

The Experiences of Critical Care Nurses Providing End-of-Life Care in the ICU

By

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

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Abstract

Background: Within the intensive care unit (ICU), where technology and cure prevail, nurses frequently accompany patients through dying and death. Providing end-of-life care (EOLC) in this curative environment requires reconciling technical proficiency with compassion and ethical sensitivity. Yet, compared with palliative settings, limited evidence explores how ICU nurses themselves make sense of this experience.

Aim: To explore and interpret the lived experiences of ICU nurses providing EOLC to critically ill patients in a Maltese tertiary care hospital.

Design and Methods: A qualitative study grounded in Interpretative Phenomenological Analysis (IPA) and informed by the Relational Ethics Framework (Bergum & Dossetor, 2005) was undertaken. Four experienced ICU nurses were purposively sampled. Semi-structured interviews were audio-recorded, transcribed verbatim, and analysed through iterative interpretative cycles consistent with IPA principles.

Results: Four Group Experiential Themes (GETs) were identified: (1) *Shaping the dying process*, advocacy and facilitation of a “good death”; (2) *Carrying the weight of end-of-life care*, emotional and psychological burdens moderated by diverse coping strategies; (3) *Care beyond the patient*, supporting families through communication and presence; and (4) *End-of-life care in a curative space*, ethical practice constrained by the ICU’s technological and institutional culture. Collectively, these themes reveal how nurses strive to humanise dying and uphold dignity and personhood despite systemic and emotional challenges.

Conclusion and Implications: The interpretative findings of this study reveal how ICU nurses strive to honour the human experience of dying in a setting designed for cure, upholding dignity and personhood through advocacy, emotional presence and relational engagement while navigating hierarchical and systemic constraints. Caring for dying patients and families was experienced as both deeply meaningful and emotionally demanding, highlighting the need for structured education, clear EOLC guidelines, and accessible psychological support. Embedding relational ethics principles into training, interprofessional collaboration, and institutional policy can strengthen compassionate communication, moral resilience, and workforce wellbeing, thereby sustaining high-quality, person-centred EOLC within technologically intensive settings.

Keywords: end-of-life care; intensive care; critical care nursing; lived experience; qualitative research, phenomenology.

Dedication

I dedicate this dissertation to ICU nurses, in recognition of their exceptional dedication and care.

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List of Abbreviations and Acronyms

ACP – Advanced Care Planning

AD – Advanced Directives

CASP - Critical Appraisal Skills Programme

COREQ - Consolidated Criteria for Reporting Qualitative Research

CRRT – Continuous Renal Replacement Therapy

EOLC – End-of-Life Care

EOLCDM – End-of-Life Care Decision Making

FATCOD - Frommelt Attitude Toward Care of Dying Scale

GET – Group Experiential Theme

HCP – Healthcare Professional

ICU – Intensive Care Unit

IPA – Interpretative Phenomenological Analysis

ITU – Intensive Therapy Unit

JBI – Joanna Brigs Institute Checklist

MAPHM – Malta Association of Public Health Medicine

MeSH – Medical Subject Heading

PEO – Population, Exposure, Outcome

PET – Personal Experiential Theme

PTSD – Post Traumatic Stress Disorder

SCS - Self-Compassion Scale

STS – Secondary traumatic stress

UoM- University of Malta

Chapter I

Introduction

1.1 Introduction

This chapter situates the study within contemporary intensive care nursing and end-of-life care (EOLC), clarifies the research aim and objectives, and explains its significance. It concludes with a brief overview of the methodological approach and the dissertation structure.

1.2 Background

Critical care, also referred to as intensive care, is a specialized type of care focusing on providing comprehensive care to patients with life-threatening conditions (Christensen & Liang, 2023). These patients typically have severe and complex illnesses and injuries that require close monitoring and aggressive treatment (Wenham & Pittard, 2009). This type of care is provided in critical care settings such as the intensive care unit (ICU) or as is also known locally, intensive therapy unit (ITU). Other critical care settings include the accident and emergency unit, coronary care units, high dependency units and operating theatres. However, this study focused exclusively on the care provided within the ICU.

Patients in the ICU often suffer from severe infection, traumatic injuries, complications from surgeries or organ failure. These patients are at high risk of rapid deterioration and require life-supporting interventions that support or replace failing body functions. The ICU is equipped with advanced medical technologies such as mechanical ventilators, continuous renal replacement therapy (CRRT) machines and invasive monitoring devices with the aim of stabilizing patients' condition, preventing further deterioration and supporting recovery (Wenham & Pittard, 2009).

Although ICU care is oriented toward sustaining life, death remains common due to illness severity and unpredictable treatment responses (Stokes et al., 2019). Indeed, mortality rates in the ICU are among the highest across hospital departments.

Reported ICU mortality ranges widely across regions. In a multinational European cohort study, the ICU mortality rate ranged from 6% to 27% (Capuzzo et al., 2014). Locally, the study setting ICU recorded 14% in 2020 which saw an increase to 16% in 2021–2022 during the COVID-19 period (Clinical Performance Unit, 2024). These patterns position EOLC as routine ICU practice rather than an exception, amplifying nurses' ethical, communicative, and emotional workload.

Given the common occurrence of death in the ICU, the role of the critical care nurse shifts from providing actions to sustain life to EOLC (Utami et al., 2020). EOLC specifically addresses the needs of patients, who are nearing the end of their life due to severe trauma or illness, and their families. EOLC focuses on ensuring comfort, dignity and quality of life to patients and their families during their final days (Rome et al., 2011). Latour et al. (2009) define EOLC as the care and supportive services given to a patient with advanced disease or trauma, and their family, after the difficult decision to withdraw or withhold treatment is taken. Withholding treatment refers to the decision not to initiate a medical intervention or life-sustaining treatment when it is deemed unlikely to benefit the patient. Withdrawal of treatment involves discontinuing a medical intervention that has already been started when it is determined that continuing treatment no longer serves the patients' best interest or aligns with the patients' wishes (Noome et al., 2016). An increasingly ageing population with complex comorbidities and unprecedented health crises such as global pandemics, have increased the demand for intensive medical treatment within the ICU along with an inevitable increase in ICU mortality rates, making EOLC a part of daily clinical practice within critical care (Noome et al., 2016).

A survey by the European Federation of Critical Care Nurses on intensive care nurses' attitudes towards EOLC found that 91.8% of nurses reported being directly

involved in providing EOLC (Latour et al., 2009). Indeed, nurses are among the main providers of EOLC for their patients and their families, being constantly present at the bedside and spending complete shifts with the patient and their families during the dying process (Holmes et al., 2014). Critical care nurses' experiences providing EOLC in the ICU are multifaceted and deeply impactful. Once the difficult decision is made to transition from curative to comfort care, nurses are committed to upholding the principles of patient-centred care and alleviating suffering for patients and families facing this difficult ordeal (Pan et al., 2023). Literature has however emphasized the challenges nurses face in providing quality EOLC in critical care, including poor communication between healthcare providers and families, lack of structured support for distressing situations, limited time for family engagement, insufficient education and training in EOLC, and the ICU's technological focus, which may prolong suffering and prevent dignified deaths (Korsah & Schmollgruber, 2023; Ozga et al., 2020). Despite these shortcomings, nurses strive to provide compassionate, holistic care that respects each patient's individual preferences and values. Giving patients and their families a comforting, peaceful and dignified death through high quality EOLC has been viewed by nurses as a rewarding experience (Vanderspank-Wright et al., 2011).

However, the provision of EOLC can also be emotionally and ethically challenging for critical care nurses. Indeed, witnessing the suffering and deterioration of patients, particularly those who are unable to communicate their wishes, can take a toll on nurses' emotional and psychological well-being (Peters et al., 2013). The shift from life-sustaining measures to EOLC can be a distressing experience for healthcare professionals (HCPs), leading to EOLC within the critical care setting to be

perceived as a failure (Efstathiou & Walker, 2014). While nurses play a crucial role in facilitating positive and meaningful end-of-life experiences for both patients and families, nurses encounter difficulty in this role. Nurses have reported difficulty separating their professional role from their personal feelings during these demanding times, resulting in feelings of anxiety, frustration, and emotional exhaustion (Ryan & Seymour, 2013). Elpern et al. (2005) reported that managing EOLC can also negatively impact the professional well-being of ICU nursing staff, resulting in reduced job satisfaction, increased risk of burnout, and potentially contributing to nurses exiting the challenging work environment. Seeing how nurses are the primary caregivers responsible for delivering direct care and dedicating the most time to patients and their families, employing their own coping strategies and receiving the necessary support is crucial (Ozga et al., 2020).

1.3 Purpose of the Study

Despite relatively high mortality rates in ICUs, there is a paucity of information about ICU nurses' experiences of providing EOLC, particularly in comparison with nurses working in specialised palliative care settings (Utami et al., 2020). Although substantial literature exists on EOLC in nursing, most studies have focused on nurses' knowledge, perceived competencies, or attitudes rather than their lived experiences of providing EOLC within the complex ICU setting.

Understanding the lived experiences of ICU nurses who care for patients and their families at the end of life provides valuable insights into the emotional, ethical, and relational dimensions of this care (Stokes et al., 2019). Exploring these experiences offers a deeper understanding of how nurses strive to achieve what they perceive as a “good death” amid the pressure of critical care, balancing professional responsibilities with personal emotions, communicating with grieving families and

employing coping strategies to sustain their own well-being (Kiziltepe & Koc, 2021).

The key research question for this study is: *“What are the lived experiences of critical care nurses providing end-of-life care to patients in the local intensive care unit?”*

This study aims to explore and interpret the lived experiences of critical care nurses as they provide end-of-life care to patients in the intensive care unit.

The study objectives are:

- To explore and interpret how critical care nurses make sense of providing EOLC in the ICU;
- To gain insight into the emotional and psychological effects of EOLC on critical care nurses;
- To understand critical care nurses’ relationships and communication with families of patients at the end of life;
- To explore the coping strategies in which critical care nurses engage in to cope with providing EOLC;
- To explore how critical care nurses perceive and experience the need for support when providing end-of-life care.

1.4 Significance and Contribution of the Study to Nursing

As the population continues to age and medical technologies advance, the number of patients and the severity of their conditions in the ICU is rising, leading to an inevitable increase in mortality rates (Akinosoglou et al., 2022). Understanding the essence and meaning of caring for the dying patient in the ICU and exploring the experiences of critical care nurses could deepen the understanding of the dying

process in the critical care setting and facilitate a dignified death within this complex environment (Stokes et al., 2019). Despite this however there seems to be a critical gap in the literature available pertaining to ICU nurses' personal experiences.

Exploring the experiences of nurses caring for dying patients in the ICU holds significant clinical relevance and importance, helping to fill this gap.

Firstly, nurses are frontline caregivers who often witness the trajectory of patients' illnesses, including death (Utami et al., 2020). The emotional weight of caring for a dying patient, especially in an environment typically focused on recovery, can be overwhelming. Understanding their experiences of providing EOLC can provide valuable insights into the emotional, psychological, and ethical challenges nurses encounter in their role (Wells & Bressler, 2023). This can help identify sources of stress, burnout, and moral distress, as well as resilience factors that enable nurses to cope effectively with the emotional demands of caring for a dying patient (Hinderer, 2012). This understanding can inform the development of supportive interventions and resources to promote quality EOLC and nurses' well-being in coping with this demanding aspect of nursing care, ultimately supporting the imperative of creating and sustaining a healthy work environment.

The ICU setting presents unique challenges in providing EOLC. Indeed, the availability of life-sustaining technologies in the ICU complicates EOLC, since these technologies can prolong life even when recovery is unlikely. Exploring nurses' experiences can shed a light on how nurses perceive and manage this technological influence which can help with improving care practices and ensuring the ethical and compassionate use of technology (Price, 2013). Moreover, insights into the emotional and practical challenges nurses face can help inform and improve nursing

education and training programmes, ensuring that nurses are better prepared for the complexities associated with EOLC in the critical care setting.

Nurses play a key role in communicating with families during end-of-life situations. Therefore, understanding nurses' experiences in interacting with families can provide valuable insights into the challenges, emotions, and communication dynamics that arise in this sensitive context (Conte et al., 2023). This understanding can inform the development of strategies and interventions to enhance communication, support, and collaboration between HCPs and families, ultimately improving the overall experience for both parties (Fox, 2014). To the researcher's knowledge, locally very little research has been conducted in this field. A local study conducted in 2022 employed a mixed methods design to examine ICU nurses' and physicians' perceptions and understandings of integrating palliative care into critical care practice (Faenza et al., 2022). This current dissertation, to the best of the researcher's knowledge, is the first qualitative study in Malta focusing specifically on ICU nurses' lived experiences of EOLC and the meanings they attribute to caring for dying patients. Therefore, exploring nurses' lived experiences will help provide culturally relevant findings, addressing existing gaps in literature and enabling evidence-based identification of strategies to improve the experiences for nurses, patients and families.

1.5 Overview of the Research Methodology

This study explored and interpreted the lived experiences of critical care nurses who provide EOLC to patients in the ICU. Since experiences are inherently subjective and context-bound, a qualitative design was considered most appropriate to capture the depth, complexity, and meaning of these personal accounts, that quantitative

approaches, focused on hypothesis testing and numerical analysis, cannot adequately reveal (Denzin & Lincoln, 2011).

A phenomenological approach was adopted to focus on understanding human experiences as it is lived and perceived. Interpretative Phenomenological Analysis (IPA) was selected to guide the study's methodological framework, as it emphasises the interpretation of participants' sense making processes and the essence of their experiences (Smith et al., 2022). This approach enabled an in-depth engagement with each participant's narrative and supported a nuanced interpretation of how nurses constructed and understood their experiences of caring for dying patients.

Given the sensitivity of the topic, individual semi-structured interviews were used to create a private and supportive environment that facilitated open reflection.

Interviews were audio recorded, transcribed verbatim, and analysed according to the stages of IPA as described by Smith et al. (2022).

1.6 Researcher's Positionality

My decision to pursue this area of study was influenced by a personal experience of EOLC in the ICU as a relative which brought to light the emotional weight and complexities of dying in a highly technological setting. This experience, together with a long-standing professional interest in EOLC led me to explore nurses' perspectives and how they themselves make sense of caring for dying patients.

As a surgical nurse for the past five years, my professional background has focused on intervention and postoperative recovery, with the primary goal being to preserve life. This background left me with the assumption that nurses in the ICU experienced EOLC as a straightforward and routine aspect of care given their constant exposure to acuity and life-sustaining interventions. However, upon extensive reading I

realised that I had underestimated the ethical, emotional and relational complexities of providing EOLC in the ICU.

Through reflexive practice, I remained attentive to how my own cure-oriented background and assumptions could influence my interpretation of participant experiences. Moreover, being a nurse myself afforded me a sense of shared understanding and empathy, allowing me to connect with participants' emotional realities while remaining mindful to allow the analysis to be guided by the participants' lived experiences. Therefore, reflexivity was central in helping me recognise any preconceived ideas, helping me to stay open to participants' meanings and respect the depth of their narratives.

1.7 Outline of Dissertation Structure

This dissertation is organised into six chapters. Chapter 2 presents a critical review and synthesis of the literature on nurses' experiences of providing EOLC in the ICU. Chapter 3 outlines the research methodology adopted to address the study's aim and objectives. Chapter 4 reports the findings derived from the data analysis, while Chapter 5 discusses these findings in relation to existing literature and highlights the study's strengths and limitations. Finally, Chapter 6 concludes the dissertation by summarising the key findings and offering recommendations for future research, education and clinical practice.

1.8 Conclusion

In summary this chapter provided a background and rationale for exploring ICU nurses' EOLC experiences together with the study aim and objectives and its significance. The next chapter critically appraises current evidence to locate the study within the existing literature.

Chapter II

Literature Review

2.1 Introduction

This chapter provides an in-depth review of the relevant literature exploring critical care nurses' experiences providing EOLC to adult patients in an intensive care unit.

Firstly, a comprehensive description of the systematic search conducted to obtain pertinent literature is presented. A critical appraisal and discussion of the findings of the retrieved studies follow this description.

2.2 Literature Search

A comprehensive literature search was systematically conducted. This approach enhanced transparency and reduced the risk of selection bias. The following section provides a detailed account of the search strategy, starting with the identification of the keywords and their synonyms, selection of appropriate databases, establishment of eligibility criteria, and the search process.

2.2.1 Keywords and Synonyms

The key terms related to the population, exposure and outcome (PEO) elements of the research question were identified. Alternative synonyms and phrases were derived to broaden the search, ensuring that no relevant literature was missed. Different synonyms were identified by utilising an English thesaurus, Medical Subject Headings (MeSH) and reading related literature. Boolean logistic operators were utilised to refine and control the searches. The Boolean logistic operator "AND" was applied to combine different search terms, narrowing the search by retrieving results that included all the specified terms. The Boolean logistic operator "OR" was applied between the different search terms, expanding the search by retrieving results that included any of the specified terms. The truncation symbol asterisk (*) was added at the root of some keywords in order to broaden the search and retrieve literature that contained different variations of the same word. For example, by adding the truncation to the word nurs*, literature containing the words

“nurse”, “nurses” or “nursing” is retrieved. Table 2.1 presents the keywords related to the PEO elements and their synonyms. These keywords were combined using the Boolean operators and searched in the selected databases as depicted in Table 2.2.

Table 2.1- PEO Elements and Synonyms

| <i>PEO Elements</i> | <i>Keywords</i> | <i>Synonyms/phrases</i> |
|---------------------|----------------------|---|
| Population | Critical care nurses | Intensive care nurs*, ICU nurs*, Intensive therapy unit nurs*, ITU nurs*, Critical care unit nurs*, CCU nurs* |
| Exposure | End-of-life care | End of life care, EOLC, EOL care, terminal care, palliative care, care for dying |
| Outcome | Lived experiences | Life experiences, personal experiences, perceptions, attitudes, views, beliefs, feelings, emotions |

Table 2.2 - Keyword Combinations

| |
|---|
| <p>(“Intensive care nurs*” OR ICU nurs* OR “intensive therapy unit nurs*” OR ITU nurs* OR “Critical care nurs*” OR “critical care unit nurs*” OR CCU nurs*)</p> <p>AND</p> <p>(“end of life care” OR “end-of-life-care” OR EOLC OR EOL care OR “terminal care” OR “palliative care” OR “care for dying”)</p> <p>AND</p> <p>(Experience* OR “lived experiences” OR “life experiences” OR “personal experiences” OR perception* OR perspective* OR attitude* OR view* OR belief* OR feeling* OR emotion*)</p> |
|---|

2.2.2 Databases

An extensive search to identify existing published literature was conducted using multiple databases accessible through the University of Malta (UoM) online library portal. In total 10 different databases were accessed through EBSCO, a search platform accessed through the UoM library which allows access to multiple databases. These included Academic Search Ultimate, AgeLine, CINAHL Complete, Cochrane Central Register of Controlled Trials, Cochrane Clinical Answers, Cochrane Database of Systematic Reviews, Cochrane Methodology Register, MEDLINE Complete, APA, PsycINFO and eBook Collection (EBSCOhost).

Separate literature searches were also conducted on PubMed, Medline (ProQuest) and Scopus databases since these are renowned databases offering a wide range of peer-reviewed

literature concerning medicine, nursing, healthcare administration, life sciences, social sciences and arts and humanities. The reference lists and citations of included articles were screened for any other relevant literature that may have been missed through the electronic search. The Hybrid Discovery (HyDi) platform (UoM) and the Google Scholar search engine were instrumental in finding the full text of articles when these were not available on the databases searched.

2.2.3 Eligibility Criteria

This review sought to systematically search for and review pertinent evidence on critical care nurses' experiences of providing EOLC in the ICU. Eligibility criteria serve to ensure that retrieved literature is directly relevant to the research question and aim (Hulley et al., 2007). Studies exploring the experiences of critical care nurses when providing EOLC were therefore included. Studies solely exploring the experiences of patients, family members, nursing students or other healthcare providers were excluded, since the population of interest for this study was critical care nurses. Moreover, included studies had to focus on the experiences nurses have when providing EOLC to adult patients in the ICU, thus excluding studies concerned with nurses providing EOLC to any other patient population in settings other than the adult ICU. Paediatric EOLC represents a distinct and specialised concept. The author determined that including both adult and paediatric patient populations may diminish the focus of the study, potentially impeding the comprehensive capture of nurses' experiences in either area. Studies included in this review had to be available in English, since it is the language with which the author is most proficient, and had to have been published in the last decade, between 2014 and 2025, both years included. This time limit was implemented to include the most contemporary research on the topic and to maintain a manageable number of studies

included in this literature review. Applying recent time limits is recommended in literature reviews to ensure relevance to current clinical practice (Boland et al., 2017). Grey literature was screened for contextual awareness since it is a valuable supplementary source of information, however it was not included in the final evidence synthesis as the eligibility criteria intentionally restricted the review to peer-reviewed studies to ensure methodological rigour. Table 2.3 summarises the inclusion and exclusion criteria applied.

Table 2.3: Inclusion and Exclusion Criteria

| Inclusion Criteria | Exclusion Criteria |
|---|---|
| <ul style="list-style-type: none"> Literature available in the English language | <ul style="list-style-type: none"> Literature published in any other language |
| <ul style="list-style-type: none"> Peer-reviewed published academic literature, i.e., systematic reviews, meta-analysis, qualitative studies, quantitative studies | <ul style="list-style-type: none"> Non-peer reviewed, non-academic literature. |
| <ul style="list-style-type: none"> Studies exploring the experiences of critical care nurses providing EOLC to adult patients | <ul style="list-style-type: none"> Studies concerning the experiences of patients, family, nursing students, physicians or any other healthcare providers |
| <ul style="list-style-type: none"> Studies focusing on EOLC in the adult ICU | <ul style="list-style-type: none"> Studies focusing on EOLC in other healthcare settings (e.g., neonatal/paediatric critical care units, medical/surgical units, oncology units, accident and emergency units) |
| <ul style="list-style-type: none"> Studies exploring nurses' experiences, attitudes, perceptions of EOLC in the ICU | <ul style="list-style-type: none"> Studies exploring nurses' knowledge related to EOLC (not experiences) |

2.3 The Search Process

The limiters and search fields were adjusted throughout the search according to each database. The following sections provide a detailed description of the search conducted on each database.

