death more regularly than what is considered normal, since her children remark that their mum always talks about death. This may be due to the fact that death has become more normal to her than to others who do not witness it with such regularity:

"Jgħidu għax il-mummy dejjem fuq il-mewt titkellem. Jiena anqas inkun konxja, imma t-tfal jgħadduh dak il-kumment jiġifieri bilfors li veru" (Jasmine, I2, p. 7, lines 7-11)

"They say that I always speak about death. I am not as conscious about it, but my children notice it, so it must be true."

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In this sub-theme, participants described how witnessing death has allowed them to focus on the present, to appreciate their life and family more, and how such experiences have affected them in the way they think and talk about death.

The above findings show how witnessing a patients' death leaves a mark on the participants, both at the moment of death and later in their personal lives. They talked about how their relationship with the patient and the patient's characteristics affect the extent to which they are emotionally impacted by the death, and how witnessing these deaths has changed their outlook on both life and death. The participants also notice that this is different from people who do not work in the palliative care unit.

In summary, the super-ordinate theme 'outlook on death' describes the perspective of nurses working in a palliative care setting on death and personal death, as well as how these nurses describe patient death, and the effects that such deaths have on them. Death leaves an impact on nurses working in a palliative care setting, and the next super-ordinate theme describes how the nurses manage to cope.

4.3 Dealing with Patient Death

As described in the previous sections, working in the palliative care setting forced the participants to witness death regularly, and some of these deaths affected them negatively. As some participants stated, in order to continue working in the same ward, they developed several coping strategies, described in this super-ordinate theme.

4.3.1 Coping with Patient Death

This theme describes the ways in which the participants cope, and the support they find to cope with witnessing patient death. These will be presented in two sub-themes named: 'coping strategies' and 'finding support'.

Coping Strategies

This subtheme describes the coping strategies that are common to all participants, as well as coping strategies specific to the participants individually. The first part of this sub-theme discusses how most participants, each in their own way, mentioned that they got used to witnessing death. This suggests that death has become familiar to most participants and does not affect them but it is important to note certain contradictions as whilst most participants stated that they got used to death, they still mentioned multiple strategies that they use to minimise the emotional burden that arises from being witness to the frequent deaths. This suggests that they may not have truly gotten used to death given their need of strategies to combat their inability to stop thinking about their patient's death, both during their workday, and once they have left the workplace.

Most participants explained how, over the years working in the palliative care setting, they got used to death given its regularity. As stated by Lukas before in the sub-theme 'change of perspective', death is not seen as something big and scary anymore. Participants stated that death started to be viewed as part of the nurse's day, and as important as any part of their work routine. Lukas compares his job as a nurse to any other job, meaning that things forming part of any job routine become

the usual. In the participants' case is death which becomes their normality, as George refers to death:

"Inkun qed nigdeb jekk ngħidlek li ma drajtx. Fis-sens, ta' spiss tkun li jmutilna patient." (Daniella, I1, p. 1, lines 37-38)	*"I would be lying if I told you I haven't gotten used to it. In the sense that, patients regularly die in the ward."*
"Mhux qed ngħidlek tiġi qisu xejn m'hu xejn, imma … tiġi n-norma" (George, I1, p. 16, lines 33-34)	*"I'm not saying it's like nothing happens, but … it becomes the norm"*
"U anke bħala l-mewt per se, jekk tkun ilek fiha, naħseb f'kull xogħol, xi ħaġa li tara regolari għalkemm ħażina, tibqa' qisha tgħaddi. Ma tantx hi xi ħaġa sabiħa li l-fatt miet pazjent u ma jkun xejn." (Lukas, I1, p. 6, lines 7-11)	*"Even death, if you've been witnessing it for a long time, like every other job, something that you see so regularly, although it is something bad, it starts being something that happens. It's not something nice that a patient dies and it's as if nothing happened."*

Daniella also gave an explanation to why it is important to get used to death, since she explains how if a nurse is affected negatively by a patient death, it can affect her whole day. As she explained, this leads to a nurse that cannot continue to provide the

best nursing care to other patients, and this can mentally tire her down throughout the rest of the workday:

"inti trid ddaħħalha f'rasek li one – [il-mewt] huwa parti mix-xogħol, u two - ġieli tiġri ta' spiss … ma tistax … imut pazjent, tibqa' taffetwak il-burdata fil-ġurnata kollha. L-ewwelnett hemm pazjenti oħra. It-tieni nett tispiċċa titkisser ix-xogħol ukoll" (Daniella, I2, p. 1, lines 13-18)

"you have to understand that, one [death] is part of your work, and two – happens often – you cannot … a patient dies and affects your mood for the whole day. Firstly, there are other patients. Secondly, you get exhausted at work too."

Despite these assertions, most of the participants describe forming a 'shell' or 'boundary' to distance themselves from the deaths they witness, in order to protect themselves and not be affected negatively by patient death:

"Ħafna drabi trabbi qoxra, ma tistax tħoss għal kull min ikun." (Lukas, I1, p. 2, lines 37-38)

"Most of the time you form a shell, you cannot feel for everyone"

"nibni ċertu boundaries jien bla naf, qisek you detach yourself minn ċertu affarijiet." (Erika, I2, p. 2, lines 40-42)

"I build some boundaries without realising myself, kind of, you detach yourself from certain things."

These boundaries are not always successful as described in the sub-theme 'nurse-patient relationship' since the participants described how they were affected negatively by some patient deaths. In addition, the forming of such a 'shell' and boundaries is in contrary to what was described previously, since most participants felt that they got used to death, and some even referred to death as part of their normal working routine. This may not be exactly the case, as shown by the forming of boundaries, and other coping strategies that will be also mentioned.

Another means of coping with patient death and getting used to death is related to the years of experience working in the ward. George explains how, when he looks back, he notices a difference in how much he has learnt in how to deal and cope with tough situations at work:

"Tgħinek [l-esperjenza], tiskanta taraha d-differenza ... f'kemm inti kapaċi nikkowpja f'dawn is-sitwazzjonijiet [diffiċli]. Tgħinek ħafna" (George, I1, p. 8, lines 19-26)

"[Experience] helps, you see the difference ... in how capable you are at coping in such [difficult] situations. It helps you a lot."

Daniella also described how, when she started working in the palliative care setting, patient death would affect her negatively for a whole day. With time, she managed to not let patient death affect her that way and started to accept death as something that is part of her work. This shows that with time and experience, she has learnt how to better cope with experiencing patient death:

"Fil-bidu kienet tkun iktar diffiċli għax qisek taffetwak il-ġurnata kollha u anke l-burdata taffetwalek."

(Daniella, I2, p. 1, lines 7-9)

"In the beginning, it was much harder because it affected my whole day, and even affected my mood."

Some participants mentioned that one way of coping with patient death was that when a patient passes away, they remember how they managed to improve the patient's quality of life during their days prior to their death and focus on the job satisfaction that comes from that:

"jiena dik li nagħmel [meta jmut pazjent] ... just nkun kuntent li rnexxieli lill-pazjent nagħmlu komdu u happy" (George, I1, p. 12, lines 11-12)

"that's what I do [when a patient dies] ... I'm just happy that I managed to make the patient comfortable and happy".

"[meta jmut pazjent] Tgħid issa kont hawn jien, ħadt is-sodisfazzjon li għintu" (Lukas, I1, p. 5, lines 38-39)

"[when a patient dies] I tell myself that I was here and got the satisfaction that I helped him".

George describes this way of thinking as something that affects him quite positively, rather than negatively, since it reminds him of the job satisfaction in making the patient more comfortable prior to their death:

"Imma ma naħsibx li taffettwani ħażin [mewta ta' pazjent], pjuttost taffetwani tajjeb ... grazzi għas-sodisfazzjoni li rnexxielek tagħmilha [ttejjeb l-kwalita' tal-ħajja tal-pazjent]." (George, I1, p. 9, lines 7-9)

"But I don't think it affects me badly [a patient's death], but rather affects me positively ... due to the satisfaction that I get from managing to do it [better the patient's quality of life]."

In situations where the participants were affected by patient death, the most common coping strategy was to take a break. In particular, some participants mentioned the need to take a break in order to let out their emotions and regain their composure, to be able to continue their working day:

"Ġeneralment insib x'imkien kwiet – jew il-linen store jew xi toilet – nibki bikja ta' żewg minuti pereżempju imbagħad niġi composed u jkun ħareġ. Inħoss dak ir-relief. Imbagħad it would be enough" (Jasmine, I2, p. 11, lines 23-26)

"Generally I find a quiet place – the linen store or a toilet – and I cry for two minutes, for example, I regain composure and I let it out. I feel relieved. Then that would be enough."

"Kelli nidħol fl-istaff room, noqgħod naqra kwieta u imbagħad nerġa' noħroġ" (Daniella, I1, p. 2, lines 6-7)

"I had to go into the staff room, stay quiet for a while, and then come back out".

Another reason for the need to take a break from work was due to burnout caused by witnessing multiple deaths, as mentioned by George. He explained how sometimes there are periods where there are multiple patient deaths during a particular shift, leading to burnout. In his opinion some time off of work would be useful if one notices that he is suffering from burnout:

"jekk tara li you're burned out, li għajjejt, ġieli tinzerta' żmien fejn tinzerta' ħafna mwiet fix-shift tiegħek. Ovjament jekk tara li inti burned out, tieħu break. Jekk hemm bżonn tieħu leave" (George, I1, p. 5, lines 14-17)

"If you see that you're burned out, that you're tired, there is sometimes a period in which you encounter a lot of deaths in your shifts. If you see you're burned out, you take a break. If need be, you take some time off work."

Taking a break from work seems to help the participants 'heal' from the emotional burden caused by witnessing patient deaths. In fact, Lukas compared such emotional burden with a wound that needs treatment to heal:

"tieħu ġurnata leave u ma tersaqx 'l hawn, għax jekk ħa tibqa' tara l-istess affarijiet, ovjament (pause) il-feriti mhux ħa jagħlqu." (Lukas, I1, p. 3, lines2-4)

"you take a day off work, and you don't come in to work, because if you witness the same thing, obviously (pause) the wound will not heal."

Every participant described a coping strategy that they individually use when they are affected negatively by a patient death. Most participants' coping strategies involve means to turn their focus on something else other than work and hence, forget about the experiences that affected them negatively at work. When mentioning these strategies, participants indicated that patient deaths impact them even after they leave work. Participants described that driving, walking, and relaxing by watching television series, were a means to clear their mind from what happened at work and focus on other things:

"naqbad it-triq u mmur triq – insuq fit-triq. B'xi mod moħħok tiklirjah." (Lukas, I1, p. 3, lines 6-7)	*"I get on the road – for a drive. You have to clear your mind somehow."*
"Niftaħ flixkun inbid … nara series … nara xi ħaġa li tkun vera ħafifa biex qisek ma toqgħodx taħseb" (Daniella, I1, p. 2, lines 31-33)	*"I open a bottle of wine … watch a series … I watch something that is light so that I don't have to think."*
"nimxi … nintefa' ġon-natura, għax hemmhekk taħseb fuq il-basic needs bħal speċi, biex tixrob, tiekol, l-importanti li ma taqax [waqt li qiegħda timxi]" (Jasmine, I1, p. 6, lines 32-33)	*"I walk … to go into nature, because there you only think about your basic needs, like drinking, eating, and not falling [while walking]."*

George, on the other hand, focuses on the fact that death is inevitable, as mentioned in the sub-theme 'death as part of the journey of life', and that he cannot control the patient's destiny. This thinking leads George to shift his focus on how he managed to improve the patient's quality of life during their stay at the ward, and on the satisfaction he gets from it, as was mentioned previously:

"il-pazjent il-condition tiegħu hi x'inhi. Trid tirraġunaha u tkun rejalistiku." (George, I1, p. 8, lines 5-7)

"the patient's condition is what it is. You have to reason it out and be realistic."

As mentioned in the sub-theme 'change of perspective', the type of humour and the different way that they talk about death, are both coping strategies that the participants use.

This sub-theme presented how nurses working in the palliative care setting cope with witnessing patient death. All participants described that the main way to cope with patient death is to get used to witnessing death. Notwithstanding this, the participants were still affected negatively by witnessing patient death, given that they mentioned several coping strategies that they used to cope with such deaths. Every participant has personal coping strategies that they utilise when a death affects them negatively, however most participants claimed that taking a break from work is a coping strategy. The next sub-theme addresses another way how participants cope with patient death, which is by finding support from colleagues.

Support from Colleagues

This sub-theme describes how support from their colleagues was the most mentioned way in which all participants cope with patient death. Support from 'the team', as participants described their colleagues, was the only support which the participants utilised. Other support available that the participants mentioned will be discussed in the sub-theme 'services available'. All participants mentioned their colleagues as the reason why they can all manage to continue working in the palliative care setting. They expressed how they always found colleagues who would be ready to listen to them if they had any issues, even personal ones. When the participants were describing how they find support from the team, they also indicated the importance of teamwork:

"staff tajjeb li jekk ikollok problema tkellimtha magħhom, kemm jekk problema ma' pazjent jew problema miegħek nnifsek, sibt ma' min titkellimha u sibt min jgħinek" (Lukas, I1, p. 1-2, lines41-2)

"Good staff, who you can discuss your problems with, both problems about a patient or problems concerning yourself, you can find someone who you can to talk to and help you."

"Għandna team tajjeb ħafna u naħdmu tajjeb flimkien. We support each other" (George, I1, p. 5, lines 19-20)

"We have a very good team and we work well together. We support each other."

Most participants described that having someone who listens to them and allows them to speak their minds, was important for them to cope with certain patient deaths that would have affected the whole ward. They mentioned that they were most comfortable talking with colleagues, since they would be the ones that best understood them, having gone through the same experience and feelings:

"Anke sentenza – kemm ħassejtni ħażin li miet it-tali. L-ewwel ħaġa l-fatt li dak li jkun semgħak ġa' biżżejjed. Li fehmek, tgħinek iktar." (Lukas, I1, p. 3, lines 28-30)

"Even a sentence – I felt bad that that patient died. The fact that someone has listened to you is enough. The fact that he understood you, it helps even more".

"anke nitkellmu aħna bejnietna, nibqgħu nsemmu l-każ – qisna hekk aħna niddealjaw magħha," (Daniella, I2, p. 1, lines 40-42)

"Even when we speak between ourselves, we keep on bringing up a case – that's how we deal with it."