2.3.1 Search on EBSCOhost

Using the advanced search option, the keyword combinations presented in Table 2.2 were searched. The initial search yielded 12,912 results without any limiters applied. To refine the results, limiters were implemented to include only peer-reviewed articles in English pertaining to adults. Furthermore, the search was restricted to include results published from 2014 to 2025 to encompass the most recent relevant literature. These limiters resulted in 621 results. Despite the application of limiters, the researcher noted a number of studies that were neither related to EOLC in the intensive care setting nor to critical care nurses. Therefore, to further refine the search, the subject field was modified from 'All text' to 'Abstract' to yield studies containing the key terms in the abstract, reducing the number of results to 484.

Following the automatic removal of duplicates, the title and abstract of the remaining articles were screened, resulting in 55 relevant articles. The full text of these articles was assessed for eligibility against the inclusion and exclusion criteria. Forty-five articles were excluded, with the remaining 10 studies retained for further appraisal.

2.3.2 Search on PubMed

The same combinations of keywords used in the previous search were used to conduct a search on the PubMed database. The *English language*, *Humans* and *Adults (19+ years)* limiters were applied to refine the search. A time frame to include studies published from 2014 to 2025 was also applied, yielding 364 results.

Following a screening of the title and abstract, 347 results were deemed irrelevant. The full text of the remaining 17 articles was assessed for eligibility, yielding 10 relevant studies, 8 of which were already retrieved from the previous search on EBSCO. Therefore, two other studies were retrieved for further appraisal from this search.

2.3.3 Search on Medline (ProQuest)

The search for literature proceeded on the Medline (ProQuest) database. After applying filters for peer-reviewed articles, human population and a specified publication date range (2014-2025), 111 records resulted. The titles and abstracts were screened, resulting in one relevant study that had already been retrieved from previous searches; thus, this search yielded no new studies.

2.3.4 Search on Scopus

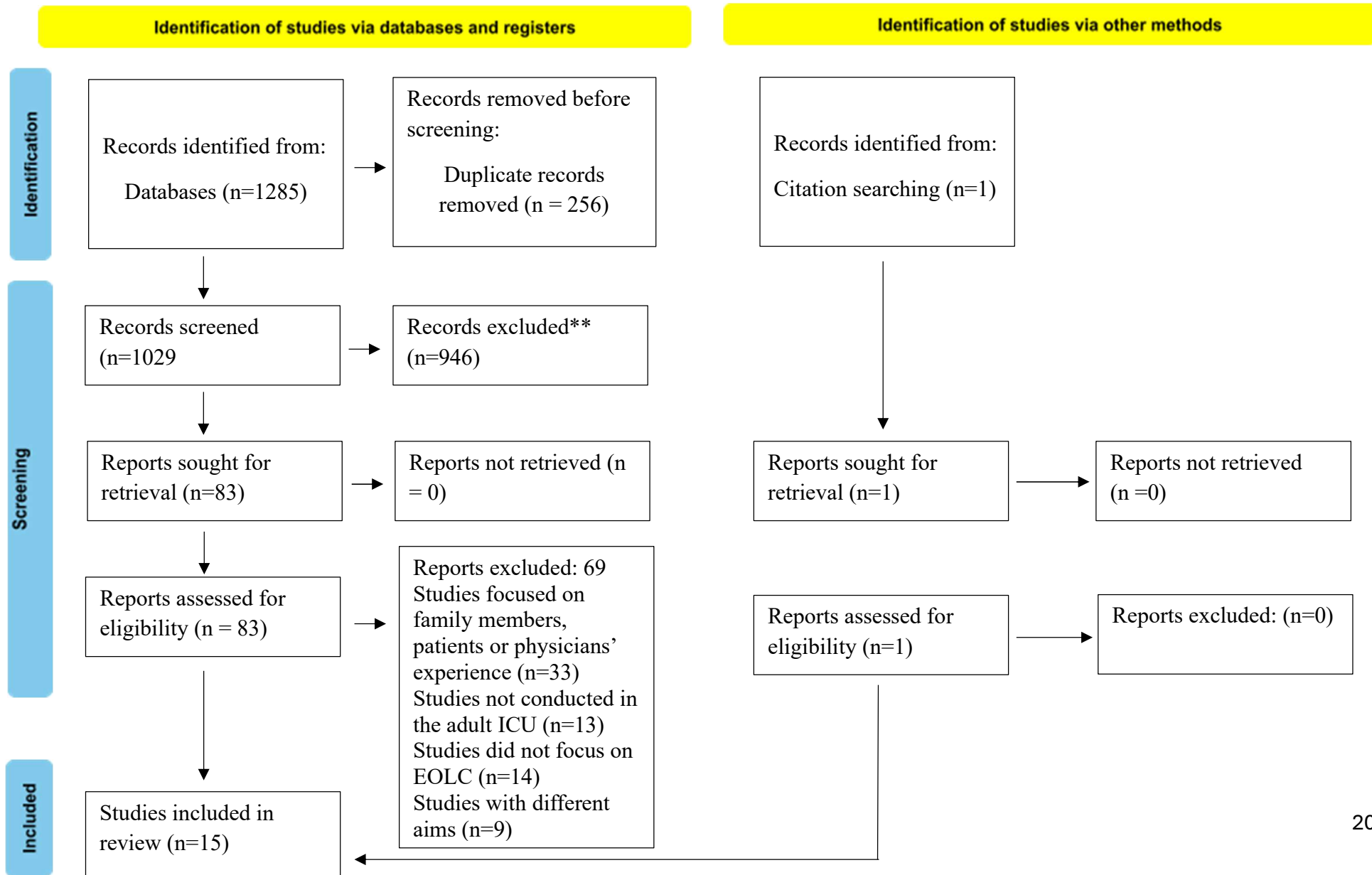
A final advanced search was carried out on Scopus. The English language and date range filter were applied. Moreover, the field searched was set to Title/Abstract to narrow down the search to studies that contain the keywords in the title and abstract, resulting in 326 records. Titles and abstracts were screened, yielding 10 potentially relevant studies. Following screening of these studies, three of them had been retrieved from previously searched databases, and five were excluded as they investigated a different population or environment, resulting in two new studies being included in the literature review

2.3.5 Summary of Literature Search

The search for relevant literature yielded a total of 1285 records. From these, 256 duplicate records were removed, and screening the remaining 1029 records based on their title and abstract removed 946 records, which were deemed irrelevant. The full text of the remaining 83 studies were assessed for eligibility according to the

inclusion and exclusion criteria. A further 69 studies were excluded based on the following criteria: 33 studies did not focus solely on nurses' experiences but included other healthcare providers' or family members' and patients' experiences; 13 studies were conducted in a setting other than the adult ICU, namely in the paediatric ICU or medical/surgical wards; 14 studies focused on nurses' experience of providing general care in the ICU setting; and the remaining 9 studies focused on different aspects of the subject which were beyond the scope of this study, specifically nurses' knowledge on EOLC rather than their experiences. A manual search of the reference lists and citations of relevant studies resulted in the retrieval of an additional study meeting the inclusion criteria. In total, 15 studies met the eligibility criteria. Figure 2.1 depicts the PRISMA flow diagram, summarising the selection process for this review.

Figure 2.1 PRISMA flow diagram. (Page et al., 2021)



2.4. Critical Appraisal of Key Studies

Critical appraisal is a process involving the systematic evaluation of a research study's methodology, data analysis, and results to determine their validity, relevance, and quality (Crombie, 2022). Critical appraisal enables the identification of potential biases and methodological limitations, allowing researchers to evaluate whether the study's conclusions are well-supported and applicable to real-world situations (Todd et al., 2021). Moreover, critically appraising literature helps prevent the adoption of flawed findings, supports evidence-based practice and ensures that clinical and policy recommendations are based on the best available evidence (Mhaskar et al., 2009).

2.4.1. Critical Appraisal of Qualitative Studies

To appraise the retrieved qualitative studies, the Critical Appraisal Skills Programme (CASP) tool for qualitative studies was applied (CASP, 2024). This structured checklist consists of 10 questions that guide the researcher in assessing key aspects of the study, including its aims, methodology, data collection and analysis, rigour and relevance (CASP, 2024). The following section presents the critical appraisal of the qualitative studies included in this literature review. Table 2.4 summarises the main characteristics of these studies.

Table 2.4 - Characteristics of Retrieved Qualitative Studies

| Author, Year and Country | Title of study | Purpose of the study (main aim) | Study design | Population and Sample Method | Data collection | Data analysis |
|--|--|---|-------------------------------------|--|---|---|
| Alanzi, 2024, Saudi Arabia | Intensive care unit nurses' experiences in caring for end-of life patients in Saudi Arabia: A qualitative study | To explore ICU nurses' experiences in providing EOLC in Saudi Arabia | Phenomenological descriptive design | 10 ICU nurses at a tertiary teaching hospital in SA Purposive/convenience sampling method | Semi-structured interviews | Thematic analysis adhering to Braun and Clarke guidelines |
| Arianto et al., 2022, Indonesia | Nurses' experiences of ethical dilemmas in end-of-life care in the Intensive care unit | To explore the ethical dilemmas experienced by nurses providing EOLC in the ICU | Phenomenological design | 8 ICU nurses (where from not specified) Purposive sampling | In-depth interviews (1 to 2 interviews per participant) | Colaizzi method approach |
| Bilal et al., 2022, Pakistan | Nurses' experiences in end-of-life care in an intensive care unit at a tertiary healthcare setting, Lahore | To explore nurses' experiences in EOLC in the ICU | Phenomenological descriptive design | 10 ICU nurses at a tertiary care hospital, Lahore Purposive sampling | Semi-structured interviews | Thematic analysis adhering to Braun and Clarke guidelines |
| Efstathiou & Walker, 2014, UK | Intensive care nurses' experiences of providing end-of-life care after treatment withdrawal: A qualitative study | To explore the experiences of intensive care nurses who provided EOLC to adult patients and their families after treatment withdrawal | Descriptive exploratory design | 13 intensive care nurses at a university ICU facility Purposive sampling | Semi-structured interviews | Interpretive phenomenological analysis (IPA) |

| Author, Year and Country | Title of study | Purpose of the study (main aim) | Study design | Population and Sample Method | Data collection | Data analysis |
|---|--|---|-------------------------|---|--|--|
| Endacott et al., 2016, Israel/UK | Perceptions of a good death. A qualitative study in intensive care units in England and Israel | To identify factors that nurses perceive to contribute to a good death and quality of ICU EOLC in England and Israel | Not specified | 55 intensive care nurses from 3 general ICUs in England and 4 ICUs in Israel Purposive sampling | Semi-structured individual interviews and focus group interviews | Thematic analysis adhering to Braun and Clarke guidelines |
| Holms et al., 2014, Scotland | A study of the lived experiences of registered nurses who have provided end-of-life care within an intensive care unit | To explore the lived experiences of ICU nurses who have provided EOLC to dying patients and their family within the ICU | Phenomenological design | 5 intensive care nurses from one general ICU Purposive sampling/ Non-probability convenience sampling | Semi-structured interviews | Thematic analysis adhering to Burnard's 14-step framework (1991) |
| Jang et al., 2018, South Korea | Exploring nurses' end-of-life care for dying patients in the ICU using focus group interviews | To explore how nurses working in an ICU perceive their professional duties regarding EOLC based on their EOLC experiences | Not specified | 12 intensive care nurses at a university hospital in SK Purposive sampling (based on ICU experience) | Focus group interviews | Thematic analysis adhering to Braun and Clarke, (2006) |

| Author, Year and Country | Title of study | Purpose of the study (main aim) | Study design | Population and Sample Method | Data collection | Data analysis |
|--|---|---|---|--|----------------------------|--|
| Kisario & Langley, 2016, South Africa | Intensive care nurses' experiences of end-of-life care | To explore intensive care nurses' experiences of EOLC in adult ICU | Exploratory, descriptive qualitative design | 24 intensive care nurses from ICUs in 3 tertiary hospitals Purposive sampling | Focus groups | Long-table approach (Krueger & Casey, 2000) |
| Kiziltepe & Koc, 2021, Turkey | Intensive care nurses' experiences related to dying patients: A qualitative study | To describe intensive care nurses' experiences of caring for dying patients | A qualitative exploratory design | 14 intensive care nurses at a university hospital ICU Purposive sampling | Semi-structured interviews | Thematic analysis (Braun & Clarke) |
| Ong et al., 2018, Singapore | The trajectory of experience of critical care nurses in providing EOLC: A qualitative descriptive study | To understand the perceptions of critical care nurses towards providing EOLC | A qualitative, descriptive design | 10 intensive care nurses at an ICU of a public tertiary hospital Purposive sampling | Semi-structured interviews | Thematic analysis (Hennink et al., 2010) |
| Rafii et al., 2015, Iraq | End-of-life care provision: Experiences of intensive care nurses in Iraq | To explore Kurdish nurses' experiences of caring for terminally ill patients in ICUs | Phenomenological hermeneutic design | 10 intensive care nurses from a hospital in Erbil city Purposive sampling | Semi-structured interviews | Van Manen's 6 methodological activities (1990) |
| Stokes et al., 2019, Canada | Meaningful experiences and end-of-life care in the intensive care unit: A qualitative study | To explore nurses' meaningful experiences of providing EOLC to patients and families in the ICU | Interpretive phenomenological design (using Van Manen's (1997) method) | 6 intensive care nurses at an ICU of a tertiary care teaching hospital Purposive sampling | Unstructured interviews | Van Manen's (1997) three-step approach |

2.4.1.1. Study Approach and Design

Each qualitative study had a clearly stated and relevant aim, focusing on exploring intensive care nurses' experiences of providing EOLC, as summarised in Table 2.4. Given the focus on exploring subjective experiences and perceptions related to EOLC, such as nurses' emotional labour and relationships with patients and their families, the choice of a qualitative methodology was deemed highly appropriate for each of the included studies. As for the study design, Alanzi (2024), Arianto et al. (2022), Bilal et al. (2022), Holms et al. (2014), Rafii et al. (2015), and Stokes et al. (2019) employed a phenomenological research design. The phenomenological approach was deemed appropriate as it aligns well with each of the study's aims of exploring and acquiring an in-depth understanding of ICU nurses' EOLC personal and emotional experiences. Efstathiou and Walker (2014), Kisario and Langley (2016), Kiziltepe and Koc (2021) and Ong et al. (2018) utilised a descriptive, exploratory design, which provides a practical description of participants' experiences rather than seeking a more profound meaning of the essence of an experience as in phenomenology. This design does not include the interpretive aspect inherent in phenomenological research. While descriptive designs provided useful practical insights, only phenomenological approaches captured the depth of meaning central to ICU nurses' lived experiences (Smith et al., 2022). Despite this, the descriptive designs were still deemed appropriate, as they effectively addressed each study's goals of describing and exploring ICU nurses' EOLC experiences. In their studies, Endacott et al. (2016) and Jang et al. (2018) specified the use of a qualitative approach; however, they did not explicitly identify the research design used, meaning that the researcher was unable to determine whether the chosen design effectively addressed the

research question. The absence of a specified research design may raise concerns about transparency and methodological rigour.

2.4.1.2. Recruitment and Sampling

The studies by Arianto et al. (2022), Bilal et al. (2022), Efstathiou and Walker (2014), Endacott et al. (2016), Jang et al. (2018), Kisario and Langley (2016), Kiziltepe and Koc (2021), Ong et al. (2018), Rafii et al. (2015) and Stokes et al. (2019) utilised a purposive sampling technique to select participants. This was an appropriate sampling method for these studies, as purposive sampling ensured that participants were selected based on specific criteria relevant to the study's objectives (Palinkas et al., 2015). All studies identified the inclusion and exclusion criteria based on which participants were selected, indicating that selected participants were the most appropriate to provide rich and meaningful insights on the topic under study. Though initially adopting a purposive approach to identify eligible participants, in the final recruitment process, Alanzi et al. (2024) and Holms et al. (2014) had to rely on nurses' availability at the time the interviews were conducted, thus aligning with convenience sampling. The strengths in this dual approach are that the purposive element ensured that only knowledgeable participants were considered, increasing the relevance of the data collected. The convenience sampling element allowed for practical recruitment in a busy ICU setting. However, the reliance on non-probability convenience sampling introduces the potential for selection bias, as only participants that were available at the time were included. This may not represent the full range of eligible participants, limiting the transferability of findings.

Regarding sampling procedures, most studies used a small sample size, ranging from 5 to 55 participants. Although qualitative samples were small, this aligns with the aim of obtaining depth rather than broad applicability (Boddy, 2016). Endacott et al. (2016) and Kisario and Langley (2016) utilised a larger sample size of 24 and 55 participants, respectively. Having a larger sample size could lead to logistical challenges, diluted findings and reduced depth of analysis because of the large volume of data generated from qualitative research, thus undermining the core strength of qualitative inquiry, richness and contextual understanding (Boddy, 2016).

2.4.1.3. Data Collection

Most of the studies utilised semi-structured interviews as their data collection method as indicated in Table 2.4. This method was deemed appropriate since semi-structured interviews are ideal for exploring lived experiences, as they allow participants to reflect deeply and share the essence of their experiences, aligning well with each of the studies' aims of exploring ICU nurses' experiences in EOLC. However, Stokes et al. (2019) utilised unstructured interviews, which were also considered fit for purpose. Unstructured interviews allow the researcher to follow participants' narratives and adapt their questions accordingly, as the flow of the interview is dictated by the participants' responses (Peters & Halcomb, 2015).

One may argue, however, that without some sort of structure, interviews may become lengthy and stray from the research aim. Moreover, not having key questions to guide the interview could limit comparability across participants since responses would vary in depth and focus, making the data analysis process challenging (Peters & Halcomb, 2015). Endacott et al. (2016), Jang et

al. (2018), and Kisario and Langly (2016) opted for focus group interviews. This too was considered an appropriate method since group dynamics can accommodate divergent views and shared experiences. Moreover, participants can build on each other's ideas, leading to richer data (Gundumogula, 2020). One must acknowledge certain drawbacks associated with focus groups when compared to individual interviews. In group settings, participants might hesitate to share deeply personal views, especially on sensitive topics such as EOLC. Moreover, participants might conform to the majority opinion, or dominant participants might overshadow others, potentially influencing data (Gundumogula, 2020). None of the three studies discussed strategies to mitigate these drawbacks, which could have compromised the transparency and rigour of the data collection process.

All studies described their interview procedures, reporting the use of interview guides with open-ended questions and prompts that encouraged participants to elaborate. None, however, reported piloting the interview guide, a step that could have identified potential ambiguities in interview questions. Interviews were conducted face-to-face in quiet, private settings, facilitating rapport, observation of non-verbal cues, and open discussion of sensitive EOLC topics. Each study recorded and transcribed interviews verbatim, enabling data verification and enhancing analytic transparency.

All studies reported reaching data saturation, indicating that the sample size was sufficient and that no new insights emerged from additional interviews. Achieving saturation strengthens the credibility and trustworthiness of the findings.

Only Ong et al. (2018) and Stokes et al. (2019) discussed engaging in reflexivity throughout their research, indicating a conscious effort to examine potential biases and their influence on the study process. Such reflective practice helps ensure that interpretations remain grounded in participants' lived experiences rather than shaped by researchers' assumptions, thereby enhancing the credibility of the findings (Adu, 2019).

All the studies addressed key ethical considerations, including obtaining approval from relevant ethics committees, securing informed verbal and written consent and maintaining participant confidentiality and anonymity.

2.4.1.4. Data Analysis and Findings

Table 2.4 illustrates the data analysis methods adopted by the selected studies. Each study detailed the analysis process and how themes were derived from the data, enhancing the transparency and trustworthiness of the findings. All studies mentioned ways of maintaining rigour, except for the study by Bilal et al. (2022). While a detailed account of data analysis and theme extraction was provided, there was no mention of strategies employed to maintain rigour. Consequently, the reader was unable to determine if the research process was thorough and free from bias. Alanazi et al. (2024), Arianto et al. (2022), Kisario and Langley (2016), Kiziltepe et al. (2021), Ong et al. (2018) and Stokes et al. (2019) adhered to the standards laid down by Lincoln and Guba (1985) to ensure the rigour and trustworthiness of their research. To ensure accuracy and reliability of the data analysis process and findings, studies conducted peer checking involving multiple qualitative research experts and experts in the field of critical care nursing (Alanazi et al., 2024; Efstathiou & Walker, 2014; Holms et al., 2014; Ong et al., 2018; Rafi et al., 2015).

Moreover, member checks were performed by some studies by having transcripts and findings validated by participants, ensuring that their experiences were accurately reflected through the researchers' interpretations and enhancing the trustworthiness of the findings (Alanzi et al., 2024; Arianto et al., 2022; Rafii et al., 2015; and Stokes et al., 2019). Studies also ensured trustworthiness of the data analysis by carrying out independent analysis of transcripts and coding by multiple researchers and cross-checking (Endacott et al., 2016; Jang et al., 2018; Kisario & Langley, 2016; Kiziltepe & Koc, 2021; Ong et al., 2018; and Rafii et al., 2015). Bias mitigation was ensured by having researchers analyse data separately, thus minimising the chances of influencing each other's interpretations (Baldwin et al., 2022). This demonstrates a thorough approach to analysis, enhancing the overall rigour of the studies.

Each of the studies explicitly presented their findings through main themes and subthemes and included direct quotes by participants to support the established themes, enhancing the credibility of the findings. A summary of each of the studies' findings is provided in Table 2.7.

All studies included a discussion section where findings were discussed in the context of relevant existent literature. The relevance and contribution of the study findings were discussed. Studies provided valuable insights into the role of nurses during EOLC, the challenges encountered, coping strategies and family dynamics, thereby enriching the body of knowledge and understanding of the complexity of EOLC in the critical care setting.

Studies identified research gaps and suggested areas warranting further research. Studies underscored the crucial need for further investigation into support systems for nurses. Practical recommendations such as stress management groups, counselling and debriefing sessions were suggested by some of the studies (Endacott et al., 2016; Efstathiou & Walker, 2014; Kiziltepe & Koc, 2021). Other studies identified nurses' emotional resilience and interventions to involve and reconnect family members with patients as areas worthy of further investigation (Jang et al., 2018, Ong et al., 2018). Improving interprofessional communication as well as communication between healthcare professionals and families were other areas suggested for further research (Billal et al., 2022; Holmes et al., 2014; Rafii et al., 2015). Several studies acknowledged that their small sample sizes and the context-specific nature of intensive care limited the generalisability of their findings. However, qualitative research seeks transferability rather than broad applicability, that is, the extent to which findings may resonate with or be applied to other contexts. Transferability was strengthened through transparent methodological reporting, acknowledgement of study limitations, and clear presentation of findings, all of which also enhanced the credibility of the research.

2.4.2 Critical Appraisal of Systematic Review and the Integrative Review

For the appraisal of the systematic review by Velarde-Garcia et al. (2016) and the integrative review by Noome et al. (2016) included in this literature review, the CASP tool for systematic reviews (CASP, 2024) was utilised to ensure the quality and reliability of the studies. Table 2.5 presents the key characteristics of the studies.

Table 2.5 - Characteristics of Systematic and Integrative Review

| Study Characteristics | <i>Velarde- Garcia et al., 2016, Spain</i> | <i>Noome et al., 2016, Netherlands</i> |
|------------------------------|---|--|
| Title | Nursing and end-of-life care in the intensive care unit – A qualitative systematic review | The nursing role during end-of-life care in the intensive care unit related to the interaction between patients, family and professionals: An integrative review |
| Aim/s of the review | To review qualitative studies that explore nurses’ experiences in terminal/EOLC in adult ICUs | To explore ICU nurses’ role in EOLC, particularly their interactions with patients, family and healthcare professionals |
| Literature Search | Databases searched: PubMed/MEDLINE, PsycINFO, EMBASE, Scopus and CINAHL. References of cited articles were also searched. | Databases searched: PubMed/MEDLINE, CINAHL, EMBASE Reference lists of relevant articles were also searched. |
| Inclusion Criteria | <ul style="list-style-type: none"> ● Qualitative studies evaluating nurses’ EOLC experiences in adult ICUs ● Studies in English or Spanish ● Studies published between January 2003 and April 2015 | <ul style="list-style-type: none"> ● Studies of all types of methodologies evaluating or describing ICU nurses’ roles in EOLC ● Studies involving adult ICU patients ● Studies in English, German or Dutch ● Studies published as “full paper” in peer-reviewed journals between 2002 and 2015 |
| Exclusion Criteria | <ul style="list-style-type: none"> ● Unpublished studies Studies carried out in a non-ICU setting ● Studies investigating other healthcare professionals ● Studies investigating EOLC among children/adolescent subjects ● Quantitative studies,review articles, case series and editorials | <ul style="list-style-type: none"> ● Unpublished studies ● Studies investigating other healthcare professionals, i.e.Physicians ● Studies investigating EOLC among children/adolescent subjects |
| Synthesis of result | Inductive thematic analysis | Inductive content analysis |

2.4.2.1. Methodology – Search Strategy, Study Selection and Quality Assessment

Both reviews addressed a clearly focused research question identifying a specific phenomenon (EOLC in the ICU), population (nurses) and setting (ICU).

Velarde-Garcia et al. (2016) exclusively included qualitative studies and justified doing so by highlighting how the inclusion of qualitative evidence aligns well with the reviews' aim of understanding nurses' subjective experiences. Keeping in line with the principles of the integrative review methodology, Noome et al. (2016) included studies of different methodologies, including qualitative, quantitative and opinion articles, aligning with the reviews' goal of synthesising evidence from multiple perspectives to gain a comprehensive understanding of the nursing role in EOLC.

To ensure the inclusion of all relevant studies, a broad range of databases was searched as indicated in Table 2.5. Moreover, references of relevant studies were also screened to identify additional studies, enhancing the comprehensiveness of the search. Velarde-Garcia et al. (2016) acknowledged, however, that the exclusion of the search term "palliative care" could have potentially limited comprehensiveness. The inclusion and exclusion criteria (see Table 2.5) were outlined in both reviews, ensuring that the selected studies were aligned with the review aims. The authors included studies in multiple languages, reducing language bias. In both reviews, the search was restricted to include studies published within a certain timeframe, potentially missing relevant studies published before. However, capturing contemporary evidence was prioritised. Both reviews presented a detailed flowchart illustrating the selection process and demonstrating transparency. Noome et al. (2016)

described how the search and study selection process was carried out by two authors, and in the case of disagreements, a third researcher was involved. This procedure promotes transparency and increases reliability by minimising researcher bias. In contrast, Velarde-Garcia et al. (2016) did not provide such a description, leaving uncertainty about the potential for bias.

To appraise methodological quality, Velarde-Garcia et al. (2016) applied the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist, while Noome et al. (2016) used tools from the Dutch Institute of Healthcare Improvement (CBO) and the CASP to evaluate the quantitative and qualitative studies, respectively. For transparency, Velarde-Garcia et al. (2016) tabulated the quality appraisal results for each included study, and Noome et al. (2016) similarly provided the corresponding evidence levels. Velarde-Garcia et al. (2016) did not apply a cut-off threshold to exclude studies of low quality. Although this inclusive strategy enables a broader synthesis of perspectives, incorporating studies with significant methodological limitations may undermine the overall credibility and robustness of the review's findings and conclusions (Booth, 2016).

2.4.2.2 Data Synthesis, Finding and Applicability

In both reviews, multiple researchers independently analysed and coded data, reducing the occurrence of researcher bias. The reviews included studies of varying methodological rigour, though no explanation was provided regarding how the quality of the studies influenced the interpretation of their findings. This shortcoming means that there is no evidence of whether findings of studies which did not meet key COREQ criteria or were classified as of lower quality were weighed differently in the synthesis. Consequently, the impact of these

studies on the overall robustness of the reviews' findings and conclusions is uncertain.

The reviews' findings were clearly organised and broken down into main themes and subthemes. The results of both reviews were relevant to their respective aims. Findings integrated evidence from all included studies, drawing upon diverse contexts and examples, and ensuring that the findings were well grounded. Notably, in both reviews, few direct quotations from the primary studies were included to illustrate how the themes were derived from the data, casting doubts about the precision and credibility of the findings.

Findings of both reviews are broadly transferable and applicable, as they address universal issues in EOLC. The reviews draw attention to existing gaps, such as lack of training in communication and organisational barriers, and provide practical recommendations which can be directly applicable to ICU settings worldwide and align with common professional development needs of nurses.

2.4.3 Critical Appraisal of Cross-Selection Study

The cross-sectional study by Asadi et al. (2023) was critically appraised using the Joanna Briggs Institute (JBI) checklist for Analytical Cross-Sectional Studies (JBI, 2020), which comprises eight criteria for evaluating methodological quality and risk of bias. Table 2.6 summarises the key characteristics of the included quantitative study.

Table 2.6 - Characteristics of Included Quantitative Study

| Author, Year and country | Title of study | Purpose of the study (main aim) | Sampling method & Sample size | Study design | Data Collection |
|---------------------------------|--|--|--|----------------------|--|
| Asadi et al., 2023, Iran | The relationship between attitudes towards caring for dying patients and self-compassion in ICU nurses | To investigate the relationship between ICU nurses' attitudes towards EOLC and self-compassion | Convenience sampling n - 219 | Cross-section design | 3-part questionnaire consisting of demographic information. Attitude of EOLC questionnaire and self-compassion questionnaire |

2.4.3.1. Methodology and Sampling

According to Wang and Cheng (2020), a cross-sectional design is suitable for investigating associations between variables and assessing the prevalence of these outcomes within a defined population, making this an appropriate design for Asadi et al.'s (2023) study, which sought to investigate the relationship between ICU nurses' attitudes towards EOLC and self-compassion. The sample inclusion and exclusion criteria were explicitly defined. Detailed demographic information on the study subjects was provided, including age, gender, education level, work experience and EOLC training. Apart from the setting, more details about the ICU environment where nurses were recruited could have been provided, as such details allow readers to assess the study's relevance and transferability to other populations (Ghanad, 2023).

The study utilised validated tools, including the Formmelt Attitude toward Care of Dying Scale (FATCOD) and the Self-Compassion Scale (SCS). The

validity and reliability of the instruments are well established with Cronbach's coefficients provided. These objective and standardised questionnaires are widely accepted in the literature, mitigating the risk of measurement bias. The scoring and framework of both scales were comprehensively reported. Additionally, confounding factors such as education level and ICU experience were identified. A multivariate regression approach was employed to account for the identified confounders, thus increasing the credibility of the results.

2.4.3.2 Data Analysis and Results

Validated and reliable tools were used to measure outcomes. Evidence of the reliability of the FATCOD and SCS was provided through the reported Cronbach's alpha coefficients. Moreover, the structured and objective Likert scales reduced subjective interpretation during scoring. The authors did acknowledge, however, that reliance on self-reported data could have potentially introduced response bias. Appropriate statistical analysis methods were employed to assess the relationship between variables, including Pearson correlation. For group comparisons, independent t-tests, ANOVA and multivariate logistic regression were employed to account for potential confounders. These statistical techniques align well with the study design and ensure a robust analysis. Results were presented with p-values and regression coefficients provided.

2.5 Summary of Appraised Study Findings

The findings of the included studies are summarised in Tables 2.7, 2.8 and 2.9 below. The following four main thematic area were identified from these findings.

- The Emotional and psychological effects of EOLC on nurses;
- Communication and collaboration;
- Holistic care for EOLC patients and their families;
- Environmental and organisational aspects impacting EOLC provision.

Each theme is discussed in relation to the study findings.

Table 2.7 - Main findings identified across the key qualitative studies

| Study | Main Findings |
|--------------------------------------|--|
| Alanazi, 2024 | ICU nurses face emotional and practical challenges when providing EOLC, emphasising the need for better organisational support services. Nurses emphasised providing holistic care to patients and families, encompassing physical, psychological and spiritual care. Nurses perceived themselves as the link between the healthcare team and families and considered interprofessional collaboration and communication as vital to the delivery of quality EOLC in ICU. |
| Arianto et al., 2022 | Nurses faced a significant emotional toll in balancing the family's expectations with the medical team's realistic prognosis, particularly when patients had minimal chances of recovery and families held unrealistic expectations. Nurses reported how families sometimes misunderstood medical information provided by the healthcare team, resulting in confusion and delays in decision-making. |
| Bilal et al., 2022 | The study highlighted multifactorial challenges faced by ICU nurses in delivering EOLC in developing countries like Pakistan. Constrained healthcare budgets resulted in EOLC being a neglected part of care, with DNR patients often receiving suboptimal care compared to those with better prognoses. Lack of administrative support and appreciation, the non-cooperative attitude of physicians and the lack of formal education and training on EOLC were among the challenges faced by ICU nurses. |
| Efstathiou & Walker, 2014 | Nurses prioritised patients' comfort and dignity by performing physical care tasks. Emotionally supporting the family was considered equally as important as caring for the patient. The ICU environment itself restricted the family's access to patients because of the monitoring equipment and invasive lines present. To overcome this perceived barrier and foster intimacy between patients and their families, nurses attempted to create a less clinical atmosphere and involve family members in patient care. |
| Endacott et al., 2016 | Nurses emphasised the importance of clear and honest communication with families, highlighting the need for better communication strategies between the healthcare team and family, especially when delivering bad news. Nurses expressed that formal support systems were lacking, resorting to informal conversations with their colleagues to cope with the emotional impact of EOLC, thus highlighting the need for better structured emotional support for nurses. |

| | |
|------------------------------------|---|
| Holms et al., 2017 | Nurses described providing EOLC as a significant source of emotional distress. They often linked this distress to inconsistent communication, a lack of training, and a challenging ICU environment, all of which impacted their ability to provide optimal EOLC. Nurses reported frequent breakdowns in communication among doctors, nurses and families, consequently resulting in inconsistencies in EOLC decisions and conflicting messages that sometimes gave families false hope. |
| Jang et al., 2018 | Working in the ICU and frequently encountering patient deaths made nurses reflect on their own mortality and their perception of death. Less experienced nurses viewed death as frightening, while more seasoned nurses viewed it as natural. Participants advocated for EOLC to be integrated into routine critical care and viewed it as a core responsibility rather than an additional task, calling for more focus on EOLC training and education in nursing courses. |
| Kisorio & Langley, 2016 | Nurses found communicating with families one of the more challenging aspects of EOLC. Nurses were hesitant and cautious when sharing information with the family, with some admitting that at times they avoided speaking to the family by referring them to doctors, as they might react in anger or violence. Nurses expressed frustration at being excluded by doctors from the decision-making process. |
| Kiziltepe & Koc, 2021 | Nurses described how with experience they become desensitised toward patient death. Nurses developed coping strategies to help them manage the emotional toll associated with providing EOLC. Some described engaging in social activities, while others found that confiding in family and colleagues helped them process their emotions. Others, however, resorted to avoidant and detached behaviours, such as avoiding forming close connections with patients or suppressing their emotions. |
| Ong et al., 2018 | Nurses emphasised physical comfort over emotional care, faced systemic challenges, experienced grief and frustration, and used education, peer support, and detachment to cope. |
| Rafii et al., 2015 | Nurses found caring for younger patients emotionally taxing and family reactions distressing. They cited improved skills and emotional resilience through repeated exposure to death. Religion fostered optimism and compassionate care. Challenges included staff shortages, resource limitations, and strained nurse-doctor relationships, which hindered collaboration and impacted care quality. |
| Stokes et al., 2019 | Nurses highlighted how honouring the patients' end-of-life preferences was crucial. Clear communication and teamwork between healthcare professionals and families facilitated this, ensuring that the care goals aligned with the patients' wishes. Nurses felt that building a relationship with the patients' family was fundamental to providing a "good" death. |

Table 2.8 - Main findings identified across the key systematic and integrative reviews

| Study | Findings |
|-------------------------------------|---|
| Velarde-Garci a et al., 2016 | The study highlighted three main themes: nurses' emotional toll during EOLC for critically ill patients, the role of the family within the ICU, and the challenges faced in providing quality care. Nurses grappled with emotional strain, communication barriers, and environmental factors, but teamwork and fostering relationships with families were crucial. Clear communication aligns family expectations with patients' prognosis. |
| Noome et al., 2016 | Nurses prioritised patient comfort mainly through pharmacological methods and basic nursing care. They also emphasised the importance of family involvement and creating a peaceful environment. However, high workloads and resource constraints hinder nurses' ability to provide quality EOLC, and they advocated for a greater role in decision-making. |

Table 2.9 - Main results reported in the selected quantitative study

| Study | Results |
|---------------------------|---|
| Asadi et al., 2023 | Nurses' attitudes towards EOLC are positively correlated with age, experience, education, and self-compassion. Higher education and EOLC training enhance nurses' understanding and ability to provide better care, reducing burnout and improving patient and family end-of-life experiences. Overall, a statistically significant positive correlation was found to exist between EOLC attitudes and self-compassion, indicating that nurses with a higher sense of self-compassion had a more positive attitude towards caring for dying patients. |

2.5.1 The Emotional and Psychological Effects of EOLC on Nurses

The theme of emotional and psychological effects of providing EOLC on nurses was a recurring focus across many studies in this literature review. Nurses frequently expressed emotional distress when caring for dying patients, especially when caring for younger patients or those whom they had formed a personal connection with (Kisario & Langley, 2016; Ong et al., 2018; Rafii et al., 2015).

Nurses expressed frustration and experienced internal conflict when administering treatment, they felt was futile to end-of-life patients, believing it caused unnecessary suffering and prolonged the dying process (Arianto et al., 2022; Endacott et al., 2016; Ong et al., 2018; Velarde-Garcia et al., 2016). Nurses described how they empathised deeply with patients and their families. This often led them to feeling emotionally exhausted as they navigated between professional obligations and personal feelings (Efstathiou & Walker, 2014). Nurses described feeling a sense of relief when the patient's death brought an end to their suffering.

Nurses acknowledged that caring for dying patients had made them think more deeply about death, including their own, and had made them more aware of the inevitability of death (Jang et al., 2018). Jang et al. (2018) demonstrated the difference in perceptions towards death between junior nurses and experienced nurses. Less experienced nurses perceived death as dark and frightening, while experienced nurses tended to view death as a natural part of life. Nurses recalled their first ICU patient's death and how it affected them physically, mentally, and professionally, with some thinking of leaving the ICU or nursing altogether.

However, nurses reported that experience made them become less sensitive towards patient death: "*The more patient death I experienced, the more I got used to it*" (Kiziltepe & Koc, 2021).

Nurses described how they employed strategies to help them cope and protect themselves emotionally and mentally when providing EOLC. Some viewed education and guidance from senior nurses as a way of coping, filling in knowledge gaps and improving their EOLC delivery and communication skills. Some nurses sought the support of their peers, whose shared understanding was especially valued (Alanzi et al., 2024, Ong et al., 2018). Others emphasised the importance of maintaining a work-life balance by spending time away from hospital and engaging in hobbies (Stokes et al., 2019). Other nurses resorted to avoidance and detached behaviour to protect themselves from emotional involvement. Some nurses avoided forming close relationships with the patient and their families to protect themselves, while others would suppress their emotions to focus on their work *“I think of my other patients who need me. I pull myself together and master my emotions”* (Kiziltepe & Koc,2021). Nurses acknowledged that such behaviours could negatively impact the quality of care provided. Studies highlighted a lack of formal support systems, such as debriefing and counselling sessions to help nurses process their experiences and continue providing quality EOLC.

2.5.2 Communication and Collaboration

This theme, reflecting the dynamic interactions among nurses, families and the wider healthcare team, is integral to the delivery of high-quality EOLC in the ICU. It emerged as both a challenge and a facilitator in shaping the provision of EOLC.

Nurses emphasised the importance of timely and clear communication with families regarding the patients’ prognosis and the end-of-life process (Endacott et al. 2016; Holms et al., 2014; Jang et al., 2018; Kisorio & Langley, 2016; Kiziltepe & Koc, 2021). They highlighted how early discussions on potential outcomes help families prepare for their loved ones’ death. Moreover, nurses noted that delayed

communication often caused stress for families, as they may lack the necessary time to accept the situation and make meaningful decisions (Arianto et al., 2022, Velarde-Garcia et al., 2016). However, despite the crucial importance of communication between the healthcare team and the family, nurses noted that doctors tended to be very superficial when speaking to relatives, not giving them the full extent of the patients' prognosis and the anticipated care plan (Stokes et al., 2019). Doctors also tended to use medical jargon, hindering understanding and decision-making. Nurses expressed how this complicated EOLC delivery and increased the emotional strain associated with providing EOLC, as they were often left to clarify information and manage families' reactions (Noome et al., 2016). One of the more challenging aspects of providing EOLC, according to nurses, was communicating with family members about the patients' condition. Nurses described being hesitant of what they disclose with the family, as *"they [the relatives] want to find someone to blame"* and may react with denial and anger (Kisorio & Langley, 2016).

Nurses experienced a lack of autonomy due to a power imbalance between doctors and nurses, restricting nurses' influence on care planning and decision-making (Bilal et al., 2022; Efstathiou & Walker, 2014; Endacott et al., 2016; Holms et al., 2014). Nurses felt that, given their close involvement with the patient, they were entitled and well-equipped to contribute towards decisions regarding patient care, advocating for the patients and ensuring that the care plan aligns with the patients' wishes. Moreover, they believed that being involved would enhance teamwork and ensure unanimity about the patients' care plan (Alanazi et al., 2024, Noome et al., 2016).

2.5.3 Holistic EOLC for Patients and their Families.

This theme emphasises the comprehensive approach to EOLC in the ICU, addressing the physical, emotional, psychological and spiritual needs of both patients and their families.

When describing the care provided to the ICU patient, nurses stated that they prioritised patient comfort by ensuring pain and symptom management, mainly via pharmacological methods (Noome et al., 2016, Stokes et al., 2018). Nurses prioritised maintaining the patients' dignity by caring for their appearance and removing any unnecessary equipment, aiming to create a peaceful environment that reflected care and respect. Nurses emphasised that patients should not be left alone when dying, encouraging family presence. In the absence of family members, nurses provided a comforting presence for the patient during the dying process. While spiritual care was viewed as an integral part of holistic EOLC, nurses felt that they were ill-equipped to address this aspect, often relying on families and spiritual leaders (Kisario & Langley, 2016; Noome et al., 2016).

Nurses felt that building a relationship with the patients' family was fundamental to quality EOLC, allowing them to establish trust and get to know the patient through their family (Stokes et al., 2019). Nurses viewed their role of supporting family equally as important as caring for the patient (Efstathiou & Walker, 2014, Velarde-Garcia et al., 2016). Nurses described how they provided support to the family by keeping them informed about patient treatments and prognosis. Nurses often mediated between families and doctors, explaining medical information in simpler terms to ensure understanding and informed decision-making. To foster a sense of involvement, nurses encouraged families to participate in patient care, such as during bathing, to help families feel close to their loved one (Ong et al., 2018,

Stokes et al., 2019). In an attempt to “give the patient back” to their family, nurses would modify the ICU environment by removing unnecessary equipment and personalizing the space with photos and music to create a home-like environment where they can say their final goodbyes. In other studies, nurses expressed how shortages of staff, time constraints, and heavy workloads limited their ability to provide comprehensive support to the family and encouraged social workers and religious leaders to share in this role (Noome et al., 2016). To help foster an inclusive and compassionate approach to family care, nurses advocated for policies such as unrestricted visiting hours, private spaces separate from waiting rooms where families can grieve, and family follow-up meetings.

2.5.4 Environmental and Organizational Aspects Impacting EOLC

Nurses elaborated on how environmental factors, such as the physical ICU environment, and organisational factors, such as resource availability and training, had a significant impact on the quality and delivery of EOLC.

The ICU environment and how it impacts EOLC featured strongly in the findings. The intrusive nature and technical focus of the ICU often create a depersonalised atmosphere, making it difficult to create a peaceful environment for patients and families and raising concerns about ICUs’ suitability for EOLC (Holms et al., 2014; Noome et al., 2016). Nurses emphasised the need to make staff aware of dying patients on the unit. The lack of quiet spaces and private rooms in the ICU limited opportunities for families to have uninterrupted time with their loved ones or grieve in private (Endacott et al., 2016; Velarde Garcia et al., 2016).

Nurses tried to mitigate the challenges presented by the ICU environment by removing unnecessary medical equipment, personalising spaces, and minimising noise (Stokes et al., 2019). Holms et al. (2014) reported that despite these challenges

nurses spoke highly of the upsides of providing EOLC within the ICU, such as the one-to-one nurse-patient ratio, which allowed nurses to devote more time to dying patients and their families.