Lukas mentioned that talking to colleagues who understand him helps him realise that he is not going through the negative emotions alone:

"jekk ħa titkellem ma' dak li jkun, mhux dejjem ħa jtik soluzzjoni. Pero' l-fatt li tkellimtha, li dak li jkun jgħidlek l-istess ħassejtha jien, b'xi mod issib lil xi ħadd jifhmek, li m'intix waħdek għaddej minn dil-biċċa tax-xogħol." (Lukas, I1, p. 3, lines 3-5)

"if you talk to somebody, they won't always give you an answer. But the fact that you talked about it, the fact that that person tells you that he felt the same, you find someone who understands you, that you're not going through this alone."

For Erika, support from colleagues that could understand her, is all the support she needs:

"Jien għalija li titkellem biżżejjed ... li tkun kapaċi titkellem ma' dak li jkun u jifhmek, għalija bizzejjed" (Erika, I1, p. 2, lines 36-38)

"For me, it's enough to speak about it ... that you can talk about it with that person and they understand you, it's enough for me."

To summarise, this sub-theme presented the support that nurses find from their colleagues when dealing with patient death. Participants find this support to be very useful.

This theme presented how nurses working in the palliative care setting cope with witnessing patient death. Although most participants believe that they got used to witnessing death, they still are affected negatively by such encounters, since they mentioned several coping strategies that they use to cope with patient death. All

participants also mentioned that the best way that they cope with patient death was by finding support from their colleagues.

The participants are aware of other support services available to them and voiced their opinions on what more could be offered. This is discussed in the next theme.

4.3.2 The Need for Support

This theme presents the support services mentioned by the participants upon which they could draw on from the hospital, particularly when facing deaths that affect them, and explains why the participants are reluctant to utilise any professional support provided to them. This theme also presents the services and help which, in the participants' view, would help them deal with patient death.

Services Available

This sub-theme presents the support services mentioned by the participants which are available for them to help them cope with witnessing patient deaths, and further, the reason as to why they do not make use of them. Although they said that support from their team was enough, most participants were aware of support services offered to them at their place of work. Participants only mentioned that these services simply include a psychologist and was usually offered to them by the charge nurse of the ward:

"[ič-Charge Nurse] kienet qaltilna ...	*"[the Charge Nurse] had told us ... if*
jekk intom tridu tkellmu lil	*you want you can talk to [the*
[psychologist] fuqha din" (Jasmine,	*psychologist] about this."*
I1, p. 12, lines 6-7)	

In Lukas' opinion, the services offered are the *"bare minimum"* (Lukas, I1, p. 3, line 41) of what could be offered, since in his opinion there are other services that could be offered, as will be mentioned in the sub-theme 'group activities'. Some participants were not sure if any services were offered to them or did not know how to access them:

"Nahseb li joffru psychological	*"I think they offer psychological*
[services] jekk tkun trid. Naħseb, ma	*[services] if you want. I think, I'm not*
nafx. Nimmaġina li joffru." (Erika, I1,	*sure. I assume that they offer them."*
p. 2, lines 29-30)	

"Imma mingħalija darba qalulna li	*"But I believe that they had told us*
jekk ikollna bżonn sapport għalina.	*there was support available to us. I*
Fejn u min ma nafx." (Daniella, I1, p.	*don't know where and who though."*
3, lines 5-7)	

None of the participants had ever used the services of the psychologist during their time working in the palliative care setting. When these services were offered, some participants explained how nobody would accept this support and utilise it:

"Imma fil-verita', sa fejn naf jien,   *"But in reality, as far as I know,*

ħadd ma kien mar." (Daniella, I1, p.   *nobody had gone."*

2-3, lines 43-1)

Most participants explained why they never used this service. Some felt, as

mentioned above, that talking to their colleagues was better than talking to the

psychologist. This was due to the fact that colleagues could understand them as they

went through similar experiences:

"jien personali aktar nħossni komda   *"personally, I feel more comfortable*

nitkellem ma' kollega tiegħi li tkun   *talking with my colleague, who has*

għaddiet minnha u konna fiha ... milli   *gone through it with me ... rather than*

... mmur nitkellem ma' xi ħadd li qisek   *... speak with someone I kind of don't*

ma' tafux biex joqgħod jismagħni."   *know, to have them listen to me."*

(Daniella, I1, p. 3, lines 1-5)

"[il-kollegi] iktar jifhmuk, għax ikunu   *"[the colleagues] understand you*

għaddejjin minnha ukoll ... li   *more, because they are going through*

nitkellem magħhom nħossha biżżejjed"   *it ... the fact that I talk to them is*

(Erika, I2, p. 1, lines 6-8)   *enough."*

As Daniella suggested in the previous excerpt, she feels more comfortable speaking

to someone with whom she has built a rapport. This feeling was also shared by

Lukas given that, when talking about why he does not speak to a psychologist, he

described the psychologist as someone *"barrani"* (Lukas, I1, p. 38, line 38), *"an*

outsider" and hence, he does not feel comfortable opening up to them. This implies that he views the psychologist as someone that he has not built a rapport with, and thus, may feel vulnerable talking about his feelings to them. Lukas mentions how gender may be an issue when it comes to seeking help. He states that for him and for most men, they feel uncomfortable to open up about their feelings. However, he also said that he would open up if a professional approached him and inquired about how he was feeling:

"Pero jien, u speċjalment aħna l-irġiel, m'aħniex imdorrijin mmorru nikxfu għajnna ma' xi ħadd. Jekk jiġi xi ħadd isaqsik kif mort, kif għaddejt, iktar hemm ċans li titkellem milli tmur int, speċjalment għand wieħed barrani ma tafux, u tgħidlu l-problemi tiegħek. Jien personalment, ma nsibnix komdu nagħmilha." (Lukas, I1, p. 3, lines 35-40)

"Although myself, and especially us men, we are not used to revealing our emotions to somebody. If someone comes and asks you how did you get on, there is a higher probability that I will talk, rather than if I go myself, especially to an outsider who I don't know, and tell him about your problems. Me personally, I do not find it comfortable to do it."

Some participants also felt that, until now, they were never affected by a negative experience at work to the extent that they would need to seek professional support. Erika also stated that what she witnesses at work does not affect her daily life since she is not aware of any negative effects to this effect:

"ma nħossnix għandi għalfejn nitkellem ma' xi ħadd professjonali, fis-sens ma narahiex li fil-fehma tiegħi taffetwani daqshekk in my daily living bħal speċi" (Erika, I2, p. 1, lines 7-9)

"I don't feel the need to speak to a professional, in the sense that I don't think it affects me to that extent in my daily life."

"ma naħsibx li taffetwani daqshekk gravi li għandi mmur ... nitkellem ma' xi ħadd professjonali." (Daniella, I2, p. 2, lines 1-3)

"I don't think it affects me that badly that I have to speak ... to a professional."

Jasmine explained how recounting an experience in detail brings back the negative emotions and feelings related to the particular negative experience. For this reason, she would not want to go talk with a psychologist, as she would have to go through the same emotional ordeal again:

"Il-fatt li mmur għand psychologist u noqgħod nispjegalha x'ġara ... Tiġi kedda doppja – inkun ħadt kedda dak il-mument li ġrat, imbagħad se nerġa' mmur xi sagħtejn wara u nerġa' nqanqal dawk l-emozzjonijiet kollha" (Jasmine, I2, p. 11, lines 28-34)

"The fact that I go to a psychologist and explain what happened ... I would go through the ordeal two times ... suffering during the moment it happened, and then again when I go two hours later and revive all of those emotions again"

The findings presented in this sub-theme described that the only support service provided to the participants is a psychologist. All participants explained why they do not feel the need to utilise such service, and why they are not comfortable talking to a psychologist.

Group Activities

This sub-theme builds on the previous one, as it presents the participants' suggestions for further support to cope with patient death, which they believe is lacking, even though they expressed that speaking to colleagues was 'enough' support for them.

All participants mentioned how more activities for the staff could be organised as a group. One type of activity is group sessions with a psychologist, where everyone could talk about their thoughts and feelings, and together with the psychologist, support each other. This is contrary to what the participants stated, as presented in the sub-theme 'services available', particulary in instances where the participants said that talking with their colleagues was enough support from them, and they did not feel the need or the comfort in talking to a psychologist. That said, when talking about such group activities, some participants suggested that there still would be some nurses who may still find it difficult to speak to a psychologist in these group sessions.

"Pereżempju, jiena nħoss il-bżonn ta' sessions ma' psychologist as a group. Tagħmilha on a voluntary basis, … imma naħseb ġid joħroġ. … niltaqgħu mas-psychologist u għidnielha bid-diffikultajiet tagħna" (Jasmine, I1, p. 10, lines 3-7)

"For example, I feel the need for group sessions with a psychologist. On a voluntary basis … but I believe that it would be beneficial. … to meet with a psychologist and we talk about our difficulties."

"li jkun hemm xi ħadd li kull tant żmien jiġi, … xi tip ta' session mas-sala kollha jew ma' żewġ xiftijiet li titkellem kif mort" (Lukas, I1, p. 4, lines 1-3)

"that there's someone that comes periodically … a sort of session with the ward, or two shifts at a time, and you talk about how you are faring at work."

Jasmine also described the organising of team building sessions as another type of group sessions. The aim of these sessions would be to discuss various topics, for example the staff's mental health, and what can be changed or improved to address any issues. She did not clarify if these sessions would be only between the staff of the ward or with a psychologist or other mental health professional:

"pereżempju team building ... tgħid ... ħa niffukaw fuq il-mental health tal-istaff. X'inhuma d-diffikultajiet? X'nistgħu nirranġaw? X'qed nagħmlu tajjeb ħalli nkomplu ninfurzawh? ... Nistgħu nirranġaw, nbiddlu l-affarijiet?" (Jasmine, I1, p. 20, lines 25-31)

"for example, team building ... let's say ... we will focus on the mental health of the staff. What are the difficulties? What can we improve? What are we doing well so we keep doing it? ... Can we improve or change things?"

Some participants also suggested group activities where they do something unrelated to work, for example an activity where the ward's staff meet up, away from work, having the time and space where they can talk with each other, also about matters not related to work. Some participants also expressed how this can also offer an opportunity to talk and support each other in a less time-restrictive environment, away from work:

"Toħroġ l-istaff bħala xi ħaġa li m'għandiex x'taqsam max-xogħol. Biex taqta' mix-xogħol u bejnietna ... ma tibqax taħseb fuq x-xogħol, u fl-affarijiet li jiġru fuq ix-xogħol. Bħala relief taf kif" (Daniella, I1, p. 3, lines 21-25)

"You have an informal outing with the staff and do something that is not work-related. To forget about work, ... and you don't think about work, and the things that happen at work. As a sort of relief."

"Anke dak li jkun qata' naqra, xorta għandu ċ-ċans jitkellem ma' xi ħadd jifhmu … [fuq x-xogħol] tkun fil-ħin limitat tal-isptar, u fis-setting limitat tal-isptar." (Lukas, I1, p. 4, lines 28-31)

"One can get away from work, but still has the opportunity to talk with someone that understands them … [at work] you are time limited and limited within the setting of the hospital"

In addition to these types of group activities, most participants also mentioned the need for more training on how to deal with patients and their relatives at the end-of-life. This is in view that the participants have faced tough situations when dealing with patients and their relatives, especially when being asked difficult questions about the patient's condition, and not being able to answer or comfort the relatives. Most participants mentioned that they learnt how to handle these situations through experience and by learning from other staff. As from what Daniella stated about training, this would also help the nurses in situations where they feel helpless as described in the sub-theme 'bad death':

"l-mod li niddiljaw mal-pazjent u mar-relative ... aħna ġibnihom mill-esperjenza tagħħna. Ħadd ma tana training jew xi tip ta' kors jew xi ħaġa." (Lukas, I1, p.4, lines 20-23)

"the way we talk to patients and handle situations with relatives ... we learnt from experience. Nobody gave us any training or some kind of course or anything."

"kif inti tista' tiddilja mar-relatives, naħseb tgħin ukoll lilna bħala staff għax kultant qisek tħossok helpless ukoll." (Daniella, I2, p.2, lines 19-22)

"how you can deal with relatives, I think it will help us, the staff, because sometimes you feel helpless as well."

Jasmine also stated how the nurses have never been offered training on how to properly cope with their emotions after witnessing patient deaths, and accordingly, she feels that they lack the knowledge on how to manage having to witness such experiences, and how she could take better care of her mental health. Jasmine also suggests that she is not able to assess whether her work is affecting her badly or not, because she wants to learn to identify any signs or symptoms if she was being affected negatively. This is interesting, since she does not utilise the psychologist service available, but the psychologist could address these questions that she wants answers to:

"Fejn qatt għamilna kors kif tieħu ħsieb tiegħek innifsek? Qed tiddilja ma' dan kollu l-ħin kollu on a daily basis m'għandekx inti jgħallmuk kif tiddilja, kif tieħu ħsieb tiegħek innifsek ... x'inhuma s-sintomi li inti m'intix coping sew?" (Jasmine, I1, p. 20, lines 14-17)

"When have we ever had a course about how you take care of yourself? You're dealing with all this on a daily basis, don't you deserve to learn on how to deal, how to take care of yourself ... or what the symptoms that you're not coping well?"

Lukas also explained how a bereavement service, or training about bereavement would be beneficial for the nurses. As mentioned in the sub-theme 'nurse-patient relationship', a good relationship is built between the nurses and patients who spend a long time in the palliative care unit before dying. Such bereavement training would benefit the staff, as when these patients die, Lukas feels that these relationships are stopped suddenly, and there is no closure for the nurse with the patient.

"xi tip ta' seminar fuq bereavement ... Dawn mal-pazjenti li jdumu tibni relazzjoni. Once li jmutu, effettivament li jiġri hawn, ir-relazzjoni spiċċajtha – mingħajr closure, jew titkellem ma' dak li jkun." (Lukas, I1, p. 4, lines 9-13)

"a kind of seminar on bereavement ... You build relationships with patients who spend a long time here. Once they die, what happens is that the relationship ends – without closure, or without speaking with that person."

The findings in this sub-theme showed what the participants said was needed as support, where they described group activities as sessions with a psychologist, and team-building exercises where the ward staff are allowed time and space away from work. The participants also mentioned how training can also teach them how to cope and deal with situations at work.