Many studies addressed the lack of standardised ICU-specific EOLC protocols. Nurses raised concerns about the lack of available guidelines that made them feel uncertain about their roles and responsibilities when providing EOLC (Efstathiou & Walker, 2014; Holms et al., 2014). Nurses reported insufficient formal training in EOLC, with most learning gained through on-the-job experience. Nurses observed that ICU training often prioritised curative skills over EOLC competencies, resulting in many feeling inadequately prepared for the emotional and ethical demands of EOLC. Nurses identified areas needing more training, particularly addressing emotional, spiritual and ethical challenges to better equip them in providing quality EOLC (Kisario & Langley, 2016; Jang et al., 2018).

2.6 Conclusion

The reviewed studies collectively highlight the complex interplay between professional responsibilities, emotional demands, and systemic constraints faced by ICU nurses when caring for dying patients. They underscore the need to strengthen nurses' coping capacities and provide structured emotional support to mitigate the psychological burden associated with EOLC. The evidence further points to the importance of effective communication within the multidisciplinary team and between healthcare professionals and families. Implementing ICU-specific EOLC guidelines and fostering ongoing workplace learning are essential to help nurses clarify their roles, build resilience, and deliver compassionate, high-quality care during the final stages of life in the ICU. The following chapter presents a detailed account of the study's methodological approach.

Chapter III

Methodology

3.1 Introduction

This chapter outlines the philosophical foundations, methodological design, and analytic processes underpinning this study, which explored the lived experiences of critical care nurses providing EOLC in the ICU. It presents and justifies the research approach and design, and the methodological choice aligning with the study's aim and objectives. Lastly, ethical considerations and strategies to ensure rigour are discussed.

3.2 Aim, Objectives and Research Question

The key research question for this study was, “*What are the lived experiences of critical care nurses providing end-of-life care to patients in the local intensive care unit?*”

This study sought to explore and interpret the lived experiences of critical care nurses as they provide end-of-life care to patients in the intensive care unit. The main objectives were:

- To explore and interpret how critical care nurses make sense of providing EOLC in the ICU;
- To gain insight into the emotional and psychological effects of EOLC on critical care nurses;
- To understand critical care nurses' relationships and communication with families of patients at the end of life;
- To explore the coping strategies in which critical care nurses engage in to cope with providing EOLC;
- To explore how critical care nurses perceive and experience the need for support when providing end-of-life care.

3.3 Research Approach and Paradigm

A study's selected research approach and design must align closely with the nature of the research problem, ensuring that the study effectively addresses the research objectives (Creswell, 2009). To properly address the research problem, one must first adopt an appropriate research paradigm, as this provides a framework for understanding the underlying philosophy of the research, ultimately determining the approach, design and direction of the study (Lincoln et al., 2011). A research paradigm is a set of beliefs and assumptions related to the three elements making up a research problem: *ontology* - the nature of reality; *epistemology* - how knowledge is acquired; and *methodology* - the strategies used to gather knowledge (Lincoln et al., 2011). The main research paradigms are positivism, constructivism and pragmatism. The positivist paradigm that assumes a realist ontology posits that reality is objective and that there is one observable truth, independent of human beliefs and perceptions (Park et al., 2020). The epistemology of positivism postulates that knowledge is acquired through measurement and empirical evidence, thus lending itself to a deductive and quantitative methodology, which aims to test hypotheses by using structured tools, such as surveys and statistical analysis (Park et al., 2020). Therefore, its emphasis on objectivity and measurable data precluded the positivist paradigm from being deemed suitable for exploring the lived experiences of nurses since it cannot capture the subjective, nuanced and complex nature of individual experiences.

Conversely, the pragmatic paradigm adopts a practical ontology as it acknowledges that reality is complex and so accommodates various interpretations shaped by contextual elements (Kaushik & Walsh, 2019). The epistemology of the pragmatic paradigm emphasises that knowledge is context-dependent, valuing both subjective

and objective perspectives. This allows for a mixed-methods methodology, combining quantitative and qualitative methods (Kaushik & Walsh, 2019). Since pragmatism prioritises problem-solving and practical outcomes rather than delving deeply into personal experiences, it does not fully support the objectives of this research.

By contrast, in the constructivist paradigm, the ontological perspective is that reality is subjective, recognising that individuals construct their own reality based on their experiences, values and interactions with others (Lincoln & Guba, 2013). The epistemology of constructivism focuses on understanding that knowledge is subjective and situated within social contexts. It emphasises the importance of understanding how individuals perceive and interpret the world around them and that knowledge is actively constructed through interactions with others and the environment (Lincoln & Guba, 2013). Constructivism aligns itself with a qualitative research approach that underscores understanding individuals' subjective and unique experiences and perspectives. Therefore, the constructivist paradigm was deemed the most suitable for this study, as a qualitative approach allowed the researcher to seek to understand the complexity of nurses' experiences by examining their subjective interpretations and gaining profound insights into their perspectives (Denzin & Lincoln, 2011).

The qualitative approach accommodates a wide array of designs, including grounded theory, ethnography, narrative, case study and phenomenology, each having a unique research purpose. Grounded theory is a design which is used to generate a theory explaining a social process or phenomenon (Corbin & Strauss, 2007), while ethnography focuses on evaluating the culture, practices and beliefs of a particular group or community within their natural setting in order to obtain a

detailed account of the group's social interactions and cultural norms (Coffey, 2018). Neither of these designs were deemed appropriate for this study, as their purpose does not align with the study's research aim and objectives. A narrative design is concerned with the chronological reconstruction of life stories, with the main focus being the story itself and how people construct meaning through the sequence and structure of their personal narratives (Bruce et al., 2016). This design offers significant biographical insights; however, it is less suited for comprehending the meanings and emotional realities that nurses associate with particular aspects of their professional practice. Similarly, a case study design was not considered appropriate, as this is concerned with exploring a specific process or organisational practice, with the goal being to explore the particularities of that "case" rather than the subjective meanings individuals ascribe to such experiences (Baxter & Jack, 2010).

Phenomenology is a philosophical approach in qualitative research which focuses on exploring and understanding a particular phenomenon through the lived experiences of human beings (Smith et al., 2022). Phenomenology seeks to uncover the underlying meaning of these experiences, emphasising the unique perspectives and interpretations of individuals (Smith et al., 2022). Therefore, phenomenology was deemed to be well suited to explore the experiences of nurses providing EOLC in the intensive care setting since, through phenomenological methods, the researcher could explore how participating nurses made sense of their experiences, emotions and interactions with patients and their families during the EOLC process.

3.4 Phenomenology

Phenomenology provides a wide array of research designs, including descriptive (Husserlian) phenomenology, hermeneutic (Heideggerian) phenomenology and interpretive phenomenological analysis (IPA) (Smith et al., 2022). In descriptive phenomenology, the researcher aims to *describe* the essence of the phenomenon under study. On the other hand, hermeneutic phenomenology emphasizes analysing and interpreting the phenomenon (Smith et al., 2022). IPA combines elements of descriptive phenomenology and hermeneutics, allowing researchers to explore and interpret a phenomenon through the lived experiences of individuals (Smith & Nizza, 2021). Based on phenomenology and hermeneutics, IPA leads to a descriptive and interpretive methodology where the researcher seeks to grasp the significance participants attribute to their experiences through phenomenological reflection and writing (Tuffour, 2017). Consequently, IPA was deemed the most suitable design to explore the experiences of nurses providing care to dying patients in the ICU.

3.4.1 The Theoretical Underpinnings of IPA

IPA is informed by three key theoretical underpinnings: phenomenology, hermeneutics and idiography (Smith et al., 2022).

Phenomenology is the philosophical foundation of the study of experience and emphasises understanding the essence of lived experiences from the perspective of the individual who has lived through them. It aims to describe the subjective meanings and interpretations that individuals attach to their experiences through reflection (Smith et al., 2022). Husserl proposed that to avoid any preconceived understandings and assumptions, the researcher should consciously engage in a process of bracketing where they suspend their own biases and assumptions to focus solely on the raw data provided by the participants. In IPA, however,

researchers acknowledge that such bracketing is neither attainable nor desirable and that having the researcher acknowledge their own preconceptions is a valuable and integral part of the research process, as this provides the researcher with a deeper understanding of the participants' experiences (Smith et al., 2022).

This leads to the next underpinning of IPA, **hermeneutics**, which is defined as the theory of interpretation. Phenomenology emphasises the description of experiences, whereas hermeneutics asserts that comprehending human experiences is fundamentally an interpretative endeavour (Smith et al., 2022). Unlike descriptive phenomenology, which seeks to set aside preconceptions to describe experiences, hermeneutic phenomenology, influenced by philosophers such as Heidegger and Gadamer, postulates that interpretation is unavoidable since individuals are always situated within specific historical, cultural and social contexts. This perspective acknowledges that researchers inevitably bring their own prior knowledge and biases into the process of understanding the participant, thus embracing that meaning is co-constructed between the participant and the researcher. This dual process is referred to as the double hermeneutic, where the researcher is trying to make sense of the participant, who in turn is trying to attribute meaning to their own experiences (Smith et al., 2022). Understanding is cyclic and an iterative process, involving moving back and forth between the parts (specific words or phrases) and the whole (the broader narrative), thereby refining and deepening interpretations. This is known as the hermeneutic circle, a fundamental concept in hermeneutic philosophy (Smith et al., 2022).

The **idiographic** underpinning of IPA emphasises focusing on the particular rather than the general. This means that IPA prioritises the detailed, in-depth exploration of each individual's experience rather than seeking broad generalisation (Smith et al., 2022). This process involves a case-by-case analysis where each participant's account is examined in depth before shared themes are identified across participants. To allow for a rich and nuanced analysis of each participant's perspective, IPA researchers typically work with small samples, which ensures that the uniqueness of each participant's experience is respected. Through these three interwoven elements, IPA allows for a deep exploration of personal, emotional and contextual factors that shape nurses' understanding and experiences of such a profound aspect of critical care nursing – providing EOLC.

3.5 Sampling and Recruitment Process

Sampling should align with the principles of qualitative research, which emphasises understanding individuals' experiences in depth rather than broad applicability. In IPA, samples are purposively selected by focusing on individuals who possess experiences and characteristics relevant to the phenomenon under study (Smith et al., 2022). This purposeful, non-probability sampling procedure ensures that the gathered data from these participants aligns with addressing the study's objectives, yielding significant data for analysis and enhancing rigour (Smith et al., 2022). In this way participants are selected intentionally, based on a set of inclusion and exclusion criteria, allowing the researcher to capture the diversity and depth of lived experiences within a homogenous sample who best align with the aim and objectives of the study (Smith & Nizza, 2021). To be included in this study, participants (i) had to be presently working in the ICU (ii) had to be working in this unit for at least one year so that they would have gained substantial experience. By

contrast, nurses in the relieving pool who sometimes worked in the ICU or nurses who used to work in the ICU but no longer did were excluded since they may draw upon experiences which did not occur in the ICU.

Due to its idiographic focus, IPA utilises small but sufficient sample sizes to facilitate in-depth exploration and interpretation of the experiences of each participant. Smith et al. (2022) recommend a practical sample size of three to six participants for the novice IPA researcher, as this enables a manageable amount of data for analysis while still capturing diverse experiences. In this study, four ICU nurses were recruited through intermediaries. The purposive nature of the sample means that findings are context specific. However, IPA does not seek broad applicability but rather prioritises depth and contextual understanding, with transferability supported through the provision of rich, transparent accounts allowing readers to judge the relevance of the findings to other contexts (Leung, 2015).

Participants were recruited from the ICU of the local public acute general hospital through intermediaries, namely the unit's charge nurses, to prevent the risk of coercion. Information about the study and participant eligibility criteria was provided to the intermediaries, who then approached prospective participants. Interested nurses received a participant information sheet (PIS) (Appendix A) outlining the study's purpose and expectations regarding their involvement, who then contacted the researcher via the phone number provided on the PIS. The researcher met with each of the participants individually at the ICU to further explain the study and address any questions. Verbal consent was obtained, and an interview was scheduled. Participants were provided with the consent form for them to review beforehand. Before the interview commenced, the researcher

reiterated the study's purpose, reconfirmed verbal consent and collected the signed consent form.

3.6 Data Collection

IPA uses methods that elicit rich, meaningful accounts from participants (Smith et al., 2022). In-depth interviews are the most effective way to obtain such accounts. Interviews help to elicit stories, thoughts, and feelings about the phenomenon under study and allow for a focused exploration of an individual's experience, thus making them the preferred method of collecting data in IPA research (Smith et al., 2022). Alternative methods of data collection exist such as focus groups, participant observation and diaries which are also appropriate depending on the circumstances of the study and the research goals. Semi-structured interviews provide participants the opportunity to share and elaborate on their stories and speak openly and reflectively, while allowing the researcher to engage directly with the participant and gain a deep understanding of their experiences by also observing their non-verbal means of communication (Smith et al., 2022). Therefore, individual semi-structured interviews were deemed to be the most appropriate data collection method for this study.

The flexible nature of semi-structured interviews allows the researcher and participant to engage in a more authentic and spontaneous conversation, encouraging the participant to express themselves freely, leading to a more genuine and open exchange of information (McGrath et al., 2018). An interview guide was used to guide the interview in a flexible manner (Appendix B). The open-ended questions included in the interview guide were curated through reading related literature, encouraging participants to reflect deeply on their experiences and provide detailed and thoughtful responses, highlighting phenomenological intent.

Prompts were utilised by the researcher when participants seemed uncertain about how to answer a question. Throughout the interviews, the researcher listened attentively, picked up significant remarks, observed non-verbal communication and probed spontaneously to elicit deeper responses. Moreover, the researcher was attentive to allow the participant sufficient time to give as full an answer as possible, only intervening to keep the conversation going. The researcher was aware that the participant was the experiential expert on the topic and so made a conscious effort to set aside any pre-existing personal thoughts, allowing the participant to lead the interview while the researcher enquired after any relevant information that arose.

The interviews were audio recorded with the participant's permission. Moreover, since the researcher was fluent in both Maltese and English, participants were allowed to use whatever language they felt most comfortable expressing themselves in. Throughout the interview, participants spoke mostly in Maltese, occasionally switching to English. Interviews were transcribed in Maltese and subsequently translated to English for analysis allowing the researcher to engage with the data in the same language as the final written dissertation and maintain consistency throughout the analytic cycle. Translation was facilitated by a bilingual researcher, ensuring meaning equivalence through close attention to idiomatic expressions, emotional tone and contextual nuance. In Chapter 4, the original Maltese excerpts were retained and presented alongside the English translations to preserve the authenticity of participants' expressions and meanings.

Interviews were conducted in a quiet and private room in the ICU at a time most suitable for the participants. A pilot interview was conducted to identify and address any ambiguity in the interview questions and assess the flow of the interview to

ensure quality data collection. Since no issues were identified during this pilot interview, the data collected was included for data analysis. Before initiating the interview, the researcher took some time to speak with the participant about light subjects to build rapport and help the participant feel more comfortable and at ease. While the researcher had initially set out to carry out two interviews per participant, this was ultimately not required due to the adequacy of the data collected from the initial interviews.

3.7 Data Analyses

To analyse the collected data, the researcher closely followed the key steps recommended by Smith et al. (2022), thus ensuring a reflective interaction with the participant's narrative. Ultimately, the analysis reflected a co-constructed product between the participant and the researcher. While IPA centres on the participant's lived experiences and their own meaning-making, the final result is shaped by how the researcher engages with and understands this sense-making (Smith et al., 2022). This aforementioned double hermeneutic features prominently throughout the analytic process. The following steps outline the various stages of the analytic process conducted in this study.

Step 1: Reading and Rereading

Initially, the researcher listened to the audio recordings and transcribed them manually. This allowed the researcher to engage fully with the original data. Listening to the audio recording multiple times whilst rereading the transcript of the interview helped the researcher become immersed and more familiar with the participant's narrative. The main purpose of this initial step was to ensure that the participant became the focus of the analysis. As suggested by Smith et al. (2022),

notes about any significant and striking observations were made while reading the transcript.

Step 2: Exploratory Noting

This phase of analysis involved exploring semantic content and language use, facilitating a deeper familiarity with the data. In practice steps 1 and 2 merge as the researcher added exploratory notes with subsequent readings of the transcript.

Smith et al. (2022) outlines three types of exploratory comments: (i) descriptive comments describe the content of what the participant is saying, (ii) linguistic comments explore the particular language used by the participant noting word choice, tone, repetitions, pauses and use of metaphors, (iii) conceptual comments involve a deeper level of interpretation, going beyond what is explicitly said and questioning underlying meanings, assumptions and implications. Here the researcher engaged with the material in a more reflective way, introducing their own interpretations of the participant's account. These three levels of comments progressing from surface level to deeper interpretation helped capture the double hermeneutic in IPA – how the participant makes sense of their experiences and, in turn, how the researcher interprets this sense-making. Table 3.1 illustrates an example of each type of exploratory comment obtained from the analysis of one participant's transcript.

Table 3.1. Exploratory Noting

| Experiential Statements | Transcript | Exploratory notes |
|-------------------------|---|---|
| | <p>You do it cautiously, because you don't want to say the wrong thing and they grasp on to it and they say because the nurse said this. Because then there's that certain fear sometimes and I say listen I'm going to bite my tongue, better I say less than I say too much... (Megan p. 9)</p> | <p>Describes taking a cautious approach when communicating sensitive information to family members to avoid misinterpretation.</p> <p>Suggests that communicating with family members is stressful for the nurse, as she is afraid of being misinterpreted and blamed.</p> <p>The metaphorical expression "bite my tongue" illustrates the deliberate self-restraint and caution she exercises when speaking with relatives</p> |

Descriptive comments in blue, Linguistic comments in green, Conceptual comments in red

Step 3: Constructing Experiential Statements

At this stage, the transcript had an additional layer of potentially significant but still tentative exploratory notes from which experiential statements could be developed. To formulate experiential statements, the researcher aimed to condense the volume of detail while preserving its complexity, creating a concise statement of the key aspects of the exploratory notes. Identifying experiential statements from exploratory notes involves analysing distinct segments of the transcript, effectively breaking down the participant's experiences into smaller meaningful parts (Smith et al., 2022). This illustrates the hermeneutic circle, wherein the original *whole* of the interview is broken down into smaller *parts* during analysis, which are then reassembled into a newly constructed whole in the final write-up. By moving between the parts and the whole, the researcher engaged with the data iteratively,

interpreting the data in a richer and more coherent manner. Table 3.2 illustrates the experiential statements which were constructed from the same transcript excerpt shown in Table 3.1.

Table 3.2. Developing Experiential Statements

| Experiential Statements | Transcript | Exploratory notes |
|--|---|---|
| <p>Role of nurse in family communication – the primary point of communication for family (pg 9)</p> <p>A cautious approach when communicating information to family members (pg 9)</p> <p>Fear of being misinterpreted and blamed (pg 9)</p> | <p>You do it cautiously, because you don't want to say the wrong thing and they grasp on to it and they say because the nurse said this. Because then there's that certain fear sometimes and I say listen I'm going to bite my tongue, better I say less than I say too much... (Megan p. 9)</p> | <p>Describes taking a cautious approach when communicating sensitive information to family members to avoid misinterpretation.</p> <p>Suggests that communicating with family members is stressful for the nurse as she is afraid of being misinterpreted and blamed.</p> <p>The metaphoric expression "bite my tongue" illustrates the deliberate self-restrain and caution she exercises when speaking with relatives</p> |

Step 4: Searching for Connections Across Experiential Statements

In this step, the researcher examined the previously identified experiential statements to explore connections between them, grouping related experiential statements into clusters.

This process involved manually isolating each experiential statement onto a separate piece of paper, arranging them in no particular order on a flat surface and grouping related statements to explore patterns of connection. Throughout this clustering process, the researcher constantly returned to participants' original accounts to ensure that the clusters were grounded in participants' experiences, illustrating IPA's iterative nature. Some experiential statements were discarded, as they were not related to the scope of the research question. Each cluster of related experiential statements was then referred to as a personal experiential theme (PET).

Step 5: Naming the Personal Experiential Themes (PETs) and Consolidating and Organizing them in a Table

PETs capture the essence of the multiple experiential statements in a cluster. The researcher organized the PETs (*written in bold upper case*) and their subthemes (*written in bold lower case*) together with the supporting experiential statements (*highlighted*) and the participant's key words/phrases, which prompted the respective statements, into a structured table. This table provides a visual representation of the interpretative process undertaken (Smith et al., 2022, p. 95). Table 3.3 illustrates one of the PETs and its subthemes related to one of the participants.

Table 3.3. Personal Experiential Theme development

| Personal Experiential Theme |
|---|
| <p>COMPLEX DYNAMICS OF NURSE-FAMILY COMMUNICATION IN END-OF-LIFE CARE</p> |
| <p>Subtheme: Communication as care in EOLC</p> <p>Role of nurse in family communication – the primary point of communication for family. p. 9</p> <p><i>“They turn to you because you’re the one that’s near the patient all the time” p. 9</i></p> <p>Communicating with families who are in shock – the importance of clear and persistent communication in EOLC to facilitate understanding and align families with care decisions. P. 16 <i>“When you explain to them you try to do it in simple words because most of the time they don’t understand because they are in shock. You keep explaining until they understand” (pg16)</i></p> <p>Knowing how to deal with distressed families – a blend of empathy, strategic communication and professional precaution. P. 21</p> <p><i>“you have to know how to deal with their initial shock” (pg21)</i></p> <p><i>“That your careful how you talk to them because they twist words or they take from them what they choose to” pg 22</i></p> |
| <p>Subtheme– The weight of words</p> <p>A cautious approach when communicating information to family members. P. 9</p> <p><i>“You do it cautiously, because you don’t want to say the wrong thing and they grasp on to it and they say because the nurse said this” pg 9</i></p> <p><i>“What I’ve found works for me is I listen to what the doctors say then I repeat that, not a word less or a word more” pg 9</i></p> <p>Fear of being misinterpreted and blamed. P. 9</p> <p><i>“Then there’s that certain fear sometimes and I say I’m going to bite my tongue, better I say less than I say too much” pg 9</i></p> |

Step 6: Continuing the Individual Analysis of Other Cases

Steps 1 to 5 were repeated for each of the other participants' transcripts. The researcher exercised meticulous care to treat each case on its own terms, respecting its individuality and adhering to IPA's idiographic commitment (Smith et al., 2022, p. 99). To that end, the researcher bracketed any insights and interpretations that arose from the previously analysed transcripts whilst analysing subsequent interviews to ensure that each transcript was valued independently.

Step 7: Working with Personal Experiential Themes to Develop Group Experiential Themes Across Cases.

After having analysed each transcript whilst adhering closely to the steps outlined by Smith et al. (2022), cross-case analysis was conducted to identify patterns of similarity and differences among the PETs of the different transcripts. This is a dynamic and iterative process, where the researcher moved back and forth between participants' PETs, experiential statements and the wider transcript to search for convergences and divergences in participants' experiences. This is another example of the application of the hermeneutic circle in IPA. This led to the development of group experiential themes (GETs) and subthemes.

These GETs encapsulated the most significant issues related to the study's aim and objectives whilst illustrating convergences in participants' experiences. The finalised GETs were organised in a table illustrating the understanding of the experience at the group level and the convergence of the participants' experience, as suggested by Smith et al. (2022, p. 101). This table provides a synthesis of the researchers' interpretative analysis of the four cases. Table 3.4 illustrates one of the GETs (*uppercase bold*) together with the group-level subthemes (*lowercase bold*). These

are in turn supported by the relevant experiential statements (*highlighted*) and respective thematic excerpts from each contributing participant.

Table 3.4. Group Experiential Theme development

| Group Experiential Theme |
|--|
| CARE BEYOND THE PATIENT |
| <p>Supporting families</p> <p>Increased attentiveness to relatives during end-of-life care (Jennifer) <i>“When we have these cases I focus more on being empathetic with relatives...even if you just offer them a coffee or ask them if they’ve eaten anything...It makes you feel good in a way (p. 13)</i></p> <p>Nurse’s dual role - balancing the physical care of the patient with the emotional care of the family (Megan) <i>“Our end-of-life care here is most of the time with a patient that is intubated and unconscious, so mostly it’s the physical aspect that I give the most attention to. However, the emotional and psychological aspect then moves towards the relatives” (p. 6)</i></p> <p>Emotional reassurance and comfort for the family (Simon) <i>“I try to put their mind to rest that he [the patient] is not in pain and not suffering” (p. 3)</i></p> <p>The nurses’ dual role in EOLC – caring for patient and family (Kevin) <i>“My role is to make the patient comfortable, to help and guide the relatives because its a shock, a trauma for them. You help them, guide them, explain to them” (p.2)</i></p> |
| <p>Communication as Care</p> <p>Communicating with family who are in shock (Megan) <i>“When you explain to them you try to do it in simple words because most of the time they don’t understand because they are in shock. (p. 16)</i></p> <p>Supporting families through reassurance and honest communication (Simon) <i>“No false hope, if he’s EOLC that’s the worst thing you could do is that you give them hope.” (p. 15)</i></p> <p>Maintaining consistent interdisciplinary communication (Kevin) <i>“You have to see that the information that you are giving is the same as the doctor is giving because it could be misinterpreted...I think that’s what I find most important, the information” (p. 8)</i></p> <p>A cautious approach when communicating information to family members. (Megan) <i>“You do it cautiously, because you don’t want to say the wrong thing and they grasp on to it and they say because the nurse said this” pg 9</i></p> <p>Maintaining boundaries and a cautious approach when sharing information with families (Jennifer) <i>“I don’t try to give them all the information myself...There is a specific line I keep with” (p. 16).</i></p> |

3.8 Strategies to Ensure Rigour

Ensuring rigour in qualitative research is essential to producing credible and trustworthy findings. Although IPA is subjective due to its interpretative nature, several strategies may be employed to enhance the rigour and transparency of the methodological process of a qualitative design. Yardley (2000) proposed an approach for evaluating and demonstrating quality in qualitative research, consisting of four key aspects.

3.8.1 Sensitivity to Context

This is crucial in IPA research, as it ensures that the study remains grounded within the research setting, the participants' experiences and existing literature. This was demonstrated by understanding the research context through acknowledging the social, cultural and institutional influences that shape participants' experiences. Moreover, sensitivity to participants was demonstrated particularly during the interview process. The researcher engaged in active listening together with empathetic and flexible interviewing techniques to help participants express themselves freely and comfortably (refer to Section 3.6). The researcher also ensured ethical sensitivity as discussed in Section 3.9. In line with Yardley's criteria, sensitivity to context was also demonstrated by situating the study findings within existing evidence-based literature, as discussed in chapter 5.

3.8.2 Commitment and Rigour

This refers to the study's thoroughness, which was demonstrated by providing detailed descriptions and the rationale underpinning every decision taken. Moreover, data collection was conducted in an in-depth and consistent manner, using an interview guide consisting of open-ended questions and utilising techniques such as prompting and probing to elicit rich and detailed narratives from

participants. Data analysis was conducted in a comprehensive and systematic manner, rigorously following the steps presented by Smith et al. (2022). These steps ensure that an IPA study produces credible and trustworthy findings. Furthermore, regular feedback was sought from the academic supervisor, an experienced researcher in the field, thus enhancing the trustworthiness and credibility of the study by allowing an independent peer to critically appraise the research design, data collection and analysis process (Noble & Smith, 2015). Moreover, through peer debriefing with an ICU-experienced colleague, the researcher was encouraged to consider different perspectives, reflect on potential biases and identify potential blind spots.

3.8.3 Transparency and Coherence

This refers to having a well-documented and logically structured research process, which is consistent with the theoretical underpinnings of IPA (Yardley 2000). Clear documentation of all the steps taken throughout the research process demonstrated transparency. An audit trail was maintained by documenting key decisions and steps such as participant recruitment, data collection records such as the interview guide and tables illustrating theme development from transcripts. This thorough documentation enhances the dependability of the study, allowing others to retrace the steps of the study for themselves and verify that findings are well founded (Fade, 2004). Furthermore, rich quotes from participants' accounts were presented to enhance authenticity and confirmability, demonstrating how the findings reflected the participants' lived experiences and are grounded in the collected data rather than being influenced by the researchers' own personal biases (Cope, 2014). Theoretical coherence was demonstrated by upholding the theoretical underpinnings of IPA, including its idiographic nature by analysing each participant's unique experiences

independently from one another, engaging in the double hermeneutic during data analysis and maintaining phenomenological engagement by staying close to participant's subjective meanings.

3.8.4 Impact and Importance

This refers to the relevance and contribution of this study. According to Yardley (2000), a study should contribute meaningful new impactful insights into the field. This was, to the researcher's best knowledge, the first local study aimed at exploring the experiences of critical care nurses caring for patients at the end of life in the ICU setting. Indeed, the findings of the current study can help inform recommendations for ICU policies, nurse training programmes and support strategies for patients, families and nurses, thus contributing to improving the EOLC experience for all stakeholders.

3.9 Reflexivity and Researcher's Positionality

Consistent with IPA's double hermeneutic stance, the researcher plays an active role in co-constructing meaning through the process of interpretation. Reflexivity is therefore crucial in IPA, requiring researchers to engage in ongoing self-awareness of how their background and assumptions may influence the research process (Clancy, 2013). The researcher kept a reflexive journal to record thoughts, emotions and evolving interpretations throughout the research process.

My background as a surgical nurse with no direct experience working in the ICU inevitably influenced how I approached this study. My position as an outsider provided me with a unique external perspective, allowing me to approach participants' experiences with curiosity and openness rather than assumed familiarity. However, I was also aware of the potential limitations this position entailed. At the beginning of the research process, I noted in my reflexive journal:

“Given my lack of first-hand ICU experience, I am a little apprehensive that I might not fully grasp the clinical, emotional and ethical complexities encountered by critical care nurses providing end-of-life care in the ICU. I must keep in mind to listen carefully during the interviews so that I know better how to follow up their responses and avoid filling in gaps with my own assumptions.”

As interviews progressed, I became more aware of my position as an insider within nursing and an outsider to the ICU. Whilst I shared their professional values of empathy and patient-centred care, I also recognised that my clinical context influenced my interpretations differently. After one of the interviews, I reflected on the following:

“I had initially held the assumption that intensive care nursing is primarily oriented towards preserving life and recovery. However, I know that this is not always possible due to the critical condition of patients in the ICU, requiring nurses to transition from providing life-sustaining care to end-of-life care. Hearing the nurse describe the withdrawal of treatment made me realise how different ICU nursing is from my own experience in surgery. There is a substantial emotional burden and moral uncertainty involved.”

This awareness helped me remain sensitive to the depth of participants’ emotional engagement with patients and families. Moreover, reflexivity was central throughout the analytic process. I often revisited my notes to question my interpretations, asking myself, *“Am I interpreting this through my own emotional reaction, or is this meaning grounded in this participant’s account?”* These moments of critical self-questioning reinforce IPA’s double hermeneutic, where

participants were making sense of their experiences and I, in turn, sought to make sense of their meaning-making whilst remaining aware of my interpretative lens. To further compensate for my lack of ICU experience, I also sought peer debriefing from an ICU-experienced colleague to help me ensure that my interpretation was firmly grounded in participants' experiences.

By engaging in reflexivity, critical questioning of my position and peer debriefing, I sought to ensure that participants' voices remained central, whilst acknowledging my interpretative stance as a researcher. This process of continuous self-examination ensured trustworthy and transparent interpretations and findings, which emerged organically from ICU nurses' experiences of providing EOLC.

3.10 Ethical Considerations

Due to the unpredictable and participant-centred nature of qualitative research, qualitative researchers are more likely to encounter ethical dilemmas compared to other researchers using different approaches (Houghten et al., 2010). Therefore, qualitative researchers bear significant responsibility for upholding ethical standards.

Ethical approval was obtained from the Faculty Research Ethics Committee (FREC) together with permissions from all the required entities(Appendix C). To prevent the risk of coercion, the researcher did not directly approach participants herself. Instead, two ICU charge nurses assumed the role of intermediaries and invited eligible participants to participate in this study. In this way the participants would not feel pressure to participate.

Participants were provided with a PIS, which reassured them that participation was voluntary and that as autonomous participants, they could withdraw at any moment

from the study without any repercussions or needing to provide an explanation. Before the interview, any questions that participants had were resolved by the researcher and after expressing verbal consent, participants were given a consent form for them to review before signing. On the day of the interview, the researcher addressed any questions raised by the participants and ensured that they understood the information provided on the consent form, collecting the signed consent forms.

Maintaining confidentiality involves altering or removing any personal or identifiable information to safeguard the participant's privacy (Allen, 2017). This was ensured throughout the study by having the audio recordings and interview transcripts stored offline in an encrypted manner on an external hard disk, accessible only to the researcher. Moreover, any written material was kept in a locked drawer. Furthermore, pseudonyms were used to conceal the participants' identity. The sensitive nature of the topic and the potential for participants to recall distressing experiences posed a risk of emotional distress. Therefore, to minimize any potential harm, participants were offered professional counselling by the hospital's psychology department free of charge, if the need arose. A contact number for the hospital psychologist was provided in the PIS.

3.11 Conclusion

This chapter presented a detailed account of the comprehensive methodology conducted for this study. The following chapter presents the findings that emerged from the collected data.

Chapter IV

Findings

4.1. Introduction

This chapter presents the findings of this research study, which aimed to explore and interpret the lived experiences of critical care nurses providing EOLC to patients in the ICU.

4.2 Theme development

The development of the following Group Experiential Themes (GETs) came from the analytic process undertaken in accordance with Smith et al. (2022) steps four to seven (Section 3.7), which focused on identifying connections across emergent experiential statements and clustering them into broader conceptual groupings.

During this stage, related experiential statements were gathered into cluster groups and organised into PETs. Through iterative comparison across all transcripts, convergent and divergent experiences were examined, leading to the formulation of four overarching GETs that include shared meanings across participants.

These GETs reflected the aim and objectives of this phenomenological study: (1) Shaping the dying process (2) Carrying the Weight of End-of-Life Care, (3) Care Beyond the Patient (4) End-of-Life Care in a Curative Space. GET 1 was divided into three subthemes: (1) Advocacy in End-of-Life Care where participants reflected on their perceived role as their patients' advocate; (2) Crafting a Good Death where participants reflected on how they provide their patients with a "good death" experience and the meanings they associate to this; (3) Navigating Power Hierarchies. GET 2 was divided into two subthemes, (1) When it Hits Home where participants addressed the emotional and psychological impacts of caring for dying patients has on them; (2) Coping in Practice where participants discussed different coping strategies they use to deal with these impacts and their support needs. GET 3 was divided into two subthemes; (1) Supporting Families where participants

discussed the importance they attribute to also caring for families of dying patients, (2) Communication as Care where participants discussed the complexities and importance of communication in EOLC. GET 4 was divided into two subthemes; (1) The ICU – A Restless Space for Dying where participants reflected on how the spatial environment and the technological influence impacts their experience of providing quality EOLC to their patients, (2) Seeking Systemic Structure in Uncertainty where participants discussed how a lack of EOLC guidelines and training leads them to experience uncertainty when caring for dying patients in the ICU.

The chapter presents excerpts taken directly from the interview transcripts to illustrate the development of themes, enhance the reader's understanding, and foster transparency. Participants chose to speak in Maltese, their native language, with occasional code-switching into English, a common practice among bilingual Maltese speakers. The excerpts are presented both in the original Maltese language and the translated English version. The participants in this study were experienced ICU nurses, whose ages ranged from 30 to 50 years. The participant sample consisted of two male and two female nurses, whose experience in the ICU ranged from four years to nineteen years in practice. All participants had direct experience providing EOLC in the ICU setting, thus well positioned to contribute rich and unique insights. The four participating nurses were given the following pseudonyms to safeguard confidentiality: Megan, Simon, Kevin and Jennifer.

Table 4.1 presents the four GETs and their respective subthemes, together with thematic excerpts from the transcripts to illustrate better the link between the developed themes and the interpreted data and how the interpretative process evolved from individual to group-level analysis.

Table 4.1: Group Experiential Themes and Subthemes

| Group Experimental Themes | Sub-themes | Thematic Excerpts |
|--|--|--|
| Shaping the dying process | <ul style="list-style-type: none"> ● Advocacy in End-Of-Lifecare ● Crafting a Good Death ● Navigating Power Hierarchies | <p><i>“You have to be the advocate of the patient, and we don’t go beyond the patients’ wishes.”</i></p> <p><i>“In these cases, you start to realise more that, listen, now you are not curing, you’re caring”</i></p> |
| Carrying the Weight of End-of-Life Care | <ul style="list-style-type: none"> ● When it Hits Home ● Coping in Practice | <p><i>“I relate to them...you start relating with these things, and you say that could have easily been me or someone I know.”</i></p> <p><i>“I go home and hug my little one...Because it brings you conscious of your mortality and how you need to cherish them</i></p> <p><i>“I maintain like an invisible block”</i></p> <p><i>“I think here there needs to be more focused psychologists here. There should be a resident psychologist here”</i></p> |
| Care Beyond the Patient | <ul style="list-style-type: none"> ● Supporting families ● Communication as Care | <p><i>“I prioritise the relatives, I try to put their mind to rest that he [the patient] is not in pain and not suffering.”</i></p> <p><i>“When you explain to them you try to do it in simple words because most of the time they don’t understand because they are in shock”</i></p> <p><i>“You have to be very careful”</i></p> |
| End-of-Life Care in a Curative Space | <ul style="list-style-type: none"> ● The ICU – A Restless Space for Dying ● Seeking Structure in Systemic Uncertainty | <p><i>“so it’s not the most peaceful environment.”</i></p> <p><i>“I agree with technology however you could get to a point where technology takes over [sighs] and you become [the patient] like a piece of meat in a bed”</i></p> <p><i>“the fact that there isn’t a structured approach, a proper protocol on end-of-life care, emm, I think that’s what I find most difficult”</i></p> <p><i>“Sometimes I don’t feel trained enough on this...to provide psychological support”</i></p> |

4.3 GET 1: SHAPING THE DYING PROCESS

This theme explored what ICU nurses prioritise and the roles they undertake to facilitate a peaceful, dignified, and compassionate death experience for their patients in the ICU, which is characterised by a highly technical and medically driven environment. Consistent among all four participants was a strong sense of duty to safeguard patients' comfort, dignity and wishes. Nurses prioritised not only clinical care but also providing holistic care that addressed the patients' physical, emotional and relational needs.

4.3.1 Advocacy in End-Of-Life Care

This subtheme captured how nurses make sense of advocating for patients and families to ensure their needs are heard and respected at the end of life.

Megan viewed it as her primary duty to act as the patients' advocate in ensuring that the patients' wishes were respected. This is particularly significant in EOLC situations, where patients in a sedated and unconscious state often cannot participate actively in their own care decisions.

“You have to be the advocate of the patient and we don't go beyond the patients' wishes because if he is intubated and sedated, you don't know what his wishes are.” (Megan, p.4)

“You have to be the advocate for the patient u ma tmurx ultra min dak li il-pazjent jixtieq ghax jekk dan se jkun intubat u sedated ma tkunx taf x'jixtieq.”

Megan viewed her role as “*part of the team*” (p. 4), attempting to influence care decisions in the best interest of her patient.

“You’re part of the team so you put your input in with that end goal of keeping the patient in mind.” (Megan, p.4)

“Qisek tkun parti mit-tim biex titfa l-input tiegħek with that end goal li il-pazjent iżzommu f’moħħok”.

Megan’s quotes revealed the moral duty she feels in representing the patient’s unheard voice. Her understanding of advocacy underscored her perceived role as both a guardian and an intermediary – the essential link between the patients’ needs and the medical team’s decisions.

Like Megan, Jennifer strongly advocated for respecting the patients’ final wishes, perceiving this as central to facilitating a good death for her patients.

“[A good death is] painless, comfortable, and I think that his wishes are respected till the very end.” (Jennifer, p.13)

In that respect, Jennifer critically referred to the tendency within the Maltese culture to avoid openly discussing or preparing for death, consequently leading to uncertainty about the patients’ end-of-life wishes among family members, who must often make difficult decisions for their loved ones in EOLC situations.

“As Maltese people in our culture we don’t really like to talk about end-of-life, I see it personally...Malta I think we’re still a bit behind in these things. We don’t plan ahead, like we’re afraid to talk about these things, when its importance is very big.” (Jennifer, p. 1-2)

“Bħala Maltese people fil-kultura tagħna ma tantx inħobbu nitkellmu fuq end-of-life, jien naraha personalment...Malta nahseb għadna naqra lura f’dawn l-affarijiet. Ma nipplanawx min qabel, qisna nibzghu nitkellmu fuq dawn l-affarijiet, meta l-importanza tagħha hija kbira hu.”

Jennifer’s insightful reflections illuminate the multi-faceted reality of EOLC in a culture uncomfortable around death, impacting the nurses’ ability to fulfil their advocacy role effectively and adding an additional layer of moral and ethical tension to their role when they do not know what the patients’ wishes are.

Indeed, both Megan and Jennifer expressed feeling a sense of moral clarity and relief when they know the care they are providing aligns with the patient’s wishes, underscoring the value they assign to patient autonomy and dignity.

“You know you’re doing the right thing for the patient.” (Jennifer, p. 7)

“You feel that sense of relief.” (Megan, p.13)

“Thoss dik in-naqa relief”

These sentiments they experience suggest that for them, advocacy is not simply another professional duty but a source of emotional and ethical fulfilment, where they uphold their patients’ dignity and autonomy in their final moments.

4.3.2 Crafting a Good Death

ICU nurses' perception of a "good death" was shaped by both physical and emotional comfort, with the patient's dignity and personhood prioritised even in their final moments.

Megan explained how in EOLC, she prioritised the physical comfort of the patient, emphasising the importance of the patient being "*pain free and comfortable*" (p. 6) in their final moments. She also stressed the importance of the patient being "*surrounded by family*" (p. 16), affirming the patient's personhood and providing a comforting presence for the patient, even if they are unconscious.

Similarly, Jennifer reflected on her responsibility to safeguard the patients' comfort and dignity, explaining how she consciously shifts her approach from focusing on the clinical aspects of care to more compassionate, person-centred care – a crucial turning point in how she redefines her professional role in EOLC.

"In these cases, you start to realise more that, 'listen, now you are not curing, you're caring'" (Jennifer, p.8)

"F' dawn il-kazijiet tibda tirealizzza iktar li 'isma issa you're not curing, you're caring'"

The phrase "*listen now*" functions almost as a reminder to herself to recalibrate her focus and relinquish the impulse to *do for* the patient and instead *be with* the patient. This moment of self-awareness demonstrated how EOLC within a cure-focused environment can prompt a reorientation of one's professional identity and

purpose and captures the tension ICU nurses face when shifting from a mindset orientated towards recovery to one grounded in care and human connection.

Jennifer emphasised the importance of ensuring that the patient is pain-free and comfortable, especially since their conditions may prevent them from verbally expressing their needs.

“You always make sure that he’s comfortable still even though he can’t talk...more so since he can’t talk. You have to be more careful that he is not in pain, that he’s calm and that he’s well respected for in everything.”

(Jennifer, p. 3)

“Dejjem trid tara li jkun komdu xorta avolja ma jkunx jista’ jittellem...anzi iktar peress li ma jkunx jista’ jittellem. Trid toqghod iktar attent li ma jkunx mugghuh, li jkun kalm u li he’s well respected for f’kollox”

Kevin also prioritised the physical comfort of the patient, emphasizing the importance of small, often overlooked actions such as adjusting the surroundings to provide the most humane death possible in a setting not naturally designed for death.

“You wet their lips...even dimming a bit the lights...Small things, basic things that sometimes we forget but sometimes it’s the most basic things that are important” (Kevin, p.3)

“ixxarrablu naqa ħalqu...anke tbaxxi naqa id-dawl...Affarijiet zgħar, affarijiet bażiċi li gieli ninsewhom imma xi kultant l-iktar affarijiet bażiċi l-importanti”

Resonating with both Megan and Jennifer, for Kevin a good death involved not only physical comfort but also a broader sense of emotional comfort and connection.

“A good death personally, you have your family, you’re not in pain, at peace” (Kevin, p.37)

“A good death personalment, għandek il-familja, m’intix muġġhuh, qiegħed għall-kwiet.”

Kevin and Jennifer both emphasised the relational aspect of care, describing the presence and closeness of family as fundamental elements to dying well, suggesting that the patient’s emotional comfort and peace are grounded in their family’s presence.