This theme presented the services offered to the participants in their own views, and the reasons why they do not utilise them. One of said reasons is the belief that the support from their colleagues is enough; however, they were still not satisfied with the services available to them. All participants suggested the organisation of group

sessions and activities, as well as training as other support services which could be offered.

This super-ordinate theme described how nurses in a palliative care unit cope with patient death. All participants found their own combination of coping strategies to deal with patient death and finding support from their colleagues. Most participants however, felt that they could be better supported at work to better deal with patient death, citing training and group activities as methods on how they could be better supported.

4.4 Conclusion

This chapter presented the two super-ordinate themes that emerged from the analysis of the data collected from the participating nurses. The first super-ordinate theme 'outlook on death' described the perspective that the participants had on death and the effects of witnessing patient death. The second super-ordinate theme 'dealing with patient death' then described how the participants coped with having to witness patient death. In this regard, this chapter presented the experience of the participants when encountering patient death, while working in the palliative care setting.

Chapter 5: Discussion

5.1 Introduction

Chapter 5 presents a discussion of the findings of the present study which focuses on the experiences of palliative care nurses in their encounters with death. A brief description of the transactional theory of stress and coping by Lazarus (1966) is presented. Subsequently, the findings of the present study will be discussed alongside this theory, as well as the extant literature. The discussion will provide the researcher's interpretations of the findings in conformity with IPA methodology (Smith, 2004) and according to the two super-ordinate themes, namely 'outlook on death' and 'dealing with patient death'. This chapter also explores the strengths and limitations of this present study.

The following section is a description of the theory that enables an understanding of the findings that represent nurses' experiences of their encounters with death in the palliative setting.

5.2 Role of Transactional Theory of Stress and Coping

In research, theory is important to build knowledge in order to understand and explain the phenomenon being studied and to explain the reasons for its occurrence (Eccles et al., 2005). The transaction theory of Lazarus (1966) was deemed as the most appropriate theory, as it suggests that the individual and the environment act upon each other. This relationship between them is considered as dynamic, since it is constantly changing. Stress arises when a situation is appraised as being harmful or threatening to the individual. The behavioural and/or cognitive action to reduce this stress is described as coping (Folkman, 1984).

The transactional theory of stress and coping proposes that stress is a result of the appraisal of a situation experienced by an individual. The theory suggests that an individual goes through two stages of appraisal – primary appraisal and secondary appraisal – before experiencing stress and responding to it.

The primary appraisal is the evaluation of the situation to determine if it is threatening or positive (Lazarus & Folkman, 1984). If it is neither, the situation is deemed as not significant and irrelevant. If it is deemed as threatening, the individual goes through secondary appraisal to evaluate if they have the resources to cope with the situation. Negative stress arises if the demands of the situation outweigh the resources to cope. These resources include: internal options, such as will power and inner strength; and external options, such as professional help and peers. To deal with stress, the individual engages in coping strategies (Folkman & Lazarus, 1987).

The transactional theory of stress and coping describes coping as having either a problem-focused or emotion-focused style (Folkman & Lazarus, 1987). Problem-based coping describes situations where the individual feels that they have control on the situation and can cope by changing the situation to reduce stress (Lazarus, 1993). In contrast, where the individual feels that they have little or no control on the situation, the individual changes their relationship with the situation to reduce stress, using emotion-based coping. This can involve avoidance, denial, or distancing from the situation, and it does not change the situation, but rather the effect that the event has on the individual (Lazarus, 1993). The transactional theory of stress and coping classifies these coping strategies as adaptive, that is, when the coping strategies

manage stress in the long term, or maladaptive, that is, when the coping strategies

only reduce stress in the short term (Lazarus, 1993).

This system of appraisal and coping mechanisms is transactional. As individuals try

to cope with a situation, they are making continuous re-appraisals of the situations,

and this affects how they cope with the situation. In turn, this reaction changes either

the situation or the individual, which then affects the re-appraisal. This results in the

re-appraising of the situation, whereby either the situation itself becomes appraised

as not stressful or changes the individual's way of coping (Lazarus & Folkman,

1984). This whole process is illustrated in Figure 5.1.

Figure 5.1

Transactional Model of Stress and Coping (Lazarus & Folkman, 1984)
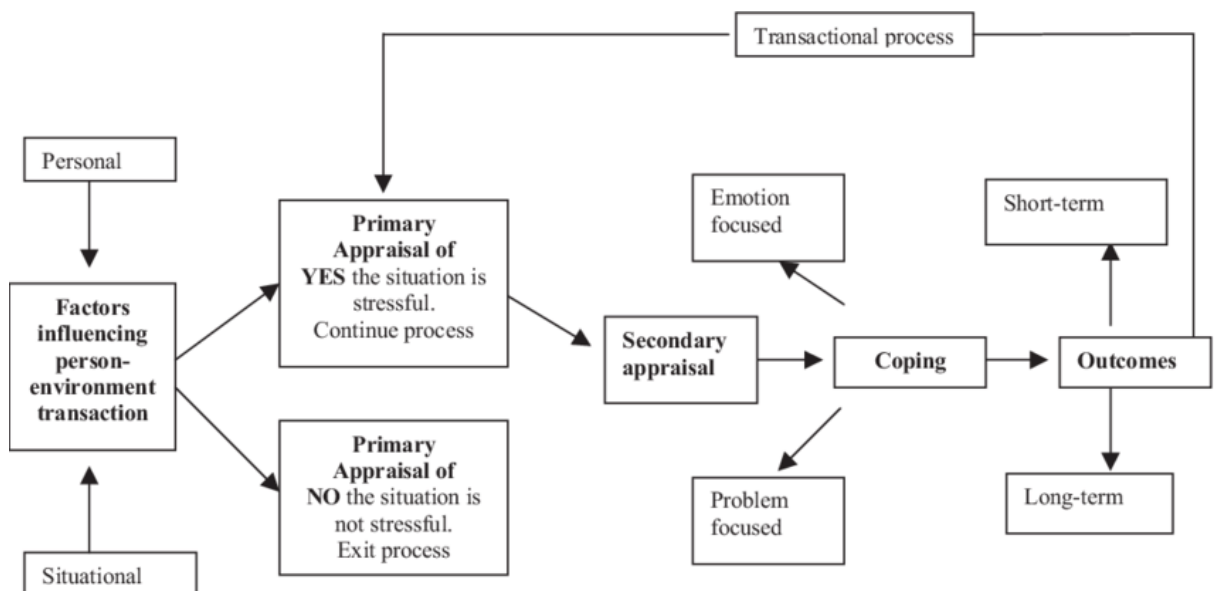
A strength of this theory is that it is dynamic, since it factors in the ability of the

individual to change their appraisal of a situation, and thus their response. It

considers how different individuals appraise a situation, leading to different needs

for coping, and identifies alternative methods for managing psychological responses to stressors (Biggs et al., 2017).

The main critique of this theory is that it lacks empirical evidence, given that it deals with humans. There is also an overlap between the primary and secondary appraisals, since they are interdependent and not mutually exclusive (Lazarus & Folkman, 1984).

The transactional theory of stress and coping (Lazarus, 1966) was deemed as appropriate since it can explain (i) how nurses appraise patient death as stressful or not stressful, and (ii) how the individual responds to stress by utilising coping strategies. As presented in the findings of the present study, the participants described coping strategies during their interviews. The relevance of this theory will be discussed throughout this chapter, where it will help explain the experiences of the nurses working in the palliative unit and their responses to patient death, and how they cope with it.

As mentioned in the literature review carried out, there is a dearth of research specifically about nurses' encounters with patient deaths in the palliative inpatient setting and therefore, studies including nurses from other settings are included in the discussion of the present study, as are studies that were carried out a substantial number of years ago. The next section discusses how nurses working in the palliative unit view death, and how encounters with patient death shaped their perception of death.

5.3 Outlook on Death

The findings in the previous chapter highlighted that the participants' encounters with patient death also shaped their perception of death. These findings will be discussed with reference to the existent literature with the first part of this section discussing the participants' perception of death and the second part discussing how such encounters shaped these perceptions. In addition, the section will also discuss how the participants appraise death, with reference to the transactional theory of stress and coping (Lazarus, 1966).

Most participants in the present study stated that they viewed death as the inevitable end-of-life, which everyone will experience. These findings corroborate the findings by Vachon et al. (2012), and Guo and Zheng (2019) from a sample of oncology nurses, and Temelli and Cerit (2021) from a sample of palliative care nurses, that nurses acknowledged death as part of life. Guo and Zheng (2019) also added that the nurses who had these views experienced more personal accomplishment, whilst nurses with a positive attitude towards death experienced less burnout. This is further discussed in the coping mechanisms mentioned by the participants, where they stated that death becomes part of the norm.

Most participants in the present study described death as a relief of suffering. Palliative care nurses in Temelli and Cerit (2021) also described death as a means to end pain. This view is associated with experience; Guo and Zheng (2019) found that oncology nurses having more than ten years of work experience tended to view death as a means to end suffering. In contrast, nurses with less experience did not perceive death as a relief of suffering (Guo & Zheng, 2019). According to the primary

appraisal of the transactional theory of stress and coping (Lazarus, 1966) nurses in this situation assess death as being 'benign-positive', where the effect of the situation is positive with pleasant emotions (Lazarus & Folkman, 1984). A participant in the present study, in fact, described how death could be seen as positive for him, since sometimes death would be the only means to end suffering. This substantiates a study involving critical care nurses by Hinderer (2012) which found that nurses viewed death as being positive when it marked the end of suffering. The findings from the present study also show that palliative care nurses view patient death as a means of relief for the family and carers of the patient and this substantiates the findings by Costello (2006), where nurses working in geriatrics described that a patient death could bring relief to the relatives of the patient.

Nurses in the present study also perceived some patient deaths as being a 'good' or 'bad' death. All participants stated that they always try to help patients achieve a 'good' death. The ideology of a 'good' death in oncology stems from the fact that cancers have a predictable trajectory and symptoms. Therefore, nurses can relatively predict their patient's death, and it is easier for them to plan for, and provide a 'good' death (Gott, 2008). In a qualitative study about the perceptions of palliative care nurses about a 'good' and 'bad' death, Kristjanson et al. (2001) suggested reasons why nurses aimed for a 'good' death. Kristjanson et al. (2001) suggested that a 'good' death provided nurses with job satisfaction and feeling privileged to have provided a 'good' death to a patient. The present study also found that when a patient died, participants focused on the care they had provided, and how this enabled the patient to experience a more comfortable death. This will be further discussed with the coping strategies the participants described.

As discussed above, nurses' perception of enabling a 'good' death for their patients has a positive impact on the meaning that they ascribe to death – and vice versa in relation to what they perceive was a 'bad' death for their patients. A discussion of the characteristics that these nurses associate with 'good' and 'bad' deaths is therefore warranted.

The findings from the present study showed how palliative care nurses described a 'good' death for their patients that include physical and psychosocial facets. Most participants cited a pain and symptom-free death, having the patient not restless, and surrounded by relatives, as a 'good' death. This corroborates with the findings of Kehl (2006), who carried out an analysis of studies about the concept of a 'good' death. Kehl (2006) found that when describing a 'good' death, nurses cited a lack of distress, good pain management, and a peaceful death.

Nurses in the present study also cited the mental wellbeing of the patients as being important for a 'good' death. This aspect was also described as important by Kehl (2006). A qualitative study by Peterson et al. (2010), involving nurses and nursing students working in different settings caring for dying patients, also found that in addition to alleviating physical suffering, nurses wanted to make sure that the emotional needs of the dying patient were met. The present study found several ways that the nurses described meeting these emotional needs. Some nurses described how a 'good' death could be achieved if the patient had resolved any conflicts they may have had and achieved closure in their relationships prior to death. The findings from Kehl (2006) agreed with the present study. Kehl (2006) found that nurses described a sense of closure of the patient's relationships, including the reconciliation and

forgiveness as part of improving relationships, and the completion of unfinished business, prior to death. The nurses in the present study also cited having the patients' final wishes granted, as an important psychological aspect of a 'good' death. Such wishes described by some participants were attending a wedding, and assuring that the patients accept that there still can be some quality of life left despite their poor prognosis. The nurses in Kehl (2006) also described how, for them, a 'good' death meant that when possible, the patients' beliefs and values were honoured, and if possible, attended any upcoming family events that the patient wished to attend. The nurses in this study by Kehl (2006) also described how they try to help patients live until they die, in order to achieve a 'good' death, as also found in the current study.

Some nurses in the present study described how during a 'good' death, the patient's relatives are calm and find it easier to accept the patient's death. This, in turn, affects how nurses cope with patient death, which will be discussed further when discussing a 'bad' death. Findings from the present study also showed how the participants explained that a 'good' death brings family members closer together, and the nurses expressed how they were saddened by this since they felt pity for the relatives in such closeness.

Similar to the studies by Kehl (2006) and Kristjanson et al. (2001), participants in this study described a 'bad' death by contrasting it with a 'good' death. Nurses in the present study described how dying alone was viewed as a 'bad' death, which agrees with Kehl (2006). The participants in the current study also described how they felt pity for the patients dying alone and felt the need to accompany them. This

substantiates the findings of Guttormson et al. (2022), where a study about critical care nurses and their experiences during the COVID-19 pandemic, found that nurses felt distress when patients died alone.

Most participants in the present study also associated terminal restlessness with a 'bad' death. Terminal restlessness is defined as agitated delirium or terminal agitation (Ferrell et al., 2010) in the last hours or days before a patient death (Lawlor et al., 2000). Kehl (2006) also described that a patient suffering or in distress was considered as a 'bad' death by nurses. A participant in the present study said that, from her experience, when a patient has emotional pain, which she described as unresolved conflicts or personal problems, the patient would end up dying restless. Terminal restlessness was in fact cited as involving emotional turmoil or unresolved emotional issues (Cooper, 2006b) which could be caused from fear, family conflict, financial concerns, and relationship issues (Head & Faul, 2005).