“The most important are the relatives. That the patient has his relatives surrounding him. That’s the most important thing, his family surrounding him...I find that very important” (Kevin, p.4)

L-iktar ħaġa importanti ir-relatives. Ikollu ir-relatives hdejh. L-iktar ħaġa importanti, ikunu imdawrin miegħu...dik importanti ħafna naraha”

“I agree with letting the relatives stay here. There are those [nurses] who are a bit more reluctant to let the relatives stay near the patient, but the patient doesn’t want me, I’m a foreigner to him.” (Jennifer, p.6)

“Jiena naqbel li inħallu ir-relatives hawn. Hawn min hu naqa iktar reluctant iħalli ir-relatives hdejn il -pazjenti imma, il-pazjent mhux lili jkun irrid, I’m a foreigner to him.”

Here Kevin and Jennifer shared an understanding that EOLC is not only about clinical and physical care but also about emotional presence and human connection, reflecting a deeply humanistic view of death. Their emphasis on family presence demonstrated respect for the patients' personhood and the life they lived. By creating a space where the patient is surrounded by those who love them, the nurse helps shape a death experience that is not only pain-free but also emotionally and relationally meaningful.

In his account, Simon too expressed a commitment to safeguarding patient dignity and comfort, despite there being a shift in care priorities from curative to palliative. Simon expressed how withdrawing active treatment did not translate to withdrawal of care, asserting how care is still provided with equal attentiveness.

“We still do a lot of the routine nursing care...the nursing care doesn't really change.” (Simon, p.2)

“Hafna mill- affarijiet nagħmluhom xorta bħal routine nursing care...nursing care ma jinbidilx daqshekk”

Simon reflected deeply on what a good death in the ICU should be, stating that being *“mifquh bil morfina”* (p. 11), full of morphine, pain-free and comfortable was the ideal scenario. This colloquial Maltese phrase he used underscored the importance Simon places on comfort and pain management.

Participants also reflected on experiencing “bad deaths”, which were often described as ones where the patient died alone, unexpectedly or with their wishes not being respected. Megan frustratingly recounted a particularly distressing case of a patient dying alone due to logistical and legal complications.

“After all that work, he ended up palliatively extubated and he died alone.”

(Megan, p.19)

“Wara dak ix-xogħol kollu spiċċa għamlulu palliative extubation u miet waħdu”

“The first thing that shouldn't have been done was that trachy [tracheostomy] especially if the relatives are telling you that he wouldn't have wanted this. They know the patient more than we do obviously but just because legally they weren't his next of kin we ignored them and indirectly we ignored the patient's wishes hu.” (Megan, p.20)

“L-ewwel ħaga li ma messix saret kienet it-trachy speċjalment jekk il-qraba qed jgħidulek isma dan ma ridtx hekk. Huma jafuh iktar minna żgur il-pazjent imma just għax legally m'humix il-next of kin we ignored them and indirectly we ignored the patients' wishes hu.”

Megan went on to state, *“When you see cases like this, it's like a roller coaster, you get frustrated but you know there's nothing you can do”* (p. 20), poignantly expressing the emotional distress nurses experience when they cannot provide the holistic care they believe is crucial for facilitating a dignified and meaningful death for their patients.

Similarly, both Jennifer and Simon recounted experiences of witnessing EOLC patients die suddenly.

“At one point they’re talking, and all of a sudden, they arrest... For me that’s not a good death, for him I think it would have been a good death. I don’t know maybe he didn’t feel anything, but it’s like [pauses] you say how did he die?” (Jennifer, p.15)

“Filli jkunu qed jirkellmu u filli jarrestjaw...For me that’s not a good death, for him nahseb it would have been a good death. Ma nafx ma hass xejn forsi imma qisek tghid kif miet?”

“It looks very ugly from outside, but it could be that the person wouldn’t have felt anything [pauses]; you cannot know in truth.” (Simon, p.13)

“Tidher kerha hafna min barra imma jista jkun il-bniedem ma jkun qed iħoss xejn, [pauses]ma’ tistax tkun taf fil-verita.”

Jennifer’s and Simon’s reflections elicited a feeling of uncertainty that nurses experience about the extent of patients’ suffering in such sudden deaths. Both participants attempted to find relief in imagining that the patient may have died without suffering pain, thus providing their patients with a “good death”.

These nurses’ encounters reflect how undignified deaths conflict with their high standards of what ICU EOLC should be and how facilitating a good death experience for their patients is simultaneously both a professional duty and a personal endeavour, which offers them a sense of meaning and fulfilment.

4.3.3. Navigating Power Hierarchies

Despite their efforts to humanise the dying process, participants acknowledged that their influence on EOLC decision-making (EOLCDM) was limited by an existing hierarchical structure in the ICU.

Megan noted a varied level of involvement in EOLCDM, depending on the consultant in charge, and lamented their constrained role.

“It depends on the consultant. It depends a lot on that.” (Megan, p.5)

“Jiddependi skont il-konsulent. Jiddependi hafna.”

“As for our role, it’s kind of our hands are tied because it’s like there’s that plan and you follow it” (Megan, p.4)

“Bħala role hu naqa idejna marbutin għax qisu hemm dak il-plan u imxi miegħu.”

The metaphor Megan used (*“our hands are tied”*) poignantly illustrated a professional culture which is medically oriented and where the nurse is expected not to overstep their perceived role.

Similarly, Kevin reflected on situations where he did not necessarily agree with the patients’ care plan and acknowledged how his influence is limited within perceived boundaries.

“It’s an issue that we don’t have a say in as a nurse...because it’s clinical. I’m not going to go tell the doctor listen stop [treatment]...how is the patient benefiting? You can’t tell him that because it’s a clinical issue.” (Kevin, p.24)

“Hija issue li m’ghandnix say fuqha bhala nurse...ghax hija clinical. It-tabib mhux se mmur nghidlu isma waqqafa...x’inhū jieħu minnha? Ma tistax tghidlu hekk ghax hija clinical issue”

In saying *“because it’s clinical”* Kevin captured the divide between clinical expertise, which is typically viewed as the physicians’ domain and the nurses’ patient-centred insights. His reluctance reflected that nurses perhaps feel that their contributions are not valued as much as those of the doctors’.

Kevin pointed out that his involvement in EOLCDM is often self-initiated rather than formally sought.

“If you involve yourself, yes. You ask them [doctors]. Like I said, if you bring it to their attention, yes, they are open to it. But you have to go yourself. They’re not going to come themselves.” (Kevin, p.25)

“Jekk tinvolvi ruħek inti iva. Isaqsihom [it-tobba]. Kif għidtlek jekk tiġbdilhom l-attenzjoni, iva, they are open to it. Imma trid tmur int. Mhux se jiġu huma”

While Kevin described doctors as being “open” to nurses’ input, they do not actively involve them, suggesting that nurse involvement in EOLCDM is not formally integrated into the work culture but rather something that the nurse must seek out themselves, underscoring the power imbalance at play.

This feeling of being undervalued also echoed in Simon’s account when he acknowledged that, though nurses’ insights are clinically valuable given their constant presence, ultimately the doctor’s input outweighs the nurse’s.

“The person that spends the most time with the patient is the nurse...The nurse, who is with the patient all day can tell the doctor...in that case the nurses’ word is given some weight.” (Simon, p.9)

“l-iktar persuna li tqatta’ hin fejn il-pazjent huwa in-nurse... in-nurse li ha jkun qiegħed hemm ġurnata shiħa jista’ jgħid lit-tabib... f’dak il-kas il kelma tan-nurse tingħata daqxejn weight”

“they [doctors] have the final say at the end.” (Simon, p.10)

minhom trid tiġi fl-aħħar mill-aħħar.”

This duality illustrates the tension nurses face within this power imbalance, where their proximity to patients puts them in the optimal position to provide valuable clinical insights, yet their contributions in decision-making are often undervalued.

These participants’ reflections illustrated how nurses’ commitment to their patients’ well-being is strongly influenced by the hierarchal structure within the ICU, thus

impacting the quality of care provided, their professional identities, and their moral fulfilment in their roles.

This theme illustrated nurses' commitment to shaping the dying process for their patients in the ICU by focusing on comfort, emotional peace and family presence. These participants' concepts of a good and bad death within the ICU are guiding principles rooted in lived experiences, which have left a lasting impression on them and which guide them in delivering the best possible care for their patients at the end of life. This theme integrates the emotional, ethical and professional dimensions of EOLC and illuminates how nurses are committed to bridging the clinical and human realms to secure a good death for their patients, often within a professional attitude that limits their formal authority.

4.4. GET 2: CARRYING THE WEIGHT OF END-OF-LIFE CARE.

This theme explored the emotional and psychological impacts experienced by ICU nurses providing EOLC. The consensus among all four participating nurses was that caring for dying patients takes an emotional toll. Participants spoke of navigating complex emotional terrain which prompted moments of personal identification, vulnerability and existential reflection. All participants reported developing adaptive strategies, ranging from maintaining emotional boundaries to humour, to help mitigate the emotional and psychological toll of repeatedly witnessing death, grief and trauma.

4.4.1. When it Hits Home

A strong convergence across all participants was the heightened vulnerability experienced when caring for younger patients or patients whose life circumstances resembled the nurses' own.

Megan explained how when caring for patients who shared her own life circumstances, such as a newlywed patient, she felt a personal connection to such patients, leading her to empathise deeply with them.

“I relate to them...you start relating with these things and you say that could have easily been me or someone I know.” (Megaan, p.14)

“Nirrelata magghom... qisek tibda tirrelata ma’ dawn l affarijiet u tghid that could have easily been me or someone I know”

Moreover, she acknowledged that EOLC cases that mirror aspects of her personal life led her to become more emotionally involved, recognising this as potentially problematic, as this could blur professional and personal boundaries.

“Maybe the case you have, in some way you relate more to it, and you try to go further than maybe you should, which is not good either.” (Megan, p.15)

“Forsi il-każ li jkollok b’xi mod tirrilata miegħu aktar u tipprova tmur ultra milli suppost xi kultant li mhux tajjeb lanqas.”

Megan’s profound reflections demonstrated how providing EOLC is not simply a clinical task but an experience that can elicit intense personal introspection.

Similarly, Kevin reflected on the lasting psychological imprint left by certain EOLC cases involving young patients, particularly in his role as a parent. Kevin

vividly recounted past EOLC experiences he had involving young patients, particularly a victim of a car accident and a young patient who had a choking incident. Kevin admitted how such EOLC cases have made him hypervigilant, almost paranoid as a parent, describing himself as becoming “*manic*”:

“Accidents involving young people, I have a daughter, accidents and things like this [sighs] You become a bit of a maniac...You relate to them that’s why you become a bit manic I think...with the carnage you see here...you become aware of everything” (Kevin, p.30-31)

“Accidents taż-żgħar, jiena tifla għandi, accidents u dawn l-affarijiet [sighs] tiġi naqa maniac... Inti tirrelathom b’hekk tiġi naqa maniac naħseb...bit-tkissir li tara hawnekk...tiġi aware ta’ kollox”

“If my daughter is eating sausages God forbid, she doesn’t cut them in half because I freak out [pauses] because I remember him [that patient] straight away and what happened to him. Or if she’s in the car God forbid, she’s not wearing the seatbelt because I remember another accident we had” (Kevin, p.30-31)

“Jekk tkun qed tiekol is-sausages it-tifla allahares ma taqşamomx min-nofs hekk għax moħħi jifrikja [pauses] għax fih niftakar mal-ewwel u x’garalu dak. Jew inkella jekk tkun fil-karozza allahares ma torbotx is-seatbelt għax niftakar għax darba kellna accident ieħor”

Kevin described how caring for young dying patients triggers a deep emotional impact on him.

“Young patients affect me a lot...Someone who is in the prime of their life their place isn't here, he's here because something happened that wasn't supposed to.” (Kevin, p.40-41)

“iz zghar jaffetwawni hafna jien... Xi hadd fl aqwa tijew postu mhux hawn, ghax inqalet xi haga li ma kellix tinqala qijed hawn.”

“That's why [these cases] upset me the most, because sometimes I see parents having to bury their own kids” (Kevin, p.41)

“Ghalek l iktar li jdamdmuni dawk ghax gili nara il genituri se jidfnu lil l ulidhom.”

Kevin's choice of emotionally charged words such as “*idamdmuni*” and his reflection on becoming “*a maniac*” clearly convey how nurses internalise experiences of EOLC and loss, carrying them into their own personal life.

Similarly, Jennifer reflected on the emotional challenge of caring for conscious EOLC patients and witnessing highly intimate family moments.

“[The patient] was still talking till the end, so even how he was speaking to his relatives, you see the relatives crying [pauses] that for me is a big challenge [sighs]. Because if you've gone through it yourself that situation, you've had your own experience, it's like you relive that experience.”

(Jennifer, p.5)

“[Il-pazjent] kien għadu jitkellem sa l-aħħar, so anke kif kien qed ikellem mal-relatives, tara ir-relatives imbikmin [pauses]dik għalija challenge kbira [sighs]. Għax tkun għaddejt minnha l-affari, you’ve had your own experience, qisek you relive that experience”

Jennifer’s reflection on the act of reliving implied that these emotionally taxing moments do not remain within the professional domain of one’s life but instead awaken personal memories and trigger recollection of personal grief and loss.

While Simon appeared to maintain a more emotionally distant stance, as illustrated in his words, *“I’m not going to have special bonding with the patient”* (p. 17) [*mhux se nagħmel xi bonding speċjali [mal-pazjent]*], he admitted that certain EOLC cases, particularly those involving younger patients or patients who have been on the ward for a while, left a lasting impact on him.

“When the patient is still young or the patient has been here a while and all of a sudden, he dies, you get more emotionally attached.” (Simon, p.17)

“Meta il-pazjent ikun għadu żgħir jew ġieli xi pazjent ikun ilu hawn u f’daqqa waħda jmut...tiġi iktar emotionally attached”

Simon also recalled the emotional challenge he experienced when faced with family grief.

“That’s the most challenging emotionally, when you see the family crying, it’s something very horrible” (Simon, p.5)

“dik l iktar li hi challenging emozzjonali, meta tara tal-familja jibku, hija xi ħaga vera kerha”

This suggested that while some nurses may try to uphold an emotional boundary, witnessing grief, particularly family grief, challenges this boundary and triggers a deeper emotional engagement.

Providing EOLC and witnessing death also prompted existential reflection among participants, impacting their personal outlook on life, mortality, and relationships.

Megan explained how frequent encounters with EOLC and death have taught her to “live life day by day” and to be “more relaxed” (p. 13).

“When we have end-of-life care patients, especially when they’re young, you learn to appreciate what you have...you appreciate what you have and not to take our health for granted...Because here the first thing you learn is how short life can be” (Megan, p.24)

“Meta jkollna end-of-life care speċjalment ikunu patients żgħar, titgħallem tapprezza li għandek...tapprezza li għandek, is-saħħa kemm ma nagħtux kasha...għax hawnekk l-ewwel ħaga li titgħallem hija kemm il-ħajja taf tkun qasira.”

Despite the emotional toll of the situations, frequent encounters with mortality have enhanced Megan’s appreciation for life and health, reflecting the nuanced, multifaceted nature of EOLC work.

Jennifer, too, echoed these sentiments, admitting to having a deeper awareness of life’s fragility and an enhanced appreciation of its value.

“Since seeing and caring for end-of-life patients, especially when they’re young...I think I’ve started to appreciate life more. Because if something comes upon you all of a sudden [pauses]that’s it...It could be like...it’s the end.” (Jennifer, p.12)

“Kemm ilni nara u nieħu ħsieb end of life patients, speċjalment ikunu żgħar...naħseb sirt napprezza iktar il- ħajja. Ghax tiġi xi haġa fuqek hekk all of a sudden [pauses]daqsekk...it could be like...it’s the end”

Similarly, Kevin reflected on developing a heightened awareness of his mortality and an understanding of life’s uncertainty, which make him more appreciative of life and his family.

“You become conscious of your mortality uwx...conscious of your mortality...today you’re here, tomorrow we don’t know.” (Kevin, p.34)

“Iggibek conscious of your mortality uwx....conscious of your mortality...illum hawn, għada ma nafux”

“I go home and hug my little one...Because it brings you conscious of your mortality and how you need to cherish them [family].” (Kevin, p.42)

“immur id-dar u nġhannaq iz-zgħira tiegħi...Għax iġġibek konxju tal-mortalita u li trid tgawdihom [familja]”

Simon’s account contrasted with the other more emotionally expressive participant accounts, as he reported no personal impact, highlighting the different ways nurses may choose to navigate the impacts of EOLC.

“I’m not really a person that is affected a lot by work, from the things that happen at work.” (Simon, p.5)

“ma tantx jien bniedem li niġi affettwat ħafna mix-xogħol, mill- affarijiet li jiġru”

Together, these participants’ reflections reveal how EOLC can profoundly impact ICU nurses, not only in their caregiving but also in their ongoing personal lives. While the emotional impact may vary, when a case “hits home”, it can shape the nurse's sense of self and worldview in lasting ways.

4.4.2. Coping in Practice

Participants reported various coping strategies which they employed to help them function effectively when caring for dying patients and their families. Megan, for instance, reflected on how the exposure to traumatic cases she has encountered has led her to become “immune” over time.

“When you see these traumatic cases you know..emm..they’re shocking, so with time, to deal with it you have to become immune to a certain extent.”
(Megan, p.12)

“Meta tara dawn it-traumatic cases taf kif...emm...ikunu xokkanti so with time, to deal with it, you have to become immune sa certu punt.”

Her use of the word “immune” evokes imagery of a bodily defence mechanism, suggesting that psychological protection is a necessary survival strategy. This emotional immunity serves as a self-protective mechanism, allowing her to continue

performing her duties effectively in an emotionally disturbing setting where loss and suffering are routine.

Importantly, Megan emphasised that becoming immune did not equate to indifference or providing suboptimal care to her patients and their families but rather a way of compartmentalising emotional responses.

“Immune in the sense that not you don’t provide the care needed, immune personally, where you say, listen, once you leave work, that’s it.” (Megan, p.12-13)

“Immune fis-sens li mhux you don’t provide the care needed, immune personally, li tgħid, isma x’hin tlaqt mix-xogħol, daqsekk”

Here she made a deliberate distinction between professional empathy and personal vulnerability. The phrase *“once you leave work, that’s it”* signals the conscious effort Megan makes to set emotional boundaries and carefully strike a balance between caring deeply and protecting herself. Similarly, Simon reflected on being able to *“switch on and switch off”* (p. 5) emotionally.

“I maintain like an invisible block [hand gesture] but again, I get along very well with the patient and relatives in some way at the same time. Maybe because of that, I don’t know” (Simon, p.17)

“inżomm qisu block invisibli [hand gesture] imma again, immur tajjeb ħafna mal-pazjenti u mal-qraba b’xi mod imbghad fl-istess ħin. Forsi ħabba hekk ma nafx”

The metaphor of maintaining an “*invisible block*” suggested that Simon emotionally distances himself but still cares compassionately for his patients and their families. Interestingly, Simon implied that this boundary he maintains may enhance his relational functioning, suggesting that it allows him to support patients and families without becoming emotionally overwhelmed.

The need to strike such a balance was also echoed in Jennifer’s reference to her attempt to maintain a boundary between her personal and professional life.

“I try to leave my work here. When I leave here, that’s it, I try to shut off my mind. It’s not always easy ta sometimes you have cases that you keep thinking and thinking but that’s my coping mechanism. When I get home now, it’s my personal life.” (Jennifer, p. 19)

“Nipprova inħalli xogħoli hawnekk. X’hin noħrog minn hawn daqshekk, nipprova moħħi jixxatja. It’s not always easy ta’ ġieli jkollok każijiet tibqa taħseb u taħseb imma il-coping mechanism dik hija tiegħi. X’hin nasal id-dar issa personal life”

The participants’ reflections point towards a broader reality in critical care nursing, where having emotional boundaries is not necessarily a lack of compassion but perhaps serves as an emotional protective mechanism that allows nurses not to internalise every loss and to function effectively in the high intensity, emotionally charged ICU environment.

Other coping mechanisms mentioned by participants were strategies aimed at self-care and restoring balance outside the clinical environment. Both Megan and Jennifer reflected on indulging in travel and leisure to help them recharge emotionally and restore a sense of normality beyond the ICU.

“I think I enjoy life more [laughs]. For example, we travel more.” (Jennifer, p.12)

“Nahseb sirt ingawdi aktar [laughs]. Eżempju insiefru iktar”

“You have to keep the wheel rolling, I guess, go out, enjoy life. From my end, I enjoy travelling, so I travel. You try to enjoy life” (Megan, p.24)

“You have to keep the wheel rolling I guess, toħroġ, tgawdi il-ħajja. Min naħa tiegħi nieħu gost insiefer so insiefer. Tipprova tgawdi il-ħajja”

Their accounts suggest that by engaging in pleasurable activities, they counterbalance the distress generated by constantly witnessing loss and grief in their professional roles. Their emphasis on enjoying life reflects almost an act of defiance against the emotional burden of EOLC and supports a pursuit of normality which reinforces their personal identity beyond their professional role.

Other coping strategies that were mentioned were humour and peer support, cited by Kevin, who employed these self-defence mechanisms to cope with the emotional heaviness of witnessing death. He described joking, teasing and laughing with colleagues *“sometimes we’re like school kids”* (p. 46) [*xi kultant qisna tfal tal-iskola.*], suggesting that humour serves as a psychological release. Here the

researcher noted that Kevin perceived coping as something collaborative: “*We try to cheer each other up*” (p. 46), reinforcing the importance of team cohesion not just as clinical colleagues but as an emotional peer support system.

Despite developing their own personal and peer-based coping strategies, all four participants viewed institutional psychological support as largely inadequate.

Megan expressed dissatisfaction with the hospital’s psychological support services, noting insufficient follow-up for nurses, particularly following traumatic events.

“That’s why I don’t seek for myself personally the psychological help [provided] at the hospital, because I don’t agree how certain things are said.” (Megan, p.22)

“Għalhekk qisu ma nfitix għalija personali ma nfitix psychological help tal-isptar, għax ma naqbilx kif jingħajdu ċertu affarijiet

“We just went for a session once...I don’t think it was sufficient.” (Megan, p.23)

“morna session darba... I don’t think it was sufficient.”