In such instances where the patient dies with terminal restlessness, nurses in the present study described how they feel helpless since as one participant said, emotional pain cannot be treated with medication, and there is nothing that the nurse can do to ease the pain. In contrast, extant literature states that unresolved emotional issues, specifically those that cause terminal restlessness, could be treated with early intervention, by utilising professional support services, without the need for medications (Cooper, 2006a). The statement by the participant could indicate that the nurse lacks knowledge and education pertaining to end-of-life issues.
The sense of helplessness described previously, could lead the nurses to appraise the situation as stressful and resort to emotional-based coping as described by the

transactional theory of stress and coping (Lazarus, 1966), which will be discussed with the coping mechanisms described by the participants. Oncology nurses in Vachon et al. (2012) and Liu and Chiang (2017), and critical care nurses in Hinderer (2012) also described that it was difficult for them in instances where they could not provide comfort to a suffering patient prior to death. Vachon et al. (2012) also found that oncology nurses felt that dealing with suffering was harder than dealing with patient death, given the helplessness and frustration felt when unable to relieve suffering.

As mentioned before, some nurses in the present study said that relatives accept the patient death better when it is a 'good' death and further stated that when the patient dies a 'bad' death, relatives find it harder to accept the patient's death. Hinderer (2012) highlighted that when relatives find it hard to accept the patient death, nurses are negatively affected, since they find it harder to cope with death. In addition, nurses in the present study also felt that they were blamed by the relatives when a patient was restless. This blame may stem from the need of the relatives to blame someone for the patient's death (Darlington et al., 2021).

Participants are not only affected negatively or positively by a patient's death when it is a 'good' or 'bad' death. The findings of the present study showed that the nurse-patient relationships that the nurses formed also had an impact on how the nurses were affected by the patient death. These relationships are discussed in the following subsection. Patient death was described as *"just another one" (Daniella)* when the participants had little or no contact with the patient prior to their death. On the contrary, with patients that the nurses had formed what they viewed as a 'good relationship', nurses said that they were affected negatively by their death. Hinderer

(2012) too found that critical care nurses were affected more by deaths of patients with whom they had formed a strong relationship, than with those patients who they did not have the time to get to know. Most participants in the present study said that they built a bond with patients who stayed for months in their wards, as was also found by Liu and Chiang (2017) in their study about end-of-life care of oncology nurses.

The nurses also described that with certain patients, they formed a closer relationship due to certain characteristics that they could not describe. This could be explained by the suggestion that nurses tend to form a strong relationship with patients who remind them of someone close in their lives (Meier et al., 2001). Meier et al. (2001) also adds that patients with similar background, appearance, or age as the nurse, draw the nurse to form a stronger relationship with said patients. In fact, all participants in the present study also said that they are affected negatively by deaths of younger patients who are close to their own age. Naidoo and Sibiya (2014) and Temelli and Cerit (2021) agree with these findings and cite critical care nurses and palliative care nurses who describe how they feel sadness and become emotional when young patients die. Most nurses in the present study said that they felt that they could relate better with such patients due to their similar age. Keidel (2002) suggests that the negative affect of the death of young patients as experienced by nurses, could be caused by the fact that relating with patients, can heighten feelings of guilt and could even revive personal pain, which could also lead to burnout (Keidel, 2002).

All participants described these factors surrounding a patient's death as shaping their perception on death. The following section discusses the attitudes of the nurses towards their own death and how witnessing death made them appreciate life more and look at both life and death differently. In line with the findings of Barnett et al. (2020), which found that hospice nurses showed low levels of fear of death, most nurses in the current study stated that they do not fear their own death.

Some participants in the present study said that witnessing death made them appreciate life more and changed their perspective to living in the present. Vachon et al. (2012) and Hinderer (2012) also found that encountering death made nurses reflect more on their life. Nurses realise that each day could be their last one, and therefore come to appreciate each day and focus on what makes them happy (Sherman, 2004). On the contrary, one of the participants from the present study, started to look at life as being unfair, since it can be taken away at any time, and any sacrifices made for the future would have been in vain. This latter view corroborates with the study about hospice caregivers, which also found that some caregivers viewed life as unfair (Mickley et al., 1998).

Participants described how they now talk more about death, and how the way they talk about it is different to before starting work at the palliative care unit. They mentioned how they have acquired a different sense of humour about death, that only the nurses working in the palliative care unit could understand. Seeing a funny side of death can act as a form of escape from the situation of patient death (Hopkinson et al., 2005), which is possibly what participants in the current study do, but conclusions cannot be made at this stage. Some participants in the present study also

said that they now think more about death than before starting to work at the palliative care unit, possibly because the frequent encounters with patient death increased their awareness of their own death (Vachon et al., 2012). In contrast to the present study's findings, Guo and Zheng (2019) found that oncology nurses avoided thinking and talking about death to reduce their death anxiety, indicating that increased encounters with death as experienced by palliative care nurse could have a reverse effect, and reduces death anxiety (Lehto & Stein, 2009; Lange et al., 2008).

The transactional theory of stress and coping (Lazarus & Folkman, 1984) suggests that nurses appraise some deaths as being 'benign-positive' and describe these as 'good' deaths. Since the transactional theory of stress and coping suggests that individuals re-appraise a situation after coping with the stress it causes (Lazarus & Folkman, 1984), it can explain how nurses may feel the need to cope with patient death by using problem-based coping. As described by Lazarus and Folkman (1984), a type of problem-based coping is planful problem solving. The nurses used planful problem solving by trying to enable a 'good' death for their patients and accompanying a patient when dying alone. Therefore, by changing the situation to achieve a 'good' death upon the re-appraisal of the situation, the nurses then appraise the situation as 'benign-positive'.

The lack of fear of death mentioned previously can be explained by coping and re-appraisal, as described by the transactional theory of stress and coping (Lazarus, 1966). Since death could have been appraised as stressful by the nurses of this study in their early encounters with it, they used emotion-based coping to reduce the stress of the situation. As described by Lazarus (1993), a type of emotion-based coping is

acceptance, whereby nurses accept that death is inevitable, and upon primary re-appraisal, they appraise death as causing no stress, and hence they do not fear death.

Acceptance is a type of emotion-based coping as described by Lazarus and Folkman (1987) where, due to lack of control on the situation, individuals come to accept or avoid the situation to reduce stress. Emotional-based coping has been regarded as ineffective and maladaptive, and even associated with negative outcomes (O'Driscoll et al., 2008; Taylor & Stanton, 2007). In contrast, problem-based coping has been associated with generally positive effects (O'Driscoll et al., 2008; Taylor & Stanton, 2007). The transactional theory of stress and coping (Lazarus & Folkman, 1984), however, does not refer to either type of coping to be necessarily effective or ineffective.

It is regarded that emotional-based coping is used in situations that evoke intense emotional distress and is useful in the short term to cope immediately with stressful situations where the individual has limited coping resources. This allows the individual to integrate problem-based coping into his or her coping resources (Ben-Zur, 2009). Long term use of emotion-based coping is regarded as not beneficial, since it encourages individuals to disengage from the problem and prevents further attempts to cope (Ben-Zur, 2009). Avoidance coping has for example been shown to lower stress in the short term but causes adverse effects in the long term (LeBlanc et al., 2008).

If the nurses rely mostly on emotional-based coping strategies tentatively, means that they are only temporarily coping with patient death and may be doing themselves psychological harm in the long term. Long term distress has also been found to hinder care that the nurses provide (Kim et al., 2020). This contrasts to what the nurses in the study described they wanted to provide, to achieve a 'good' death as will be discussed in the next section. Such coping strategies could be discussed with a professional such as a psychologist, but as will be discussed, all nurses in the present study stated that they did not feel the need for professional support.

This section discussed how encountering patient death shaped the perspective on death of the participants and how patient death affects them. The next section discusses the findings of the present study on how nurses working in the palliative unit deal with patient death with reference to the transactional theory of stress and coping (Lazarus, 1966).

5.4 Dealing with Patient Death

In the present study, participants described several strategies they presently use to cope with death, the services which are provided at work, and what further services they would like to be offered. The first part of this section presents the way that the nurses in the present study appear to attempt to manipulate their own attitudes to death and dying to one of acceptance of death as an inevitable part of life and of work. This helps them cope with the stress caused by patient death.

Most participants stated that with time and experience, they got used to death. For them, death had become part of the norm and was seen as part of their job routine and nursing practice. However, the participants' experiences of some patient deaths showed that there are instances where these deaths could have a negative impact. Therefore, they have developed strategies to avoid the negative experiences mentioned previously, such as sentiments of loss and helplessness.

'Getting used' to death was stated as an important coping mechanism for them to deal with witnessing patient death. This reinforces what previous studies about palliative (Temelli & Cerit, 2021) and critical care nurses (Hinderer, 2012) found, particularly that after witnessing patient death for a long time, nurses are less shocked and more comfortable with such circumstances. The findings in the present study reinforce the findings from Hinderer (2012), that with experience, nurses cope better with patient death. Some participants in the present study also described that another coping strategy that they use to deal with patient death was to accept that they cannot change the patient's destiny. As mentioned previously, nurses see death as an inevitable end-of-life. This helps them deal with providing end-of-life care (Hinderer, 2012), and makes it easier for them to accept patient death (Hinderer, 2012; Gillman et al. 2015; Naidoo & Sibiya, 2014).

Most nurses in the present study described that with experience, they developed a shell and started to set up boundaries between themselves and the patients to protect themselves from the stress caused by patient death. Hinderer (2012) found that with time, critical care nurses became hardened and also describing setting up a wall to cope with patient death. This corroborates the findings of the present study. In a

literature review about coping strategies of oncology and palliative care nurses, Gillman et al. (2015), in agreement with the present study findings, described that nurses set up boundaries in their relationships with patients and their relatives. The ability to emotionally distance themselves as a way to cope is supported by studies done in other nursing speciality areas, such as paediatrics, operating theatres, and critical care units (Hinderer, 2012; Onstott, 1998; Papadatou et al., 2001). Peterson et al. (2010) found that general nurses and nursing students too were concerned that they would become too involved with a dying patient, and always try to keep their emotions separate. Hopkinson et al. (2005) also found that general nurses strive to control their emotional involvement with dying patients, but they were unable to describe how they balance their emotional involvement and emotional distancing. These general nurses only stated that this balance was learnt through experience and not by any type of guidance. The participants of the present study also showed that they are unable to balance between emotional involvement and emotional distancing, since although they tried to set up boundaries to emotionally distance themselves, they sometimes ended up getting too emotionally involved and got affected negatively by patient death. Nurses utilise this emotional distancing as a coping mechanism since it helps them go on with their day-to-day life (Yang & Mcilfatrick, 2001).

The creation of such boundaries is in contradiction to what the same nurses stated in the present study: that a 'good' death encompasses addressing the patients' psychosocial and emotional needs in addition to their physical needs. In fact, by providing the best possible care prior to death of their patients makes accepting the death much easier for nurses (Hinderer, 2012). Michaelsen (2012) argues that setting

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up such boundaries could hinder the provision of quality end-of-life care, which is needed to achieve what the nurses described a 'good' death. In addition, the provision of good quality care is also a type of coping strategy that the nurses described they used, as will be discussed in the next section.

Some participants in the present study described how a way to cope with a patient death, was by focusing on how they managed to improve the patient's quality of life during their days prior to their death, with a participant in the current study describing how this gives him professional satisfaction. Studies by Vanderspank-Wright et al. (2011) and Ranse et al. (2012) suggested that by focusing on the care provided may even make nurses feel privileged that they were the one that provided the patients with the best quality of life prior to their death.

Despite using the above-mentioned strategies, most participants in the present study suggested that these were not always successful in reducing their own suffering in relation to patient death. They further described strategies that were used to cope with a patient death that affected them negatively. Such strategies included taking a break away from work, utilising coping strategies even when they were away from work, and seeking support from their colleagues.

Most of the nurses described taking a break as a way to deal with the negative impact, which could be in the form of a short break away during the workday or some time off work when feeling felt burnt out. Palliative nurses in the study by (White et al., 2004) also mentioned the importance of taking time off work when experiencing stress at work.

Most participants also described individual coping strategies that they use such as walking, going for a drive, and relaxing by watching a movie or television series. These coping strategies are done when they are not at work, suggesting that the nurses keep thinking about patient death when they are away from work, even though they stated that they tried to keep work at work during the interviews. These corroborate the findings of Barnard et al. (2006), where palliative nurses tried to not bring work into family relationships, but some situations were too overwhelming and they felt that they had to talk to a family member.

Support from colleagues was cited by all participants as being an important way to cope with patient death. They also referred to the good teamwork that they have between the staff in their ward, which further helps in making this type of support easier to utilise. Several studies have found similar findings, that communicating with colleagues about patient deaths is an important coping mechanism for critical care nurses, and general nurses (Hinderer, 2012; Hopkinson et al., 2005; Naidoo & Sibiya, 2014). In the study by Lobb et al. (2010), palliative care nurses described debriefing as being most important emotional support for the nurses, which was defined as informal talk with their colleagues or family. Lobb et al. (2010) found that debriefing may help in the grieving process of palliative care nurses. Debriefing with their colleagues provides the opportunity for nurses to express their sadness, fears, and concerns (Malloy et al., 2013), and unburden themselves of negative emotions (Gillman et al., 2015). Hopkinson et al. (2005) added that nurses find support from the colleagues as important, since colleagues are the ones who have a shared understanding of the experience of patient death. This agrees with the findings of the present study, which highlighted that all nurses feel that colleagues can understand

them the most and talking to colleagues helps them feel that they are not alone in feeling the negative emotions. Another participant from the present study even stated that for her, support from colleagues was all the support that she needs to cope with patient death, reinforcing the importance of colleague support for palliative care nurses.

In addition to support from their colleagues, some participants also mentioned that there are professional services provided by the organisation. All nurses stated that they have never utilised such services, as well as the reasons behind this. When discussing this, all nurses suggested what support strategies they feel they need, and should be implemented.

With regards to formal support services offered by the organisation, some nurses in the present study also mentioned that the only support service provided was that of a psychologist; a service which none of the participants had ever used. In a study about palliative care nurses, Lobb et al. (2010) found that only 17% of the participants reported that they had utilised counselling services provided at work, which also indicates a low uptake of such services. Lack of rapport with the psychologist and the fact that they were more comfortable talking with colleagues, who could understand them best as mentioned before, were cited as the reasons why they did not refer to professional services to cope. Shorter and Stayt (2010) support this claim, since they found that informal conversations with colleagues were more important than any formal support. A participant from this study also stated that for him, it would be easier to open up if a professional approached him, rather than seeking help himself. On the other hand, another participant stated that she does not

utilise the professional support service since she would not want to experience the same negative emotions while recounting the same bad experiences that affected her. It is also worth noting that although participants are hesitant to speak to a psychologist, they expressed several of their worries and questions that a psychologist is in the perfect position to help with. Contrary to what the participants stated, Melvin (2015) suggests that debriefing sessions with a psychologist would be highly beneficial, even though the author also states that debriefing with a colleague or friend would also be beneficial. In a study about nurses working in gynaecology wards who encountered pregnancy loss, McCreight (2005) found that none of the nurses used formal support. McCreight (2005) suggested that the nurses might feel that utilising formal support might imply that they are not managing to cope with work. Similar to the present study, nurses in the study by McCreight (2005) also preferred support from their colleagues. McCreight (2005) also suggested that there might be cultural norms that the nurses might feel they have to follow.

Despite the initial lack of enthusiasm with regards to individual psychology services as an effective support system, most participants of the present study then referred to the possible benefits of being offered group sessions with a psychologist, where they could talk about their feelings and express their thoughts. Literature does suggest that group bereavement debriefing sessions are effective for nurses to learn how to deal with grief after a patient death (Keene et al., 2010; Papadatou et al., 2002). Some participants, however, indicated that some nurses may still find it difficult to speak to a psychologist, even in these group sessions. The participants did not indicate why they would prefer group sessions with a psychologist rather than individual sessions. Such regular group sessions between colleagues could help

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create an environment to discuss and manage difficult situations, by debriefing in a supportive environment (Barnard et al., 2006). As will be discussed further later on, Fessick (2007) suggests that such group sessions where nurses are able to express their feelings and thoughts in a supportive environment can be of benefit to the nurses both as a group and also individually.

Most participants further expressed their wish that they receive more education and training about how they can cope with witnessing a lot of patient deaths during their work and this agrees with previous findings by Guo and Zheng (2019). As explained before, this could be due to appraising their resources to cope as not enough, even though the participants also state that they are currently coping. Research has shown that preventative measures are necessary for nurses working in the palliative care setting, to maintain the nurses' psychological wellbeing (Gillman et al., 2015). Such a measure that could be provided by the organisation is regular training with regards to self-care, developing resilience to enable nurses to cope with patient death (Gillman et al., 2015).

Training about death education was found to be important by Guo and Zheng (2019), since it was found that oncology nurses that attended such training reported significantly lower death avoidance and emotional exhaustion scores. Hopkinson et al. (2005) found that general nurses learnt how to cope with patient death through their experience and observing how other nurses cope with patient death, which is how most participants in the present study described they had learnt how to cope with patient deaths.

Nurses in the present study also indicated that they do not know how to deal with certain situations during their palliative care giving. Palliative care training was found to improve perceived self-efficacy of palliative care nurses in several studies (Dehghani et al. 2020; Joy, 2015; Wen et al., 2012). Such training was also found to help nurses manage patients' pain and distressing symptoms better (Dehghani et al., 2020; Shaw et al., 2010; Turrillas et al., 2019). This would be beneficial to the participants of the present study, since they stated that they are affected negatively with the death of distressed patients, but at the same time they suggested that they do not know how to effectively treat such patients. More educational training would help the lived experience of these nurses by decreasing the nurses' stress that result from what they perceive as 'bad' deaths (Fillion et al., 2005).

Participants in the present study also mentioned how they would like more group activities organised for the staff at the palliative care unit, outside of the work setting. The findings showed that this would provide the nurses with time and space to talk to each other outside the limitations of time and setting at work. Such social activities for staff were also recommended as a prevention and remedy for burnout in paediatric oncology nurses (Spinetta et al., 2000). Some participants in the present study also mentioned that such group activities could be a whole day where, in addition to the opportunity to meet with colleagues outside of work, educational and training sessions are also held. In a study about oncology nurses, Fessick (2007) conducted such a retreat with educational sessions about coping strategies and dealing with grief, and group sessions to discuss their thoughts and express their emotions with a professional. Nurses in this study found these sessions very helpful

to improve their coping abilities, and to also form a stronger bond with their colleagues.

Some coping strategies mentioned in this section included setting up boundaries, accepting death as inevitable part of work, and taking a break from work are types of emotion-based coping mentioned by the participants. According to the transactional theory of stress and coping (Lazarus & Folkman, 1984), these are described as distancing, acceptance, and avoidance respectively and as mentioned previously, these coping strategies have been shown to be only beneficial in the short term. To be effective in reducing stress, they should be used to reduce stress in the short term, until the nurses integrate a problem-based coping strategy (Ben-Zur, 2009). Therefore, if nurses only rely on only emotional-based coping, this tentatively means that they are not managing to cope, as previously discussed.

On the other hand, the coping strategy mentioned where nurses focus on how they managed to improve the patient's quality of life during their days prior to death is a type of problem based coping. In this strategy, the nurses redefine the situation in a positive way, to obtain some benefit from a stressful situation (Lazarus & Folkman, 1987). The support from colleagues, which was mentioned by all participants, is a type of external resource to cope according to the secondary appraisal of a situation, where an individual appraises peers as a resource for coping with stress (Lazarus & Folkman, 1987). Hence, it seems that the participants employed different types of coping strategies to deal with patient deaths. Thus, it seems that it is imperative that palliative care nurse employ different coping strategies in their daily work.

This section discussed how participants cope with patient death by accepting death as being an inevitable part of work, creating shells and boundaries to emotionally distance themselves from death, and taking a break from work. These coping strategies are important for the nurses themselves to cope with encountering patient death and also their nursing care since as mentioned previously, stress could hamper nursing care (Kim et al., 2020). The perceptions of the support services available and what further support the nurses feel they need were also discussed. The next section presents the strengths and limitation of the present study.

5.5 Strengths and Limitations

The strengths and limitations of the present study are discussed in this section.

5.5.1 Strengths

A noteworthy strength of the current study is the fact that it is the first local study to look at the lived experience of Maltese palliative care nurses and their encounters with patient death. Focusing on the lived experiences of this population helps to reduce the gap in knowledge about this subject.

This study consisted of two interviews for each participant. The second interview helped strengthen the results of the study, since it provided additional exploration of significant topics that were discussed in the first interview. The pilot interview carried out before the start of the interviews was included in the study too.

Since the interviews were conducted in the participant's preferred language, which was Maltese, they were able to express their thoughts and feelings more comfortably.

The use of an IPA approach is a major strength, since it provided the participants the best opportunity to express their experiences. The impact of subjectivity was acknowledged and a reflexive diary was kept to reduce any possible bias, by making any assumptions and preconceptions held by the researcher clear. The findings of this study also provide information that can be used to support the training needs of nurses working in the palliative care setting, and for nurses who care for dying patients.

5.5.2 Limitations

The limitations of the current study are presented below. The author of this study is a novice researcher and this was his first attempt in phenomenological research, which is itself a limitation.

The researcher has some previous experience working in the same palliative care unit from where the participants were recruited, which would have led to the possibility of preconceived ideas and beliefs affecting the research study. As mentioned previously, a reflexive journal was kept to minimise their effect on the study. As mentioned in Chapter 3, an intermediary approached the potential participants, to reduce the possibility of coercion.

The researcher translated the interviews from Maltese to English, and although the utmost was done to keep the same meaning of the text, some meanings and metaphors may have been undermined by the translation. The excerpts hence have been presented in both the original language and the translated English language to

minimise this limitation. This study was also limited by the time limitations due to it being part of a Master's degree research project.

5.6 Conclusion

This chapter presented a discussion of the findings of this study in relation to the available literature. The coping strategies and the services used by nurses to help them deal with patient death were also discussed. The transactional theory of stress and coping (Lazarus, 1966) was utilised to explain how witnessing death shaped the perceptions on death of these nurses, and how they cope with witnessing death during their work. The next chapter provides a summary of the present study, implications of this study, and recommendations for future research.

Chapter 6: Conclusions and Recommendations

6.1 Introduction

This chapter presents a summary of the research study and its findings. The educational, clinical practice and research recommendations are also presented.

6.2 Summary of the Research Study

The study aimed to explore the lived experiences of nurses who encounter patient death in a palliative inpatient setting. My past working experience in this setting was the motivation behind the choice of this area of study. From searching the literature, a dearth of research was noted about the lived experiences of palliative care nurses relating to patient death and there is no evidence of any local study, up to the time of this present study, about the lived experiences of Maltese palliative care nurses.

To explore the lived experiences, a qualitative, hermeneutic, phenomenological approach was deemed the most appropriate design to utilise and the research process was guided by IPA as defined by Smith et al. (2012). Using purposeful sampling, five nurses working in an inpatient palliative care setting were chosen to participate. Data were collected using two one-to-one semi-structured interviews. The second interview was carried out to delve deeper on certain topics that were explored in the first interview.

From the analysis of the transcripts, two super-ordinate themes emerged, namely 'outlook on death' and 'dealing with patient death'. The former theme describes how witnessing patient death shaped the participants' perception of death. The latter theme describes how the participants cope with witnessing patient death, and their

views on how they could be further supported in their work. Death was seen as part of life's journey by the participants as it marks the inevitable end of this journey. Participants described how death sometimes meant the relief of suffering for their patients. Describing their own death, the participants described how they neither fear nor look forward to it.

When describing the deaths of their patients, participants referred to 'good' deaths and 'bad' deaths. Participants described how they always aim for a 'good' death for their patients, which for these nurses meant that the patient was pain- and symptom-free, while being surrounded by their relatives. Nurses also described that emotional and mental wellbeing was important for a patient to achieve a 'good' death. Participants also mentioned that they feel bad and pity patients that die alone, since this goes against the 'good' death that they try to achieve, and some nurses mentioned how they had accompanied patients who were dying alone.

Even though participants tried to keep a boundary between them and their patients, in order to not let themselves be affected by the patient death, they mentioned how they still involuntarily formed relationships with some of these patients. The nurses described how, having these relationships had an effect on how deaths of such patients affected them. Some participants described how deaths of patients with whom they had no relationship, did not affect them since it was seen as 'just another' death. Further to this, some participants described how they formed relationships with younger patients who were similar in age to them and when these patients died, they were negatively affected. Witnessing their patient's death left a mark on the participants by shaping their views on life and death. A few of the participants

described how, since working in a palliative care setting, they started to appreciate their family and life. The nurses changed their perspective to now and on enjoying life more.

Some participants stated that now they think about death more and see death as something normal and, from the analysis of the findings, this was also noted to be a coping mechanism the nurses utilised to deal with patient death. Participants also referred to getting used to death and accepting death as part of their work as ways to cope with patient death. Despite describing a sense of normality and not being fazed by death, nurses stated that death still affected them negatively. Furthermore, the participants stated that they felt they needed more support at work. Most participants described forming a shell or boundaries to emotionally distance themselves from the patient, to not let patient death affect them, although this was not always effective. Nurses stated that they accepted that they cannot control the destiny of the patient. Participants also expressed their need to take a break to let out and calm their emotions. On mentioning coping strategies, participants indicated that they keep thinking about patient death away from work too.

Participants also added that they receive a lot of support from their colleagues, and this was an important way of coping with patient death. The nurses described that their colleagues were the ones who could best understand them, and in talking with each other, they felt that they were not alone in feeling the negative emotions.

Although most participants were aware of the psychologist service offered to them at work, they were hesitant to utilise it, since they felt more comfortable talking with

their colleagues. Contrary to this, participants still mentioned that they would like group sessions with a psychologist. Although the participants said that they did not feel the need to use the psychological support services, from the analysis of the findings, it was noted that the participants had many queries and questions that could be answered by a psychologist. In addition, participants also talked about the need for more training on how they can better take care of their mental health in relation to witnessing death, and on how they can better handle certain situations while providing end-of-life care. They stated that the knowledge that they currently use to deal with such situations was gained through experience.

Participants also referred to group activities, such as team building activities held outside of work, where they could meet together as colleagues and have the time and space to talk with each other, away from the time limitations at work.

6.3 Recommendations for Education and Training

Nurses cited a lack of knowledge and training about how to answer certain questions asked by the patient and relatives. Therefore, nurses working in the palliative care unit should be provided with training on how to communicate with their patients and the relatives. The participants felt that they are not provided with sufficient support. Ongoing education on healthy ways to cope with witnessing patient death and its effects was found to benefit palliative care nurses. Education on palliative care and death should also be emphasised in nursing curriculum to better prepare nurses for encounters with patient death. Such education should tackle pain and symptom control, which are necessary to enable a 'good' death, as discussed previously.

6.4 Recommendations for Clinical Practice and Management

Nurses being allocated to a palliative care setting should be provided with in-service specialised orientation and training on caring for dying patients and death, since most participants mentioned that they felt they were not trained to work in this setting, and only learnt through experience.

As mentioned by the participants, adequate support systems are needed at work, to assist nurses to cope with patient death. As a participant mentioned, nurses are reluctant to seek support themselves, but would prefer healthcare professionals approach them themselves. For this reason, a more active psychological support service whereby the professional approaches the nurses, and is more present in the nurses' day-to-day life, would increase uptake of such services.

Good teamwork between the nurses was also noted in the findings, which helps them support each other. As also mentioned by the participants, team building activities and social events outside of the work setting would help foster an even better working environment between the staff and provide them with an opportunity to further talk and support each other away from the work setting.

6.5 Recommendations for Further Research

Further research is needed on what training should be provided for nurses prior to starting to work in a palliative inpatient care unit, and for nurses already working within such setting. Nurses in this study referred to setting up boundaries between them and their patients. Further research on how this emotional disconnect affects nurses' experiences, as well as the nurse patient-family relationships is suggested.

Further research is also needed on why palliative care nurses do not utilise the support services provided, even though they feel the need and would benefit from such services. Moreover, research should be done on what can be done to improve such services to better support nurses working in the palliative care unit. Research is also needed on the long term effects of frequent exposure to death, that palliative care nurses experience, to determine if this exposure to death is detrimental to nurses.

6.6 Conclusion

The perceptions of death of nurses working in an inpatient palliative care setting were shaped by their encounters with patient death. Patient death also left an impact on the participants, who felt the need of coping strategies to deal with patient death. All participants found their own combination of coping strategies to deal with patient death, as well as support from their colleagues. Further to this, participants felt that they could be better supported at work to better deal with patient death, citing training and group activities as ways that they could be better supported.