Megan’s discontent with “*how certain things are said*” suggests a perceived lack of emotional attunement and understanding from institutional services. Her dissatisfaction suggests that the failure of psychological support to relate with ICU nurses’ emotional experiences inadvertently makes nurses reluctant to seek help. Simon expressed a vague awareness of the availability of psychological support services for nurses:

“I think who wants there is some access to a psychologist I think...maybe it should be more promoted. I am not 100% aware but I think there is.”

(Simon, p.18)

“Naħseb min irrid hawn xi access għal xi psychologist naħseb...forsì għanda tkun iżjed promoted. Jien m’hiniex aware mija fil-mija imma naħseb hawn”

His uncertainty suggested a potential awareness gap, as staff wellbeing resources may well exist but are not integrated into the work culture or actively promoted, leaving staff unaware or disinterested.

Jennifer advocated for more proactive, peer-based support strategies. She advocated for group sessions, where colleagues can meet in a more social and relaxed setting outside of work, fostering peer connection and normalising emotional struggles.

“I prefer if we would have group meetings with a psychologist... because you meet outside of work, you have more fun, you meet with your colleagues but at the same time you’re talking about work and you see that you’re struggles weren’t just your struggles and that your colleagues also had the same struggles.” (Jennifer, p.20)

“Nippreferi kieku jkollna group meetings ma’ psychologist...Għax int qisek toħrog mix-xogħol, tieħu iżjed pjaċir, tiltaqa’ xorta ma sħabek imma fl-stess hin qed titkellem fuq ix-xogħol u tara li l-istruggles tiegħek ma kienux tiegħek biss, kienu anke f’ ta madwarek”

Here, Jennifer conveyed a desire for shared understanding and mutual validation. Like Kevin, Jennifer viewed coping as collaborative, where sharing work struggles can help reduce stigma and alleviate emotional burden.

Similarly, Kevin expressed a preference for group initiatives and emphasised the need for ICU-embedded psychological support:

“[I would like to have] Support groups where we can talk among ourselves”

(Kevin, p.47)

“Support groups li nistgħu nitkellmu bejnietna”

“I think here there needs to be more focused psychologists here. There should be a resident psychologist here.” (Kevin, p.46)

Jien naħseb irid ikun hawn iktar focused psychologists hawnekk. Kwazi iridu ikun hawn psychologist residenti hawnekk”

Kevin’s call for a “*resident psychologist*” reflected a desire for setting specific, accessible psychological support that acknowledges and values the emotional and psychological labour of working in a high trauma/mortality setting.

These participant accounts illuminate the diverse ways ICU nurses cope with the emotional demands of EOLC. While nurses rely on their individual coping mechanisms, they are often left to manage the complex emotional and psychological terrain inherent in EOLC alone, underscoring a concerning gap between the emotional demands of ICU EOLC and the support structures in place.

4.5. GET 3: CARE BEYOND THE PATIENT

A recurring theme across participants' accounts was how for ICU nurses EOLC extends beyond the dying patient and encompasses family needs, focusing on two interconnected aspects: family support as a core component of holistic EOLC and navigating the complexities of emotionally charged communication.

4.5.1 Supporting Families

Across all four accounts, ICU nurses consistently emphasised the emotional requirements of patients' families as a fundamental aspect of EOLC. Participants viewed family care as a primary responsibility underpinning their commitment to providing holistic care.

In her account, apart from emphasising patient comfort and pain relief, Jennifer also underscored her dual role in EOLC in becoming more attentive to and empathetic with family members' needs, given their emotional vulnerability in such scenarios.

“When we have these cases, I focus more on being empathetic with relatives...even if you just offer them a coffee or ask them if they've eaten anything...It makes you feel good in a way because at the same time you feel emm helpless because you cannot do anything for the patient but at the same time, you're giving your care to the relatives.” (Jennifer, p.13)

“Meta jkollna dawn il-każijiet, niffoka aktar on being empathetic mar relatives, anke li toffrilhom kafe jew tara kielux xi ħaġa...It makes you feel good in a way għax fl-istess hin thossok naħseb emm helpless għax ma tista tagħmillu xejn lill-pazjent imma at the same time, you're giving your care to the relatives”

Jennifer's reflections on "feeling good" when caring for the patients' grieving relatives suggested that she finds a sense of comfort and renewed sense of purpose when comforting families, especially when feeling otherwise helpless in changing the patients' outcome. These compassionate gestures do not only comfort relatives but perhaps help nurses to mitigate this emotional helplessness and fulfill their professional duty and commitment to providing holistic EOLC.

Similarly, Simon emphasised his role in supporting families and offering reassurance, explicitly linking pain management with easing family distress.

"I prioritise the relatives, I try to put their mind to rest that he [the patient] is not in pain and not suffering." (Simon, p.3)

"il-qraba li niprioratizza, nipprova iserħilhom rashom li mhux muġġuh u mhux ibati"

We start the morphine first of all for the patient, so the breathing isn't laboured, and even for the relatives because it's one thing seeing someone dying and gasping for air and it's another seeing someone dying like they're sleeping, peacefully. You're putting the relatives' minds to rest too." (Simon, p.12)

"Nibdew il-morfina one għall-pazjent biex in-nifs ikun iżjed mistrieħ u anke ħabba il-qraba għax mod tara lil xi ħadd imut u qed jaqta nifsu u mod tara lil xi ħadd imut qisu rieqed b'mod peaceful. Tkun qed isserah ir- relatives ukoll"

Simon's comment shows that physical comfort for the patient can translate into symbolic comfort for the family. He reveals how nurses try to influence how families see and make sense of death. By ensuring that the patient looks peaceful, nurses help families witness death as a dignified, less traumatic event.

Megan also emphasised her dual responsibilities in EOLC, explaining a shift in care priorities from the unconscious patient to the family.

“Our end-of-life care here is most of the time with a patient that is intubated and unconscious, so mostly it's the physical aspect that I give the most attention to. However, the emotional and psychological aspect then moves towards the relatives.” (Megan, p.6)

“L-end-of-life care tagħna hawnekk most of the time tkun ma pazjent intubat u unconscious so mostly the physical aspect l-iktar li nagħti attenzjoni. Pero l- emotional u is-psychological aspect imbghad timxi lejn ir- relatives”

Megan's statement highlights how nurses reorientate their focus and emotional investment when they can no longer communicate directly with their patient. This shift demonstrates a form of continuity of care where the family becomes an extension of the patient, allowing the nurse to continue providing emotionally meaningful care.

Megan highlighted her efforts to include family members in the patient's care by acting as an intermediary between them and the medical team.

“During the ward round you subtly mention it to them [doctors]: ‘Where are we going with this?’ or ‘Listen, I was speaking to the relatives, and they told me...’” (Megan, p.10)

“Waq t il- ward round i zerzaqilhom ‘Fejn se naslu hawn?’ jew ‘Isma kont qed inkellem il-graba u qaluli’”

This subtle act of advocacy illustrated how Megan enacts a form of moral labour by voicing families’ concerns.

Kevin also considered family support as an integral part of his role in EOLC.

“My role is to make the patient comfortable, to help and guide the relatives because it’s a shock, a trauma for them.” (Kevin, p.2)

“My role is to make the patient comfortable, to help and guide the relatives għax hija xokk, hija trawma għalijhom hu.”

“You try to help them, you give them privacy, close the curtains, and you explain to them what’s happening and how and why.” (Kevin, p.2)

“Tipprova tgħinhom, ittihom privacy, tagħlqilhom il- purtieri u tispjegalhom x’hinu jigri, kif u għala”

Kevin’s account illustrated how, through these symbolic acts, he tries to facilitate meaningful moments of closure, demonstrating a deeply relational and humanistic view of dying.

These nurses' reflections reveal a shared understanding that EOLC reaches beyond the patient, positioning family care as a core nursing aspect and presenting a dignified death as a collective experience shaped by both patient and family needs.

4.5.2 Communication as Care

A strong convergence emerged across all four participant accounts around the emotional, ethical and professional complexities of family communication and the facilitative role nurses play in this vital aspect of EOLC.

Megan emphasised being the primary person relatives seek for questions and clarifications.

“They turn to you because you’re the one that’s near the patient all the time.” (Megan, p.9)

“lejk se jduru għax inti se tkun il-ħin kollu hemmek [fejn il pazjent]”

Her observation demonstrates how being physically near the patient makes the nurse more accessible and positions her as both a caregiver and a communicator.

In their accounts, Megan and Kevin highlighted the communication techniques they employed when communicating with distressed relatives.

“When you explain to them, you try to do it in simple words because most of the time they don’t understand because they are in shock. (Megan, p. 16)

“You help them, guide them, explain to them, ‘Listen, this is being done because..we are doing this because’ You need to speak to them in the simplest way possible because don’t forget they see things tunnel vision; they are in big shock. (Kevin, p.2)

“Tgħinhom, tigwidahom, tispjegalhom, ‘isma qed isir hekk għax hekk, se nagħmlu hekk għax hekk.’ Trid titkellem bl- iktar mod sempliċi possibili għax huma tinsiex li qishom qed jaraw kollox tunnel vision, huma qegħdin f’xokk qawwi”

These accounts demonstrate nurses’ recognition of families’ diminished ability to understand information due to their shock, and an understanding that communication is not merely the delivery of information but an emotionally sensitive process where nurses help families make sense of these difficult moments. Megan and Jennifer described how communication involved managing family reactions, ranging from aggression to misplaced blame.

“You have to know how to deal with their initial shock that one of their loved ones is in the ITU...They could get aggressive, they could be rude ,emm, so you have to learn how to deal with that.” (Megan, p.21)

“you have to know how to deal with their initial shock li xi hadd mill- qaba tagħhom qiegħed l- ITU... Jafu jkunu aggressive, jafu jkunu pastazi emm so you have to learn how to deal with that”

“Sometimes they [relatives] see us a bit [pauses] like we killed him [patient]. I think it’s part of the grieving process, in fact, because you try to blame someone. But ehe, I think certain information how you give it, makes a difference as well.” (Jennifer, p.17)

“Xi kultant jarawna naqra qisna qtilnieh aħna. Naħseb it’s part of the grieving process filfatt, għax you try to blame someone. Imma ehe, naħseb ċertu informazzjoni kif ittiha ukoll tagħmel differenza”

Jennifer’s statement highlights the moral responsibility she feels to manage not only the way the message is conveyed but also its emotional impact, underscoring the moral labour inherent in EOLC communication.

Moreover, Kevin explained how he takes an active role in facilitating understanding, particularly during doctor-family interactions.

“...sometimes, I jump in and ask them, ‘Have you understood? Do you want to ask something?’ Because they would look literally hundreds of miles away with the news they’ve gotten.” (Kevin, p.18)

“...ġieli naqbez jien u ngħidilhom, ‘Fhimtu? Tridu isaqsuh xi ħaġa?’ Għax ikunu jidhru litteralment hundreds of miles away bl-aħbar li jkunu ħadu”

His account demonstrates how Kevin remains vigilant over families and actively tries to re-establish connection. Participants also emphasised the challenge of imparting information to relatives, both in terms of content and manner. Kevin emphasised the importance of exercising caution, particularly among relatives with limited health literacy, due to the increased risk of misinterpretation.

“You have to be very careful... if they are not understanding, they start adding in the pieces to fill in the blanks.” (Kevin, p.9)

“Trid toqgħod ħafna attent... k’ma jkunux qed jifmhu jibdew iżidu il-biċċiet huma biex jimlew il-vojt”

His reflections reveal the delicate balance nurses must strike between what to say, how to say it and how much information to share or withhold.

Similarly, Megan expressed the fear of being misinterpreted and blamed, justifying her vigilance when speaking with relatives.

“You do it cautiously, because you don’t want to say the wrong thing and they grasp on to it and they say, ‘Because the nurse said this.’ Because then there’s that certain fear sometimes, and I say, ‘I’m going to bite my tongue, better I say less than I say too much.’” (Megan, p.9)

“You do it cautiously il-ħaga għax ma tkunx trid tgħid xi ħaġa żejda li sort of they grasp u jaqbdulek magħha u jgħidu ‘Għax dik qaltli hekk’. Għax imbgħad tidhol dik il-biża forsi xi kultant u ngħid ‘isma ħa nigdem ilsieni aħjar kelma nieqsa milli kelma żejda’”

“What I’ve found works for me is I listen to what the doctors say, then I repeat that.” (Megan, p.9)

The idiomatic expression “bite my tongue” underscores Megan’s self-restraint when sharing sensitive information. Moreover, it captures the potential psychological

burden of having to monitor carefully what one says and the responsibility of communicating sensitive information to families. By repeating what the doctors say, she maintains a consistent message while shielding herself from potential blame. Jennifer too expressed reluctance to break bad news to families, restricting herself to basic clinical updates and avoiding giving too many details. She acknowledged past instances of miscommunication which made her opt for a more cautious approach, allowing the doctor to be the first to communicate certain details.

“I don't try to give them all the information myself...There is a specific line I keep with.” (Jennifer, p.16)

“Bhala informazzjoni ma nippruvax intijhom kollox jien...There is a specific line li inzomm.”

“I prefer to tell them that the doctor is coming and he will speak to you and explain everything to you. Because sometimes there was miscommunication of information, so I prefer if the doctor speaks to them first.” (Jennifer, p.17)

“Nippreferi ngħidlihom ġej it-tabib jkellimkom u jfhemkom kollox. Għax ġieli kien hemm miscommunication ta' information, so naħseb nippreferi it-tabib ikellimhom l-ewwel”

Both Kevin and Jennifer highlighted the importance of interdisciplinary consistency and collaboration in communication, especially in emotionally charged end-of-life situations.

“If you don’t know how to answer a question, you can tell them I’ll tell the doctors to come and speak to you [relatives]. That is a very good thing, that we have the doctors with us.” (Jennifer, p.18)

“Jekk mistoqsija ma’ tkunx kapaċi tirrispondiha tgħidilhom ħa ngħid lit-tobba ħa jiġu jkellmuk. Dik hija ħaġa tajba ħafna li għandna t-tobba magħna”

“You have to see that the information that you are giving is the same as the doctor is giving because it could be misinterpreted...I think that’s what I find most important, the information.” (Kevin, p.7-8)

“Trid tara li l-informazzjoni li qed tagħti tkun l- istess kif se jtijha it-tabib għax tista’ tiġi misinterpretata... Dik naħseb naraha l-iktar ħaġa importanti, l- information.”

Their commitment to ensuring consistency reveals how communication becomes a shared moral responsibility, which requires collaboration and coordination to protect families from confusion and false hope.

Kevin reflected on the impact of interprofessional communication breakdown, particularly between ICU consultants and external consultants. Kevin frustratingly recounted instances when he witnessed doctors giving conflicting messages to relatives, revealing the moral distress such inconsistencies can create.

“Our doctor comes to speak to and explain to the relatives and the patient, and then the outside consultant comes and tells them something different and confuses them more! Sometimes, there are instances where I say, 'What is he saying?!' [raises voice].” (Kevin, p.11)

“tiġi it-tabiba taġhna tkellem u tispjega lil relatives u l-pazjent imbgħad jiġi l-consultant ta' barra u jgħidilhom xi haġa differenti u iktar igerfxuhom! Ġieli ikun hemm instanzi li ngħid, 'x'hinu jgħid?!”

“It's like you're giving them false hope... [I feel like] A hypocrite, because you feel like telling him [doctor], 'What are you telling them?!' [frustrated]” (Kevin, p.17)

“Qisek qed ittihom false hope... [Ihossni] Ipokrita għax ikollok aptit tgħidlu, 'x'qed tgħidilhom lil dawn?!”

Kevin's frustration conveys the moral discomfort he feels in witnessing doctors giving misleading information to relatives who are already vulnerable and relying on guidance from HCPs. His comment about feeling like a hypocrite suggests that he feels complicit in what feels like an act of deception, reflecting how breakdowns in communication not only harm families but can also undermine nurses' sense of moral integrity in their role as caregivers.

Similarly, Simon too insisted on the importance of clear and honest communication, highlighting the ethical imperative of honesty in EOLC situations.

“No false hope. If he’s end-of-life care the worst thing you could do is that you give them hope uwx.” (Simon, p.15)

“No false hope. Jekk qiegħed EOLC l-għar ħaga li tista’ tagħmel hija ittihom tama uwx”

These participant accounts reveal that nurses experience communication in ICU EOLC as a moral and relational act of care through which they balance clarity, consistency and compassion whilst maintaining professional integrity.

4.6. GET 4: END-OF-LIFE CARE IN A CURATIVE SPACE

In their accounts, participants revealed the challenges they must navigate when providing EOLC in a setting fundamentally designed for curative intent rather than palliative practice. Their experience portrays the ICU as an inherently paradoxical space – highly technical, fast-paced, intervention-focused, yet increasingly tasked with providing care for the dying. The tensions that emerged from their experiences included the physical and technological environment of the ICU and the lack of systemic structures to support nurses in providing consistent and ethical EOLC.

4.6.1 The ICU – A Restless Space for Dying

This subtheme addresses the spatial challenges nurses experience when providing care for dying patients and their families in the ICU. Moreover, participants also addressed the relationship between technological dominance within the ICU and EOLC.

Participants acknowledged the misalignment of the ICU environment with the needs of dying patients and their families. Nurses experienced the ICU as not merely a physical, technological space but as a moral and emotional landscape which shaped their capacity to provide quality EOLC. The restless reality of the

ICU contradicted nurses' visions of a dignified death, which they characterised by peace and privacy.

Kevin poignantly articulated this feeling in his account.

“When a patient is dying, what do you want? Quiet, the lights are dimmed... Even the relatives are together in peace, they can speak to him. But here 24/7 always going.” (Kevin, p.19)

“Inti meta pazjent ikun qed imut xi trid? Kwiet, anke id-dawl mhux qawwi...Anke relatives miġburin għal kwiet jistgħu jikkellmu miegħu. Imma hawnekk 24/7 għaddej”

His rhetorical question, *“What do you want?”* suggested a deeply held moral belief that death should be accompanied by peace and presence. The ICUs' technological and operational imperatives compromise Kevin's values, which prioritise dying well, evoking a sense of moral unease. The phrase he used, *“24/7 always going”*, underscores the hectic ambience inside the ICU, exposing the tensions between life-sustaining care and EOLC in the ICU.

Similarly, both Jennifer and Simon reflected on the unsuitability of the ICU environment as a setting for EOLC. They expressed frustration particularly at the lack of private spaces and how this limited their ability to provide holistic patient and family-centred care, illustrating how the ICU environment actively impacts their practice and how they experience providing EOLC.

For them, the lack of privacy is not only an inconvenience but also symbolises a setting denial of death.

“There is only a curtain in the middle.” (Jennifer, p.10)

“Kull m’hemm purtiera biss fin-nofs”

“The space doesn’t always allow us to give them what they need at the end.

Ideally, they would be alone in a single room, quiet, with their family, but we don’t always have that luxury.” (Simon)

“L-spazju mhux dejjem iħallina nagħtuhom dak li jkollom bżonn fl-aħħar.

Idealment, ikunu waħedhom ġo single room, għall-kwiet, ma tal-familja, imma mhux dejjem ikollna dak il-lussu”

Jennifer was highly critical of the lack of privacy, which exposes surviving patients to distressing sights.

“It’s not the first time you have a patient in bed and the patient next to you dies. They tell you to close the curtain...The other patients they get terrified, they imagine themselves instead of the other patient” (Jennifer, p.10)

“Mhux l-ewwel darba, ikollok pazjent ġos-sodda u ta’ ħdejk miet. Jgħidulek għalaqli l-purtiera...Il pazjenti l-oħra jitwerwru, they imagine themselves instead of the other patient”

Her reflections on such distressing scenarios convey an empathic awareness of how death reverberates throughout the unit, affecting both the dying and the surviving patients. Jennifer's reference to the fear felt by those who unwillingly witness death highlights her sensitivity to the vulnerability of all patients and suggests that the ICU could be a psychologically unsafe space for patients.

Megan pointed out the difference in caring for a patient in a single room vis-à-vis in an open-bay area.

The environment could be chaotic. If the patient is in a single room, you can provide that peacefulness that the patient needs...But if he's in the 8-bedded, even if poor thing he's trying to rest for a bit, if you get an admission in the middle of the night, you have to turn on all the lights, all the noise, emm so it's not the most peaceful environment.” (Megan, p.11)

“l-environment jaf ikunu iktar chaotic. Ghax jekk ikun f-single room mod, you can provide that peacefulness li jkollu bzonn il-patient... Imma jekk ikun f-8 bedded, anke jekk miskin ikun qed jipprova jistrieh ftit, dan jekk tigielek admission f'nofs ta' lejl, trid tixgħel id-dawl, l-istorbju, emm so it's not the most peacefull environment.”

Megan's resigned tone reflected an undertone of helplessness and subdued acceptance of the inevitability of disturbances inside the ICU, thus impacting nurses' ability to provide patients with a dignified, meaningful death.

Megan mentioned moving patients to a ward setting in order to give them a more peaceful environment.

“From the aspect of the relatives, for them it’s not ideal. Sometimes we’ve had end-of-life cases where we opt to move them to the wards so maybe they can be more at peace and have a quieter environment” (Megan, p.11)

“Mill-aspett tal-qraba, għalihom ma jkunx ideali. Ġieli kellna cases li jkun end-of-life we opt li immexuhom għos-swali biex forsi jkunu jistgħu ikunu naqa iktar kwieti u l-environment ikun naqa iktar kwiet”

This reflects an act of moral agency, where nurses are committed to creating conditions for a meaningful death, even within structural limitations. In seeking a quieter environment, Megan not only advocates for patients but also for their families, acknowledging how the environment also impacts families’ experiences.

In their accounts, participants also reflected on the technological dimensions of the ICU environment and its complex relationship with EOLC. In their nuanced accounts participants reflected on its potential to alleviate suffering in EOLC whilst also acknowledging its capacity to prolong it.

Jennifer acknowledged technology’s therapeutic potential, recognising that advances in technology can support EOLC by improving patient care and symptom control.

“It’s a positive thing as well because technology always helps us to advance forward, so even for pain management and end-of-life care, it makes it much better.” (Jennifer, p.11)

“It’s a positive thing ukoll, għax it-teknologija dejjem tgħina navvanzaw il-quddiem, so anke bħala pain management u end-of-life care ħa tkun ħafna aħjar”

However, she also voiced her concern over how the availability of advanced technologies in the ICU can exert moral pressure to exhaust every available option, even when the prognosis is poor.