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Appendices

Appendix A: Critical Appraisal Skills Programme (CASP) (2018) qualitative checklist

www.casp-uk.net

info@casp-uk.net

Summertown Pavilion, Middle Way Oxford OX2 7LG

CASP Checklist: 10 questions to help you make sense of a **Qualitative** research

How to use this appraisal tool: Three broad issues need to be considered when appraising a qualitative study:

- Are the results of the study valid? (Section A)
- What are the results? (Section B)
- Will the results help locally? (Section C)

The 10 questions on the following pages are designed to help you think about these issues systematically. The first two questions are screening questions and can be answered quickly. If the answer to both is "yes", it is worth proceeding with the remaining questions. There is some degree of overlap between the questions, you are asked to record a "yes", "no" or "can't tell" to most of the questions. A number of italicised prompts are given after each question. These are designed to remind you why the question is important. Record your reasons for your answers in the spaces provided.

About: These checklists were designed to be used as educational pedagogic tools, as part of a workshop setting, therefore we do not suggest a scoring system. The core CASP checklists (randomised controlled trial & systematic review) were based on JAMA 'Users' guides to the medical literature 1994 (adapted from Guyatt GH, Sackett DL, and Cook DJ), and piloted with health care practitioners.

For each new checklist, a group of experts were assembled to develop and pilot the checklist and the workshop format with which it would be used. Over the years overall adjustments have been made to the format, but a recent survey of checklist users reiterated that the basic format continues to be useful and appropriate.

Referencing: we recommend using the Harvard style citation, i.e.: *Critical Appraisal Skills Programme (2018). CASP (insert name of checklist i.e. Qualitative) Checklist. [online] Available at: URL. Accessed: Date Accessed.*

Critical Appraisal Skills Programme (CASP) part of Oxford Centre for Triple Value Healthcare Ltd www.casp-uk.net

Paper for appraisal and reference: ....

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
• what was the goal of the research
• why it was thought important
• its relevance

Comments:

2. Is a qualitative methodology appropriate?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
• If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants
• Is qualitative research the right methodology for addressing the research goal

Comments:

Is it worth continuing?

3. Was the research design appropriate to address the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
• if the researcher has justified the research design (e.g. have they discussed how they decided which method to use)

Comments:

4. Was the recruitment strategy appropriate to the aims of the research?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the researcher has explained how the participants were selected
- If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study
- If there are any discussions around recruitment (e.g. why some people chose not to take part)

Comments:

5. Was the data collected in a way that addressed the research issue?

Yes ☐
Can't Tell ☐
No ☐

HINT: Consider
- If the setting for the data collection was justified
- If it is clear how data were collected (e.g. focus group, semi-structured interview etc.)
- If the researcher has justified the methods chosen
- If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide)
- If methods were modified during the study. If so, has the researcher explained how and why
- If the form of data is clear (e.g. tape recordings, video material, notes etc.)
- If the researcher has discussed saturation of data

Comments:

3

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6. Has the relationship between researcher and participants been adequately considered?

Yes ☐

Can't Tell ☐

No ☐

HINT: Consider
- If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location
- How the researcher responded to events during the study and whether they considered the implications of any changes in the research design

Comments:

Section B: What are the results?

7. Have ethical issues been taken into consideration?

Yes ☐

Can't Tell ☐

No ☐

HINT: Consider
- If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained
- If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study)
- If approval has been sought from the ethics committee

Comments:

8. Was the data analysis
sufficiently rigorous?

Yes ☐

Can't Tell ☐

No ☐

HINT: Consider
- If there is an in-depth description of the analysis process
- If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data
- Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process
- If sufficient data are presented to support the findings
- To what extent contradictory data are taken into account
- Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation

Comments:

9. Is there a clear statement
of findings?

Yes ☐

Can't Tell ☐

No ☐

HINT: Consider whether
- If the findings are explicit
- If there is adequate discussion of the evidence both for and against the researcher's arguments
- If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)
- If the findings are discussed in relation to the original research question

Comments:

CASP
Critical Appraisal
Skills Programme

Section C: Will the results help locally?

10. How valuable is the research?

HINT: Consider
- If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g. do they consider the findings in relation to current practice or policy, or relevant research-based literature
- If they identify new areas where research is necessary
- If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used

Comments:

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Appendix B: AXIS critical appraisal tool (Downes et al., 2016)

Appraisal of Cross-sectional Studies

	Question	Yes	No	Don't know/ Comment
Introduction				
1	Were the aims/objectives of the study clear?			
Methods				
2	Was the study design appropriate for the stated aim(s)?			
3	Was the sample size justified?			
4	Was the target/reference population clearly defined? (Is it clear who the research was about?)			
5	Was the sample frame taken from an appropriate population base so that it closely represented the target/reference population under investigation?			
6	Was the selection process likely to select subjects/participants that were representative of the target/reference population under investigation?			
7	Were measures undertaken to address and categorise non-responders?			
8	Were the risk factor and outcome variables measured appropriate to the aims of the study?			
9	Were the risk factor and outcome variables measured correctly using instruments/measurements that had been trialled, piloted or published previously?			
10	Is it clear what was used to determined statistical significance and/or precision estimates? (e.g. p-values, confidence intervals)			
11	Were the methods (including statistical methods) sufficiently described to enable them to be repeated?			
Results				
12	Were the basic data adequately described?			
13	Does the response rate raise concerns about non-response bias?			
14	If appropriate, was information about non-responders described?			
15	Were the results internally consistent?			
16	Were the results presented for all the analyses described in the methods?			
Discussion				
17	Were the authors' discussions and conclusions justified by the results?			
18	Were the limitations of the study discussed?			
Other				
19	Were there any funding sources or conflicts of interest that may affect the authors' interpretation of the results?			
20	Was ethical approval or consent of participants attained?			

Appendix C: Information Letter to Intermediary

Ms. Annabelle Magro Conti,

Charge Nurse Palliative Care Unit,

Sir Anthony Mamo Oncology Centre,

Msida

12th August 2021

Request to act as Intermediary for research project in the Palliative Care Unit at the Sir Anthony Mamo Oncology Centre

Dear Ms. Annabelle Magro Conti,

My name is Joseph Xuereb, and I am a student at the University of Malta reading a Master of Nursing degree. As part of this degree, I am required to conduct a research study which I intend to explore the lived experiences of palliative care nurses and their encounters with patient death. This project is being conducted under the supervision of Dr. Joanna Depares and co-supervised by Mr. Daren Chircop.

In order to conduct this research, I need to collect data from a sample of four nurses currently working in the palliative care unit at the Sir Anthony Mamo Oncology Centre. The selected participants are to be registered nurses currently working in, and with more than six months' experience of an inpatient palliative care setting. Data will be collected through two separate in-depth interviews, with the first one lasting approximately 60 minutes, and the second one approximately 30 minutes. If the participants have no objections, these will be audio-recorded. These interviews will take place at a time and place of convenience to the participant, either face to face or online, according to the participant's preference. In the case that the interview is done online, the participant will have a choice to either turn on or keep the camera off throughout the interview. In either case, only the audio of the interview will be recorded and saved to the computer, and not to the cloud. Each participant will be interviewed on two different occasions. It is anticipated that the data will be collected approximately between the months of October and January.

Informed consent will be acquired by myself from the participants, after explaining what participation will entail. Participation will be entirely voluntary, and participants will be free to withdraw at any point, without any negative repercussions. In case of any distress, psychological support, participants can make use of the services of the Psychological department at SAMOC at no financial costs. Data collected will be solely used for research purposes and the participants will only be asked to share data that is necessary for the research. Their identity will not be noted on transcripts, audio-recordings or notes from the interviews, but instead, a code will be assigned. The codes that link the participants data to their identity will be stored securely and separately from the data, in an encrypted file on the researcher's password-protected computer. Supervisors and examiners will typically have access to coded data only. There may be exceptional circumstances which allow the supervisor and examiners to have access to personal data too, for verification purposes. Any material that identifies the participant as a participant in this study will be stored securely for the duration of the study. All data collected will be erased on completion of the study and following publication of results. Extracts from the interviews may be reproduced in these

outputs, either in anonymous form, or using a pseudonym. Names or identifiable characteristics of the participants will not be published or shared with any third parties.

I am requesting that you kindly invite potential candidates to participate in this research study and ultimately, with their approval, provide me with the contact details of four potential participants. The participants' acceptance will be attained once you have provided these potential candidates with information about the purpose of the study, as well as the risks and benefits of their participation, while also providing re-assurance that they are under no obligation to participate and accordingly, refusal to participate will not affect their work. I will only approach the participants to set up an interview once they confirm their willingness to participate in the study. Additionally, I will not be informed of the nurses who were approached and declined to participate.

In addition to the four participants of the study, I am requesting you to recruit an additional participant for a pilot interview.

Your support for this research is greatly appreciated and will be carried out following ethical approval by UREC and FREC. Should you have any questions or concerns, please do not hesitate to contact me on 79219710 or by email joseph.xuereb.16@um.edu.mt, or my supervisor Dr. Joanna Depares on 2340 1840, or by e-mail joanna.depares@um.edu.mt.

Sincerely,

Joseph Xuereb

Master of Nursing Student

Appendix D: Information Letter

4/8/2021

Information letter

Dear Sir/Madam,

My name is Joseph Xuereb, and I am a student at the University of Malta reading a Master of Nursing degree. As part of this degree, I am required to conduct a research study in which, I intend to explore the lived experiences of palliative care nurses and their encounters with patient death. This project is being conducted under the supervision of Dr. Joanna Depares and co-supervised by Mr. Daren Chircop. This letter is an invitation to participate in this study. Below you will find information about the study and what your involvement would entail, should you decide to take part.

The focus of my study is on how regular experiences of patients' deaths affects palliative care nurses. Your participation in this study would help contribute to a better understanding of the experiences of palliative care nurses that regularly experience patient death and the affect that this has on nurses. Any data collected from this research will be used solely for the purpose of this study.

Should you choose to participate, you will be interviewed in two separate one-on-one interviews with the researcher, with the first one lasting approximately 60 minutes, and the second one approximately 30 minutes. If you have no objections, these will be audio-recorded. These interviews will take place at a time and place of your convenience, either face to face or online, according to your preference. In the case that the interview is done online, you can choose to either turn on, or keep the camera off throughout the interview. In either case, only the audio of the interview will be recorded and saved to the computer, and not to the cloud. It is anticipated that the data will be collected approximately between the months of October 2021 and January 2022.

Data collected will be solely used for research purposes and you will only be asked to share data that is necessary for the research. Your identity will not be noted on transcripts, audio-recordings or notes from your interviews, but instead, a code will be assigned. The codes that link your data to your identity will be stored securely and separately from the data, in an encrypted file on the researcher's password-protected computer. The academic supervisors and examiners will typically have access to coded data only. There may be exceptional circumstances which allow the supervisor and examiners to have access to personal data too, for verification purposes. If you want to enquire who accessed your data, please contact me on 79219710 or by email joseph.xuereb.16@um.edu.mt. Any material that identifies you as a participant in this study will be stored securely for the duration of the study. All data collected will be erased on completion of the study and following publication of results. Extracts from your interview may be reproduced in these outputs, either in anonymous form, or using a pseudonym. Names or identifiable characteristics of the participants will not be published or shared with any third parties.

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. Please also note that, as a participant, you have the right under the General Data Protection Regulation (GDPR) and national legislation that implements and further specifies the relevant provisions of said regulation, to access, rectify and where applicable ask for the data concerning you to be erased.
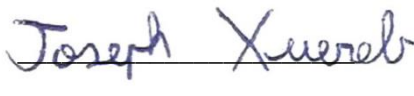
By participating in this study, you can benefit by offering insight into the needs of palliative care nurses, and the needs that you might have that are not being met. It may also benefit others by offering insight on the effects of frequent death on palliative care nurses and provides a basis for further research on how to meet their needs. In the event that you feel that the interview has distressed you in any way and you would benefit from the services of a psychologist, you can make use of the services of the Psychological department at SAMOC (who can be contacted on 2545 2300, or by email on benna.chase@gov.mt) at no financial costs on your part.

This study has been approved by the Research Ethics Committee of the Faculty of Health Sciences at the University of Malta.

A copy of this information sheet and the consent form will be 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 on 79219710 or by email joseph.xuereb.16@um.edu.mt, or my supervisor Dr. Joanna Depares on 2340 1840, by e-mail joanna.depares@um.edu.mt.

Sincerely,

Joseph Xuereb

joseph.xuereb.16@um.edu.mt

79219710

Master of Nursing Student

Dr. Joanna Depares

joanna.depares@um.edu.mt

2340 1840

Research Supervisor

Appendix E: Consent Form

Participant's Consent Form

The lived experiences of the palliative care nurses and their encounters with patient death.

I, the undersigned, give my consent to take part in the study conducted by Joseph Xuereb. 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 two separate one-on-one interviews in which the researcher will ask me questions about my experiences of patients' deaths to explore the effects of regular experiences of patients' deaths on palliative care nurses. I am aware that the first interview will last approximately 60 minutes, and the second one approximately 30 minutes. I understand that the interview is to be conducted in a place and at a time that is convenient for me. I understand that I will only be asked to share data that is necessary for the research.
4. I understand that my participation may cause some distress due to recalling memories and experiences of death. To mitigate these risks, psychological help will be available free of charge.
5. I also understand that this research may benefit me by offering insight into the needs of palliative care nurses with regards to the frequent encounters of the death of their patients and additionally, provides a basis for further research on how to meet the needs of palliative care nurse.
6. I understand that, under the General Data Protection Regulation (GDPR) and national legislation that implements and further specifies the relevant provisions of said regulation, 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 and following publication of results.
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, either in anonymous form, or using a pseudonym [a made-up name or code – e.g. respondent A].

11. I am aware that my data will be pseudonymised, i.e. my identity will not be noted on transcripts or notes from my interview, but instead, a code will be assigned. The codes that link my data to my identity will be stored securely and separately from the data, in an encrypted file on the researcher's password-protected computer. Academic supervisors and examiners will typically have access to coded data only. I am aware that there may be exceptional circumstances which allow the supervisors and examiners to have access to personal data too, for verification purposes. If you want to enquire who accessed your data, please contact me on 79219710 or by email joseph.xuereb.16@um.edu.mt. Any material that identifies me as a participant in this study will be stored securely for the duration of the study.

12. I am aware that my identity and personal information will not be revealed in any publications, reports or presentations arising from this research.

13. I am aware that I may ask to be given the opportunity to review relevant extracts of the transcript of my interview before the results of the study are published. I am also aware that I may ask for changes be made if I consider this to be necessary.

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

Name of participant: _____

Signature: _____

Date: _____

Joseph Xuereb

joseph.xuereb.16@um.edu.mt

79219710

Master of Nursing Student

Dr. Joanna Depares

joanna.depares@um.edu.mt

2340 1840

Research Supervisor

Mr. Daren Chircop

dchir02@um.edu.mt

Research Co-Supervisor

Appendix F: Interview Schedule

1. **What is your experience of working at the Palliative Care Unit?**

   Is it stressful? How?
   Is it rewarding? How?

2. **Can you tell me about your experience of caring for patients at their end of life?**

   What, if anything, makes the experience better?
   What, if anything makes the experience worse?

3. **How do you feel when a patient you are caring for passes away?**

   Can you give me an example of a particular experience?

4. **How do you view death?**

   What meaning does it have for you? (If any)

5. **How did your perceptions about death and life change, if it all, since starting to work at the Palliative Care Unit?**

6. **What strategies, if any, do you utilise to deal with stressors associated with caring for dying patients and their families?**

7. **Is there anything you would like to add?**

Appendix G: Ethical approval by FREC

L-Università ta' Malta

UREC FORM V_15062020 9585 Joseph Xuereb

Rita Pace Parascandalo <rita.pace-parascandalo@um.edu.mt>   27 September 2021 at 12:54
To: Joseph Xuereb <joseph.xuereb.16@um.edu.mt>
Cc: Research Ethics HEALTHSCI <research-ethics.healthsci@um.edu.mt>, Joanna Depares
<joanna.depares@um.edu.mt>

Dear Joseph,

your recently submitted amendment has been reviewed. Approval for your study is granted oBo FREC. You may proceed with your study and collect the data.

Good luck

Regards
Dr Rita PP

L-Università ta' Malta

Dr Rita Pace Parascandalo PhD (UCLan)
BSc(Hons) (Melit.), MSc(Melit.), RM

Senior Lecturer, Department of Midwifery

Chairperson, Faculty Research Ethics Committee

Faculty of Health Sciences
Office No. 48
+356 2340 1176
rita.pace-parascandalo@um.edu.mt

[Quoted text hidden]

Appendix H: Approvals from Cooperating Institutions

Permission Letter Sent

Clinical Chairperson

Chief Nursing Officer

Human Resources officer

Chief Executive Officer

Data Protection Office

Charge nurse of the palliative ward

Permission Letter Sent

Request for permission to conduct research in the Palliative Care Unit at the Sir Anthony Mamo Oncology Centre

Dear

My name is Joseph Xuereb, and I am a student at the University of Malta reading a Master of Nursing degree. As part of this degree, I am required to conduct a research study in which, I intend to explore the lived experiences of palliative care nurses and their encounters with patient death, with a focus on how regular experiences of patients' deaths affects palliative care nurses. This project is being conducted under the supervision of Dr. Joanna Depares and co-supervised by Mr. Daren Chircop.

I am hereby seeking your permission to collect data from a sample of not more than 4 nurses currently working in the palliative care unit at the Sir Anthony Mamo Oncology Centre. The selected participants will be registered nurses with more than six months' experience in an inpatient palliative care setting. Data will be collected through two separate in-depth interviews, with the first one lasting approximately 60 minutes, and the second one lasting approximately 30 minutes. If the participants have no objections, these will be audio-recorded. These interviews will take place at a time and place of convenience to the participant, either face to face or online, according to the participant's preference. In the case that the interview is done online, the participant will have a choice to either turn on or keep the camera off throughout the interview. In either case, only the audio of the interview will be recorded and saved to the computer, and not to the cloud. Each participant will be interviewed on two different occasions. It is anticipated that the data will be collected approximately between the months of October 2021 and January 2022. Qualifying participants will be approached by an intermediary, Ms. Annabelle Magro Conti, who is the current Nursing Officer of the palliative care unit at the Sir Anthony Mamo Oncology Centre, where she will provide a participant information sheet, which will include details regarding the present study. In this way, I will not be aware of the participants who were approached and, additionally those individuals who declined to participate.

Informed consent will be acquired by myself from the participants, after explaining what participation will entail. Participation will be entirely voluntary, and participants will be free to withdraw at any point, without any negative repercussions. In the event that any participants feel that the interview has distressed them in any way, and would benefit from the services of a psychologist, the participants can make use of the services of the Psychological department at SAMOC at no financial costs for the participants.

Data collected will be solely used for research purposes and the participants will only be asked to share data that is necessary for the research. Their identity will not be noted on transcripts, audio-recordings or notes from the interviews, but instead, a code will be assigned. The codes that link the participants data to their identity will be stored securely and separately from the data, in an encrypted file on the researcher's password-protected computer. Supervisors and examiners will typically have access to coded data only. There may be exceptional circumstances which allow the supervisor and examiners to have access to personal data too, for verification purposes. Any material that identifies the participant as a participant in this study will be stored securely for the duration of the study. All data collected will be erased on completion of the study and following publication of results. Extracts from the interviews may be reproduced in these outputs, either in anonymous form, or using a pseudonym. Names or identifiable characteristics of the participants will not be

published or shared with any third parties. The participants will have the right under the General Data Protection Regulation (GDPR) and national legislation that implements and further specifies the relevant provisions of said regulation, to access, rectify and where applicable ask for the data concerning you to be erased.

Should you require further information, please do not hesitate to contact me on 79219710 or by email joseph.xuereb.16@um.edu.mt, or my supervisor Dr. Joanna Depares on 2340 1840, or by e-mail joanna.depares@um.edu.mt.

Thank you for your kind consideration of this request.

Sincerely,

Joseph Xuereb	Dr. Joanna Depares	Mr. Daren Chircop
Master of Nursing Student Supervisor	Research Supervisor	Research Co-

Clinical Chairperson

FORM :	**Oncology Proposal/Approval Audit/ Research purposes**
Document Code: ONCO-GeFO-P/A-001. Ver.01	Reference SOP : ONCO-Ge-PD.AP--001.Ver.01

PROJECT TITLE: The lived experiences of palliative care nurses and their encounters with patient death.

Name & Surname (Researcher/ Student): **Joseph Xuereb**

Email address: joseph.xuereb.16@um.edu.mt

Tutor's name & Surname: Dr. Joanna Depares

Proposal

Introduction:

Research on palliative care nurses mostly focuses on the lived experiences of palliative care nurses caring for the dying patient. There are studies focusing on the experiences of nurses in different settings who experience death regularly, such as in the intensive care unit, but there is limited research on the lived experience of palliative care nurses, who are experiencing death on a more frequent basis.

Aim/s:

The aim of the proposed study is to explore the lived experiences of palliative care nurses and their encounters with patient death. This study aims to explore the effect that frequent patient death has on palliative care nurses, and offer insight on what needs palliative care nurses require.

Method (include the sample size)

Data will be collected by using individual semi-structured interviews. Maximum number of participants will be 4 nurses currently working in the palliative care unit at the Sir Anthony Mamo Oncology Centre. The selected participants will be registered nurses with more than six months' experience in an inpatient palliative care setting. These will be recruited using purposeful sampling. The data collected will be transcribed verbatim and analysis will be done using Interpretative Phenomenological Analysis.

Data will be collected through two separate in-depth interviews, with the first one lasting approximately 60 minutes, and the second one lasting approximately 30 minutes. If the participants have no objections, these will be audio-recorded. These interviews will take place at a time and place of convenience to the participant, either face to face or online, according to the participant's preference. In the case that the interview is done online, the participant will have a choice to either turn on or keep the camera off throughout the interview. In the latter case, only the audio of the interview will be recorded and saved to the computer, and not to the cloud. Each participant will be interviewed on two different occasions. It is anticipated that the data will be collected approximately between the months of October 2021 and January 2022. To reduce the risk of coercion, qualifying participants will be approached by an intermediary, Ms. Annabelle Magro Conti, who is the current Nursing Officer of the palliative care unit at the Sir Anthony Mamo Oncology Centre, where she will provide a participant information sheet, which will include details regarding the present study. In this way, I will not be aware of the participants who were approached and, additionally those individuals who declined to participate. As the researcher is currently working as a reliever at the Sir Anthony Mamo Oncology Centre, permission was granted from the Chief Nursing Manager, that he

Generic Form Template Prepared By: Mr. Edward Falzon	Generic Form Template Reviewed By: Ms. Dorothy Aquilina	Issue Date:	Version 01
Generic Form Template Approved By: Dr Stefan Laspina	Authority of Issue:	Revision Date:	Page 1 of 3

FORM :	**Oncology Proposal/Approval Audit/ Research purposes**
Document Code: ONCO-GeFO-P/A-001. Ver.01	Reference SOP : ONCO-Ge-PD.AP--001.Ver.01

will not be placed in the Palliative Care Unit for the duration of the recruitment period, to further minimize the risk of coercion.

Informed consent will be acquired by the researcher from the participants, after explaining what participation will entail. Participation will be entirely voluntary, and participants will be free to withdraw at any point, without any negative repercussions. In the event that any participants feel that the interview has distressed them in any way, and would benefit from the services of a psychologist, participants can make use of the services of the Psychological department at SAMOC at no financial costs.

Data collected will be solely used for research purposes and the participants will only be asked to share data that is necessary for the research. Their identity will not be noted on transcripts, audio-recordings or notes from the interviews, but instead, a code will be assigned. The codes that link the participants data to their identity will be stored securely and separately from the data, in an encrypted file on the researcher's password-protected computer. Supervisors and examiners will typically have access to coded data only. There may be exceptional circumstances which allow the supervisor and examiners to have access to personal data too, for verification purposes. Any material that identifies the participant as a participant in this study will be stored securely for the duration of the study. All data collected will be erased on completion of the study and following publication of results. Extracts from the interviews may be reproduced in these outputs, either in anonymous form, or using a pseudonym. Names or identifiable characteristics of the participants will not be published or shared with any third parties.

Generic Form Template Prepared By: Mr. Edward Falzon	Generic Form Template Reviewed By: Ms. Dorothy Aquilina	Issue Date:	Version 01
Generic Form Template Approved By: Dr Stefan Laspina	Authority of Issue:	Revision Date:	Page 2 of 3

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FORM :	**Oncology Proposal/Approval Audit/ Research purposes**
Document Code: ONCO-GeFO-P/A-001. Ver.01	Reference SOP : ONCO-Ge-PD.AP--001.Ver.01

Heads of:
(Name, Surname and Section (in block letters) and Signature)

Nursing

Clinical Chairperson (Haematology - Oncology):
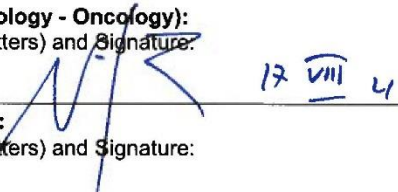Name and Surname (in block letters) and Signature:
Dr Nick Refalo
Chairman & Consultant Oncologist
Sir Anthony Mamo Oncology Centre
Reg No: 2662

17 VIII 4

Quality Assurance Manager:
Name and Surname (in block letters) and Signature:

An approval is granted to carry out the study/audit at any SAMOC Department. Patient information can be accessible only by complying with the following data protection principles, which are set out in the General Data Protection Regulation 2016. In summary these state that patient's data shall:

- *Be obtained and processed fairly and lawfully and shall not be processed unless certain conditions are met. Therefore patient's information (including scans) should be made anonymous by an appointed radiotherapy staff (from the Head of section)*
- *Be obtained for a specified and lawful purpose and shall not be processed in any manner incompatible with that purpose.*
- *Be adequate, relevant and not excessive for those purposes (in the case of a study or audit).*
- *Be accurate and kept up to date.*
- *Not be kept longer than is necessary for that purpose*
- *Be processed in accordance with the data subject's rights.*
- *Be kept safe from unauthorized access, accidental loss or destruction.*
- *Not be transferred to any third party unlawfully.*

Generic Form Template Prepared By: Mr. Edward Falzon	Generic Form Template Reviewed By: Ms. Dorothy Aquilina	Issue Date:	Version 01
Generic Form Template Approved By: Dr Stefan Laspina	Authority of Issue:	Revision Date:	Page 3 of 3

Chief Nursing Officer

Approval for Research Study to be carried out at Palliative Care Unit at SAMOC
3 messages

Joseph Xuereb <joseph.xuereb.16@um.edu.mt>   12 August 2021 at 11:41
To: mario.hili@gov.mt
Cc: Joanna Depares <joanna.depares@um.edu.mt>, mandy.a.caruana@gov.mt

Dear Mr. Hili,

Good morning,

I am Joseph Xuereb, Master of Nursing student, requesting approval for a study to explore the lived experiences of palliative care nurses and their encounters with patient death. Please find attached the permission letter with the details about the study.

I am therefore asking your kind permission to be able to conduct the study.

In addition, I am requesting that for the recruitment period (which will happen between October and November), I will not be placed in the Palliative Ward, to minimize the risk of coercion.

Your support for this research is very much appreciated. While I thank you in advance, should you require further details regarding my study please feel free to contact me on 79219710.

Regards,
Joseph Xuereb

📄 **Permission Letter - Mr. Mario Hili.docx**
24K

Hili Mario at Health-SAMOC <mario.hili@gov.mt>   17 August 2021 at 16:19
To: Joseph Xuereb <joseph.xuereb.16@um.edu.mt>
Cc: Joanna Depares <joanna.depares@um.edu.mt>, Caruana Mandy A at Health-SAMOC <mandy.a.caruana@gov.mt>

Dear Joseph,

Your research study has been approved from my side. You may come collect a signed hard copy from my office.

Regards,

Mario

Mario Hili
Chief Nursing Manager
Administration
Health-Sir Anthony Mamo Oncology Centre

t +356 25452638   e mario.hili@gov.mt

MINISTRY FOR HEALTH

Human Resources Officer

Approval for Research Study to be carried out at Palliative Care Unit at SAMOC
3 messages

Joseph Xuereb <joseph.xuereb.16@um.edu.mt>
To: donna.b.micallef@gov.mt
Cc: Joanna Depares <joanna.depares@um.edu.mt>

12 August 2021 at 12:17

Dear Ms. Micallef,

Good morning,

I am Joseph Xuereb, Master of Nursing student, requesting approval for a study to explore the lived experiences of palliative care nurses and their encounters with patient death. Please find attached the permission letter with the details about the study.

I am therefore asking your kind permission to be able to conduct the study.

Your support for this research is very much appreciated. While I thank you in advance, should you require further details regarding my study please feel free to contact me on 79219710.

Regards,
Joseph Xuereb

📄 **Permission Letter - Ms. Donna Micallef.docx**
24K

Micallef Donna at Health-SAMOC <donna.b.micallef@gov.mt>
To: Joseph Xuereb <joseph.xuereb.16@um.edu.mt>
Cc: Joanna Depares <joanna.depares@um.edu.mt>

12 August 2021 at 16:39

Approved from my end. Copying in our data protection officer for his input.

Kind Regards,

Donna

Donna Micallef
HR & Administration Manager

SIR ANTHONY MAMO ONCOLOGY CENTRE

T +356 +356 25452636

E donna.b.micallef@gov.mt

Sir Anthony Mamo Oncology Centre, Triq id-Donaturi tad-Demm, l-Imsida, Malta, MSD 2090 | https://deputyprimeminister.gov.mt/en/MDH/Pages/Home.aspx | https://www.facebook.com/materdeihospital/

Think before you print.

Chief Executive Officer

L-Università ta' Malta

Approval for Research Study to be carried out at Palliative Care Unit at SAMOC
2 messages

Joseph Xuereb <joseph.xuereb.16@um.edu.mt>   24 August 2021 at 13:26
To: ceo.mdh@gov.mt
Cc: Joanna Depares <joanna.depares@um.edu.mt>

Dear Ms. Falzon,

Good morning,

I am Joseph Xuereb, Master of Nursing student, requesting approval for a study to explore the lived experiences of palliative care nurses and their encounters with patient death. Please find attached the permission letter with the details about the study.

I collected approval from cooperating disciplines: SAMOC chief nursing manager, SAMOC Clinical chairperson, and SAMOC HR Manager and from the Nursing and Midwifery director, and Data Protection Officer. Please find attached the mentioned approvals.

I am therefore asking your kind permission to be able to conduct the study.

Your support for this research is very much appreciated. While I thank you in advance, should you require further details regarding my study please feel free to contact me on 79219710.

Regards,
Joseph Xuereb

6 attachments

Permission Letter - Ms. Celia Falzon.docx
24K

Mr. Mario Hili.pdf
90K

Carmen D'Amato.pdf
105K

Dr. Nick Refalo.pdf
122K

Data Protection Approval Email.pdf
126K

Ms. Donna Micallef.pdf
93K

CEO at Health-MDH <ceo.mdh@gov.mt>   26 August 2021 at 08:18
To: Joseph Xuereb <joseph.xuereb.16@um.edu.mt>

Dear Mr Xuereb,

Kindly note that approval has been given by Ms Celia Falzon for you to conduct this study in line with applicable hospital protocols.

Regards

Carmen Farrugia
Personal Assistant To CEO

From: Joseph Xuereb <joseph.xuereb.16@um.edu.mt>
Sent: Tuesday, 24 August 2021 13:26
To: CEO at Health-MDH <ceo.mdh@gov.mt>
Cc: Joanna Depares <joanna.depares@um.edu.mt>
Subject: Approval for Research Study to be carried out at Palliative Care Unit at SAMOC

CAUTION: This email originated from OUTSIDE the Government Email Infrastructure. DO NOT CLICK LINKS or OPEN attachments unless you recognise the sender and know the content is safe.

[Quoted text hidden]

Data Protection Office

Approval for Research Study to be carried out at Palliative Care Unit at SAMOC

Data Protection at MDH <datapro.mdh@gov.mt>   24 August 2021 at 13:13
To: Joseph Xuereb <joseph.xuereb.16@um.edu.mt>
Cc: Young Sharon at Health-MDH <sharon.young@gov.mt>, Data Protection Approval Form at Health-MDH <dpaform.mdh@gov.mt>

Dear Mr Xuereb

On the basis of the documentation you submitted, from the MDH data protection point of view you have been cleared to proceed with your study titled ***The lived experiences of palliative care nurses and their encounters with patient death*** provided that you obtain approval from MDH CEO (ceo.mdh@gov.mt - please provide the relevant documents including Dr Nick Refalo's and Ms Carmen Damato's approval with this email).

- Your intermediary to approach potential participants is ***Ms Annabelle Magro Conti – Charge Nurse at the Palliative Care Unit SAMOC***
- Your potential participants are ***four nurses currently working in the palliative care unit SAMOC***

-

All data stored must be anonymized and in no way should you retain any personal details you obtain from your research and these should be destroyed at the end of your study and /or if any of your participants decides to withdraw. Remember that participants reserve the right to be forgotten.

Anonymisation and Data minimisation

Participant consent forms must be separated from the answered questionnaires / interview answers at source meaning that there will be no correlation between one and the other that will indicate how participants replied.

-

ALL data presented to your supervisors / tutors or examiners or any other personnel from UOM or anyone else must be already anonymized; meaning that you must not divulge to anyone the identity of your participants and / or how they replied. If any participant wants to enquire who may have accessed personal data for verification purposes (in exceptional circumstances), one may enquire by contacting you through the contact details included with the information letter and consent form.

Consent Criteria

This clearance does not allow viewing of medical records nor access to Health Information Systems since you haven't declared so in the consent form.

Since you haven't declared otherwise, all your participants must be reached and approached when physically at MDH grounds (by Ms Annabelle Magro Conti) and NOT via postal services, email, telephone or any other means. You cannot be handed any contact details of potential participants, otherwise consent would be bypassed and breach GDPR.

Potential participants must be approached by Ms Annabelle Magro Conti for invitation and not directly by you. You can approach only after they accept.

Personal identifiable data such as signed consent forms or pseudonym lists are not to be sent via email (not even relayed to yourself), replicated and/or uploaded in any server, cloud storage, site or any other media since participants will not consent any service provider to store their personal identifiable data.

Audio recordings must be strictly accessed and listened <u>only by you</u> (not even by your tutors, supervisors or any personnel from UOM/ FHS) and that all data (including transcripts) presented to UOM / FHS must be completely anonymised. Such recordings are not to be sent via email, replicated and/or uploaded in any server, cloud storage, site or any other media. Audio recordings must be destroyed after the conversation will be transcribed or if a participant decides to withdraw from your study.

If a transcription software will be used, it is in your responsibility to ensure that this is not connected online to any cloud or server and that such software operates in an offline mode. All cashed data and any other personal identifiable data should be immediately wiped out after the transcript is produced and anonymised.

Since you declared that only audio recordings will be carried out, you must ensure that the whole audio – visual stream is not recorded. (only audio).

Video recordings and photography are not allowed for this research.

Clarifications

This clearance does not cover ethical approval.

Your submitted documentation must remain unchanged.

This clearance does not allow patient contact.

What was declared during this clearance process is what you will abide to.

You must abide with all the articles of the GDPR (EU) 2016 / 679 throughout the data collection process and thereafter.

You are requested to submit a copy of your findings to this office at the end of your study.

Please communicate with Ms Annabelle Magro Conti before you start to present this clearance email.

To sign the data protection form, please contact Ms Graziella Aquilina through dpaform.mdh@gov.mt *to provide the following:*

1. *This clearance email in PDF –* to provide in PDF
2. *CEO's approval in PDF -* pending
3. *The name of the Chairperson and Director who approved your research –* Dr Nick Refalo and Ms Carmen Damato
4. *The period of data collection –* October 2021 – January 2022
5. *Title of your research -* The lived experiences of palliative care nurses and their encounters with patient death
6. *Your ID number, Dr Depares' (* joanna.depares@um.edu.mt) *and Mr Chircop's (*dchir02@um.edu.mt) *ID number -* pending

NB: Together with your supervisor (Dr Joanna Depares) and your co supervisor (Mr Daren Chircop) you must sign this form before you start

In summary – next step

1. Approval from MDH CEO through ceo.mdh@gov.mt
2. Together with your supervisor and your co supervisor to sign the Data Protection form at Ms Aquilina through dpaform.mdh@gov.mt (provide her the above six points)

Regards

Simon Caruana

Senior Manager (Compliance)

From: Joseph Xuereb <joseph.xuereb.16@um.edu.mt>
Sent: Tuesday, 24 August 2021 12:53 PM
To: Data Protection at MDH <datapro.mdh@gov.mt>
Subject: Re: Approval for Research Study to be carried out at Palliative Care Unit at SAMOC

Charge Nurse of the Palliative Ward/Intermediary Approval

Approval for Research Study to be carried out at Palliative Care Unit at SAMOC

3 messages

Joseph Xuereb <joseph.xuereb.16@um.edu.mt>   12 August 2021 at 11:43
To: annabelle.magro-conti@gov.mt
Cc: Joanna Depares <joanna.depares@um.edu.mt>

Dear Ms. Magro Conti,

Good morning,

I am Joseph Xuereb, Master of Nursing student, requesting approval for a study to explore the lived experiences of palliative care nurses and their encounters with patient death. Please find attached the permission letter with the details about the study.

I am therefore asking your kind permission to be able to conduct the study.

Your support for this research is very much appreciated. While I thank you in advance, should you require further details regarding my study please feel free to contact me on 79219710.

Regards,
Joseph Xuereb

📄 **Permission Letter - Ms. Annabelle Magro Conti.docx**
24K

Magro Conti Annabelle at Health-SAMOC <annabelle.magro-conti@gov.mt>   12 August 2021 at 13:56
To: Joseph Xuereb <joseph.xuereb.16@um.edu.mt>
Cc: Joanna Depares <joanna.depares@um.edu.mt>

Dear Mr Xuereb,

Don't worry. I will do my best to facilitate your study and will contact all your potential participants.

Kind regards,

Annabelle

Annabelle Magro Conti
Charge Nurse

SIR ANTHONY MAMO
ONCOLOGY CENTRE

T +356 +356 25452496

E annabelle.magro-conti@gov.mt

Sir Anthony Mamo Oncology Centre, Triq id-Donaturi tad-Demm, l-Imsida, Malta, MSD 2090 | https://deputyprimeminister.
gov.mt/en/MDH/Pages/Home.aspx | https://www.facebook.com/materdeihospital/

Appendix I: Counsellor Agreement Letter

Dr. Benna Chase

Clinical Support Services

Sir Anthony Mamo Oncology Centre

Msida

7th August 2021

Request to offer psychological help if required by any participants in a research study in the Palliative Care Unit at the Sir Anthony Mamo Oncology Centre

Dear Dr Benna Chase,

My name is Joseph Xuereb, and I am a student at the University of Malta reading a Master of Nursing degree. As part of this degree, I am required to conduct a research study which I intend to explore the lived experiences of palliative care nurses and their encounters with patient death, with a focus on how regular experiences of patients' deaths affects palliative care nurses. This project is being conducted under the supervision of Dr. Joanna Depares and co-supervised by Mr. Daren Chircop.

I am hereby seeking your counselling services, if any is required from the participants in this research. This research will include a sample of not more than 4 nurses currently working in the palliative care unit at the Sir Anthony Mamo Oncology Centre. The selected participants will be registered nurses with more than six months' experience in an inpatient palliative care setting. Data will be collected through two separate in-depth interviews, with the first one lasting approximately 60 minutes, and the second one lasting approximately 30 minutes. If the participants have no objections, the said interviews will be audio-recorded. The interviews will take place at a time and place of convenience to the participant, either face to face or online, according to the participant's preference. In the event that the interview is done online, the participant will have a choice to either turn on or keep the camera off throughout the interview. In case of the former, only the audio of the interview will be recorded and saved to the computer, and not to the cloud. Each participant will be interviewed on two different occasions. It is anticipated that the data will be collected approximately between the months of October 2021 and January 2022. Qualifying participants will be approached by an intermediary, Ms. Annabelle Magro Conti, who is the current Nursing Officer of the palliative care unit at the Sir Anthony Mamo Oncology Centre, where she will provide a participant information sheet, which will include details regarding the present study. In this way, I will not be aware of the participants who were approached and, additionally those individuals who declined to participate.

Informed consent will be acquired by myself from the participants, after explaining what participation will entail. Participation will be entirely voluntary, and participants will be free to withdraw at any point, without any negative repercussions. Data collected will be solely used for research purposes and the participants will only be asked to share data that is necessary for the research. Their identity will not be noted on transcripts, audio-recordings or notes from the interviews, but instead, a code will be assigned. The codes that link the participants data to their identity will be stored securely and separately from the data, in an encrypted file on the researcher's password-protected computer. Supervisors and examiners will typically have access to coded data only. There may be exceptional circumstances which allow the supervisor and examiners to have access to personal data too, for verification purposes. Any material that identifies the participant as a participant in this study will be stored securely for the duration of the study. All data collected will be erased on completion of the study and following publication of results. Extracts from the interviews may be reproduced in these outputs, either in anonymous form, or using a pseudonym. Names or identifiable characteristics of the participants will not be published or shared with any third parties. The participants will have the right under the General Data Protection Regulation (GDPR) and national legislation that implements and further specifies the relevant provisions of said regulation, to access, rectify and where applicable ask for the data concerning you to be erased.

Should you require further information, please do not hesitate to contact me on 79219710 or by email joseph.xuereb.16@um.edu.mt, or my supervisor Dr. Joanna Depares on 2340 1840, or by e-mail joanna.depares@um.edu.mt.

Thank you for your kind consideration of this request.

Sincerely,

| Joseph Xuereb | Dr. Joanna Depares | Mr. Daren Chircop |
| Master of Nursing Student supervisor | Research Supervisor | Research co- |

L-Università ta' Malta

Request to offer psychological in a research study carried out in PCU at SAMOC

2 messages

Joseph Xuereb <joseph.xuereb.16@um.edu.mt>   9 August 2021 at 08:00
To: benna.chase@gov.mt

Dear Dr. Benna Chase,

Hope this email finds you well.

As discussed over the phone, please find attached the request for your services at SAMOC, and details about a research study that I will be carrying out as part of my Master of Nursing degree.

Would it be possible to provide me with the contact details on which any participants requiring your services can contact you?

Thanks in advance,
Joseph Xuereb

📄 **Counseller Permission.docx**
24K

Chase Benna at Health-SAMOC <benna.chase@gov.mt>   11 August 2021 at 13:30
To: Joseph Xuereb <joseph.xuereb.16@um.edu.mt>

Dear Joseph

Participants of your study can make use of the services of the Psychological department at SAMOC.

They can contact us in person, through the phone number below, or by sending an e-mail to this e-mail address.

Regards

Benna chase

Dr Benna Chase

Principal Psychologist

Sir Anthony Mamo Oncology Centre

Malta