“Sometimes there are times that we prolong things. Now with these technologies we try new things to try and do everything we can..but sometimes we prolong the torture.” (Jennifer, p.10)

“Xi kultant aħna intawlu naqra l-affarijiet. Issa b’dawn it-teknologiji iktar nippruvaw affarijiet godda biex nippruvaw nagħmlu min kollox...imma xi kultant inżidu it-tul tat-tortura”

Her admission that *“sometimes we prolong the torture”* illustrates a shift from appreciation to ethical discomfort, evoking a visceral image of machinery-prolonged suffering. This inner conflict illustrates how nurses do not experience technology as just equipment but as a moral presence that can both empower and constrain their care.

Similarly, Kevin acknowledged that invasive technology often prolongs the dying process, leading to a loss of dignity and the patient’s dehumanisation.

“I agree with technology however; you could get to a point where technology takes over [sighs] and you become [the patient] like a piece of meat in bed.” (Kevin, p.43-44)

“It-teknoloġija naqbel magħha, imma taf tiġi fi stat fejn it-teknoloġija tiegħu over...[sighs] u tispiċċa biċċa laħam ġos-sodda”

The metaphor Kevin used, *“bicca laham go sodda”* (a piece of meat in bed), strongly evokes an image of the patient’s body being reduced to flesh stripped of its personhood. His sigh before speaking signifies a sense of moral discomfort at the futile use of technology for the sake of prolonging biological survival, insisting on quality of life over its extension.

“It’s true we do things to prolong life, but you have to see the quality of life you’re giving.” (Kevin, p.43)

“Inti veru tagħmel biex itawwal il-ħajja imma trid tara x’kwalita ta’ ħajja qed tagħti”.

Nurses experienced the ICU environment as a factor that actively shapes both the dimensions of care and their ability to provide care in alignment with their ideals. Their accounts reveal how nurses interpret and navigate their surroundings to facilitate death in a place designed to resist it. Moreover, technology was viewed as a double-edged sword in ICU EOLC, able to facilitate a peaceful death if applied with care but also capable of prolonging suffering in the final stages of life. These nurses’ reflections raise questions about whether life is being extended or whether death is being prolonged, underscoring the need to meticulously explore the ethical implications of the ICU’s technological dominance in EOLC.

4.6.2 Seeking Structure in Systemic Uncertainty

As EOLC features prominently in ICU care, participants expressed the need for formal structures, such as targeted training and ICU-specific guidelines, to better support them in providing quality EOLC.

Megan and Kevin expressed frustration and ethical discomfort at the lack of formal EOLC guidelines, revealing how this lack of a “*structured approach*” challenged their sense of professional stability.

“There’s not really a structured approach. If the consultant this week deems fit that with a little morphine the patient is fine, for that week the patient will be like that, he could be comfortable, he could be uncomfortable. Then another consultant comes and says, ‘no, increase the morphine so that he’s comfortable’... So, the fact that there isn’t a structured approach, a proper protocol on end-of-life care, emm, I think that’s what I find most difficult.”

(Megan, p.7)

“There’s not really a structured approach. Jekk konsulent minnhom dil-gimgha deems fit li b’naqa morphine il-patient jgħaddi għal dik il-gimgha l-pazjent se jkun hekk, jaf ikun komdu jaf ikun skomdu imbgħad jaf jigi il-konsulent ta’wara u jgħid, ‘le židlu se jkun komdu.’... So, il-fatt li ma hemmx a structured approach, a proper protocol on end-of-life care, emm, naħseb dik li insibu l-iktar diffiċli.”

“There isn’t a straight line that everyone follows...From Monday to Thursday we could have a plan and when we get to Friday to Monday we have another plan, from Monday onwards we have another plan.” (Kevin, p.27-28)

“M’ hemmx qisha linja dritta jimxi kulhadd magħha...Mit-Tnejn sal-Ħamis jaf ikollna pjan, kif jaqilbu il- Gimgha, sat-Tnejn għanda pjan ieħor , mit-Tnejn l’hemm nerggħu nibdew b’pjan ieħor.”

Their references to “*a straight line*” and “*proper protocol*” convey a desire for order amidst the moral chaos of dying in a space designed to preserve life. In seeking structure, they are not simply requesting instructions but seeking a moral framework to guide and reassure them in their professional practice.

Megan’s emphasis on how protocols give her a sense of professional security further extended the meaning for their desire for structure.

“For as long as I’ve been here, it’s one of the most things that I feel comfortable working with, protocols, because it guides you and you feel safe. You are providing safe care from one end to the patient and to safeguard yourself legally” (Megan, p.7)

“Jien kemm ilni naħdem hawn its one of the most things li inħossni komda naħdem bihom, protocols hu għax it guides you u tħossok safe. You are providing safe care min naħa to the patient and to safeguard yourself legally”

Megan’s reflections illustrate how guidelines restore a sense of control and confidence in that they reassure her that she is providing the best possible care to her patients and protecting herself from blame and the emotional vulnerability of having to face ethical decisions alone.

Moreover, both Megan and Kevin implied that having an EOLC protocol in place could provide nurses more autonomy in making EOLC decisions instead of constantly depending on doctors.

“Why should we rely all the time on doctors?” (Megan, p.8)

“For example, sometimes you have a patient renal failure, and they have a catheter for like 3 weeks, and they’re anuric..that can be removed. ‘Doctor can I remove this?’ [the catheter] Yes or ‘he has a central line and 3 venflons or the central line has been there 3 weeks. ‘Can we remove it?’” (Kevin, p.26)

“Perezempju ġieli jkollok pazjent renal failure, ikun ilu xi tlett ġimghat bil-catheter u jkun anuric jista’ jitneħħa. ‘Tabib dan nistgħu inneħħuh?’ Iva, jew ‘isma għandu central line u tlett v/f jew ic-central line ilu hemmek tlett ġimghat nistgħu inneħħuh?’”

Whilst they seek institutional guidance, Megan’s final question illustrated a desire for their professional judgement to be acknowledged. Kevin seemingly suggested that even small decisions in EOLC, such as removing an unnecessary catheter or intravenous cannula, require the doctors’ permission. Therefore, for these nurses, having a protocol provides more than just guidance but also a tool to help them reclaim professional authority in making such decisions.

Contrastingly, while Jennifer acknowledged that protocols could serve as a helpful framework in ensuring thorough and meticulous care, she also recognised the limitations of standardisation, particularly in end-of-life situations.

“Not every person is the same, so you can’t really have an algorithm for this sort of thing. For certain things it would help that’s true...But it must be individualised still...you cannot treat everyone the same”. (Jennifer, p.11)

“Not every person is the same so ma tistax qisu jkollok algorhythem għal din il-ħaga...Għal ċertu affarijiet naħseb jgħin vera..Imma irid ikun individualized still...ma tistax titratta lil kulhadd l-istess.”

Her emphasis that EOLC cannot be reduced to an algorithm revealed that, for Jennifer, death is a deeply personal experience, and EOLC must be adapted to preserve the individuality of the patient’s end-of-life experience.

Viewing this through the hermeneutic circle, Megan and Kevin’s desire for structure—the part—may initially be interpreted as dependence on institutional authority. However, when one looks at the wider context of their narratives – the whole – their desire for standardised guidelines is not about being told what to do but about having a consistent and supportive guideline, which allows them to practise and advocate confidently within the ethically complex EOLC situations encountered in the ICU. Conversely, Jennifer views death as a unique human experience, which cannot be standardised, suggesting that an EOLC protocol can be utilised as a supportive tool but must not replace person-centred EOLC.

Some participants also highlighted a lack of formal preparation for the emotional and communicative demands of EOLC. Jennifer admitted to experiencing significant uncertainty and discomfort when communicating and disclosing information with families, insisting that her increased confidence stemmed from experience, not from formal structured training.

“At the beginning when I started working here, I used to find it very difficult, how far should I go, how much should I say emm but with experience you get more confidence.” (Jennifer, p.18)

“Għall-ewwel li bdejt naħdem hawnhekk, kont inħossa ħafna bi tqila, sa fejn għandi nasal, sa fejn għandi ngħid affarijiet emm qisek bl-esperjenza imbgħad iġġib iżjed kunfidenza.”

Jennifer’s comment sheds light on the anxiety which accompanies such encounters and the common reliance on experiential learning instead of formal structured training, suggesting that formal training in communication, particularly in emotionally charged EOLC situations, could help ease nurses, particularly those new to the ICU, into such sensitive responsibilities.

Similarly, Megan also expressed her anxiety about being inadequately trained to provide psychological support to families. Like Jennifer, Megan noted improvement through experience, highlighting the dire need for formal training, particularly in the competences needed to meet the psychological and communicative demands of the role.

“Sometimes I don’t feel trained enough on this, to provide psychological support, however, I think with time you sort of gain experience, and you start getting used to it.” (Megan, p.6)

“Xi kultant I don’t feel trained enough fuq din il-ħaġa, to provide psychological support pero naħseb with time you gain experience u qisek tibda tidra.”

I think that there is the need for more institutional support for us nurses as well as for us nurses to be able to speak to relatives, so they train us how to speak to and support relatives not just having to learn from experience. That would help. (Megan, p.23)

“I think li hemm bżonn ta more institutionalized support kemm għalina u kemm għalina biex inkunu nistgħu inkellmu r-relatives, so they train us how to speak to and support relatives mhux you have to learn that from experience. That would help.”

These participants’ struggles reveal a broader systemic gap, that nurses are underprepared for managing the interpersonal and emotional aspects of EOLC and are expected to learn on the job without formal training. Their acknowledgement of the need for training in communication and trauma-informed care highlights that within the emotionally charged space of ICU EOLC, clinical skill alone is not enough, underscoring that apart from improving their competence, training can help nurses engage in EOLC with more confidence, empathy and resilience, enhancing the experience for patients, families and themselves.

4.7. Conclusion

Together, these four themes interrelate to form an overarching experiential structure that reveals the deeply human, emotionally charged, and ethically complex nature of EOLC in the ICU. For ICU nurses, EOLC is more than managing clinical decline, they shape the dying process with intention, compassion, and advocacy. Their responsibilities encompass not only the patient but also the emotional support of families, all while contending with spatial, technological, and systemic obstacles in a setting not designed for death. Despite limited authority and support, nurses are committed to upholding dignity and meaning at the end of life, drawing on personal values and professional instincts. These findings elucidate EOLC in the ICU as a multifaceted practice of emotional labour, moral responsibility, and resilience. The following chapter discusses the overall findings in light of existing relevant literature.

Chapter V

Discussion

5.1. Introduction

This chapter aims to contextualize the findings presented in the previous chapter within the theoretical framework of Relational Ethics, as articulated by Bergum and Dossetor (2005). Initially, a concise overview of this framework will be provided, followed by a discussion of how the study's findings align with its principles. Subsequently, each theme will be examined vis-à-vis existing literature, highlighting convergences and discrepancies. Finally, the strengths and limitations of the current study are critically evaluated, acknowledging both its contributions to the field and the constraints inherent in the research design.

5.2. The Relational Ethics Theoretical Framework

This study's findings align well with the Relational Ethics Framework by Bergum and Dossetor (2005). This theoretical framework posits that ethical care is grounded in lived experiences, emotional connection, and the social and institutional context in which care occurs.

Relational ethics reorients ethical inquiry from abstract rules and individual decision-making to the lived, interpersonal dimensions of care. It recognizes that ethical practice emerges within relationships between nurses, patients, families, colleagues, and the healthcare system, where moral action is shaped by trust, mutual respect, empathy, and engagement (Bergum, 2012).

This framework centres around five key principles: *mutual respect* - acknowledging the dignity and voice of others; *embodied knowing* - acknowledging the emotional and experiential foundations of moral insight; *relational engagement* - being present and emotionally responsive in care relationships; *uncertainty* - accepting the ambiguity inherent in ethical situations

and *environment* - recognizing how institutional culture and context influences the capacity for ethical care.

In the high-intensity environment of the ICU, where caring for the dying is profoundly relational but must unfold among competing curative priorities, the Relational Ethics Framework offers a meaningful interpretive lens for understanding how ICU nurses make sense of their role and uphold patient dignity, support families, manage emotional burdens, and navigate systemic challenges in EOLC.

In the first theme, nurses reflected on how they try to give their patients the best possible dying experience, shaped by what they believe to be a good death and the meaning they attribute to this. Viewed through the framework of Relational Ethics, nurses' efforts are seen as morally grounded in the nurses' commitment to preserve dignity, respect and human connection at the end of life. By striving to advocate for and provide care they believe is in line with their patients' wants and wishes, nurses reflected an ethical practice which aligns with the principle of *mutual respect*, where they affirm their patients' personhood and autonomy. Nurses' concerns over their limited influence and authority in EOLCDM and how they must navigate the hierarchal structure within the ICU to have their voices heard, aligns with the core principle of *environment*. This principle recognizes that the environment, both institutional and cultural, influences, for better or for worse, the provision of ethical care and nurses' moral actions (Bergum, 2012). Participants reflected on how their experiential knowledge is undervalued within the medical hierarchy, challenging the principle of *mutual respect* between professions which in the context of Relational Ethics, mutual respect recognises that differences can complement rather than divide (Benhabib, 1987). Bergum (2012) described the principle of *embodied*

knowing as an integrated consciousness, meaning that ethical understanding and moral insights arise from one's lived experiences. This notion resonated strongly with participants' accounts, where their efforts to provide a "good death" arose from previous experiences of multiple patients' deaths, which imprinted within them a form of moral understanding and commitment to their patients.

In the second theme, the emotional and psychological impacts of providing EOLC emerged as a profound and recurring feature of participants' experiences. Viewed through the lens of the Relational Ethics Framework, this theme can be seen as stemming from ICU nurses' close relational involvement with dying patients and their families aligning it with the principle of *relational engagement*. Within the framework of Relational Ethics, nurses' engagement with their patients nurtures an understanding of that person's individuality and humanity allowing the nurse to "*hear the other's voice*" (Pollard, 2015 p. 366). This engagement reduces the professional distance and produces an overlap between the self and other, heightening the nurses' emotional exposure and resonance. This is congruent with participants' reflection on experiencing heightened vulnerability when caring for patients whose life circumstances resonated with their own. Megan's reflections "*that could have easily been me or someone I know*" and Kevin's account of cases that stay with him as a parent, exemplify how personal identification amplifies relational engagement.

To manage the emotional weight of these experiences, nurses reflected on employing coping strategies ranging from humour to maintaining emotionally boundaries. Examined through the Relational Ethics Framework, this can be understood as efforts to maintain *mutual respect*, for both themselves by protecting their own emotional and mental wellbeing, and in turn for their patients by

performing their duties effectively without becoming overwhelmed by the emotional and psychological weight inherent in caring for dying patients.

The principle of *environment* was particularly relevant in this theme where nurses expressed concern over the lack of psychological support in the workplace. Within the framework of Relational Ethics, this is not simply a resource issue but an ethical one, as in the absence of such institutional support, their ability to engage in compassionate care is limited, impacting on the quality of care provided.

In the third theme, participants reflected on how their experiences of providing EOLC go beyond the patient and encompass the family. The principle of *mutual respect* was evident in this theme where nurses recognized that families are key stakeholders who had their own experiences with the patient and whose needs must also be addressed. In this current study, Jennifer's acts of kindness such as offering families coffee and food exemplify the principle of *mutual respect*. Moreover, Simon's view of pain management as being equally important for relatives also aligns with *mutual respect* in that nurses prevent the trauma of families watching their loved ones suffer.

The fourth theme centered around how nurses navigate providing a peaceful death for their patients in a setting oriented toward cure and recovery rather than comfort and EOLC. In Relational Ethics, the principle of *environment* is an active concept, which can either constrain or enable quality ethical care (Bergum & Dossetor, 2005). This concept aligns with this theme as nurses reflected on how the restless nature of the ICU environment hindered EOLC, undermining their ability to provide compassionate, patient-centred support.

In line with the principle of *uncertainty*, was the ambiguity caused by the lack of training and guidelines around EOLC. Participants reflected on feeling unsure of how to handle complex EOLC situations, which was further exacerbated by a lack of institutional structures to help guide their actions.

This study's findings illustrate how the experiences of nurses providing EOLC in the ICU both affirm and extend the Relational Ethics Framework. Nurses' actions, advocating for their patients, remaining present with patients and families and negotiating care within a hierarchy, can be understood as moral actions arising from a commitment to providing dignified, ethical care. The findings illuminate all five principles, *embodied knowing* in how nurses' moral actions are guided by their intuition from previous experiences, *relational engagement* in their intentional presence which steadies moments of grief and crisis, *mutual respect* in how nurses protect the voice and dignity of both patients and families, *environment* in how the architecture as well as the institutional culture shape what and how care is provided and *uncertainty* in how nurses navigate the ethical and emotional ambiguity inherent in critical care.

In the following sections the findings of this study are discussed in relation to existing literature.

5.3. SHAPING THE DYING PROCESS

This theme centred on ICU nurses' experiences of providing EOLC in the ICU and the interpreted meanings they attribute to this. Participants of this study demonstrated a commitment to facilitating the dying process for their patients, prioritising physical comfort and emotional peace. Three main aspects emerged within this theme including the nurse's perceived role as the patient's advocate,

ways of facilitating a “good death” and how they navigate the existing power hierarchy within the ICU. Each subtheme is discussed in relation to the existing literature.

5.3.1 Advocacy in End-of-Life Care

According to Adam et al. (2011), nurses may enact advocacy by conveying the patient’s perspectives and wishes to the clinical team or conversely by speaking to the family on the patient’s behalf. In critical care, clinicians and families often tend to resort to a curative mindset, pursuing aggressive treatment even when benefit is unlikely. Consequently, to advocate for their patients, nurses frequently challenge physicians and families to reconsider shifting their care goals from curative to comfort care (Adam et al., 2011). A grounded theory study about ICU nurses’ roles in EOLCDM yielded the theme “*a voice to speak up*” in which participating nurses addressed different ways of advocating for their end-of-life patients including relaying families’ wishes to physicians and questioning physicians about the proposed care plan (Bach et al., 2009).

In this current study, advocacy was viewed by participants as an ethical commitment to keep their patients’ wishes at the centre of care, particularly when they are unable to speak for themselves due to their condition. Megan’s stance about being “*part of the team...with the end goal of keeping the patient in mind*” (p. 4) is consistent with Alanzi’s, (2024) study, where nurses perceived themselves as being the link between the patient, family and the clinical team. The current study’s participants emphasized the importance of respecting their patients’ wishes as a way of honouring their humanity and dignity. These findings align with the systematic reviews of Noome et al. (2016) and Velarde-Garcia et al. (2016), in which nurses expressed willingness to assume an advocacy role to ensure that care goals always

align with the patients' best interests. Participants' active moral involvement and responsiveness to their patients' wants and needs reflected the principle of *relational engagement* within the Relational Ethics Framework where their advocacy stems from engaging relationally with their patients and their family, getting to know them as the person they are.

When advocacy succeeds and care aligns with patient wishes and values, participants reported experiencing relief which the researcher interpreted as a sense of moral clarity. These findings resonate with an extensive body of literature linking misaligned care to moral distress among ICU nurses (Andersson et al., 2022; Giannetta et al., 2022; Wiegand & Funk, 2012). These studies indicated that moral distress among ICU nurses was significantly correlated to EOLC issues particularly futile care and nurses' feelings of powerlessness to provide care that aligns with the patients' wishes. Conversely, moral distress among nurses was mitigated when care aligned with patient values, corroborating with participants in this current study expressing satisfaction at "*doing the right thing for the patient*" (Jennifer, p. 7).

Jennifer's reflections on a cultural reluctance to discuss and prepare for death in Malta, thus leaving wishes and preferences undocumented is particularly salient as such reluctance imposes a heavier advocacy burden on nurses at the bedside.

Indeed, advanced care planning (ACP) and advanced directives (AD) have gained attention in recent local literature precisely to address this gap, documenting patients' preferences in advance so that HCPs can uphold patient autonomy and provide care which aligns with their wishes (Abela, 2025). The Malta Association of Public Health Medicine (MAPHM) viewed ADs as a means to initiate conversations about foreseeable care preferences. However, ADs currently lack any legal standing in Malta highlighting ACP and ADs as an area requiring much further development

(MAPHM, 2025). Therefore, participants' experiences add to local discourse by underscoring how this legal and cultural gap intensifies nurses' advocacy burdens and moral tensions when providing EOLC. This resonates with the principle of *uncertainty*, as advocacy requires nurses to face grey area ethical dilemmas when patient's wishes are not clearly documented.

Overall, this subtheme is consistent with evidence that ICU nurses act as patient voice brokers in EOLC and goes further by adding a culturally situated insight; where there is a reluctance to discuss death and ADs are uncommon, advocacy becomes both more necessary and morally taxing.

5.3.2 Crafting a Good Death

This subtheme centred around ICU nurses' experiences of creating and facilitating the best possible dying experience for their patients within the ICU by upholding dignity and personhood through both physical and emotional care.

Participants of the current study underscored the physical aspect of care, explaining how in EOLC they prioritise the comfort of the patient both through pharmacological and non-pharmacological methods. Participants emphasized the importance of pain management through appropriate analgesia and sedation, with some participants pointing out a more liberal use of analgesia within the ICU compared to ward settings. Participants also highlighted the importance of non-pharmacological actions, such as deeming bright lights, wetting the patients' lips when on oxygen and removing nonessential equipment to make the environment less clinical and more physically comforting to the patient and their family.

Participants also recognized the relational aspect of care, framing family presence and human connection as vital aspects of dying well.

These findings coincide with multiple studies included in the literature review of this study. Efstathiou and Walker (2014) and Stokes et al. (2019) all reported on how nurses reflected on creating a “good death” for their patients mainly through pain and symptom management, encouraging and enabling family presence and creating a more peaceful and personalised space by adapting the ICU environment, echoing the actions reported by the participants in this current study. Unlike Noome et al ‘s (2016) systematic review where non-pharmacological measures were less emphasised by nurses, this study assigned equal importance to both analgesia and relational acts which honour the patient’s personhood.

Indeed, participants’ accounts foreground emotional care, particularly through family presence, not only as intrinsic to the patient’s comfort but as a way of respecting the patients’ personhood and the life they lived. Their commitment to uphold dignity and give their patients a humane death, reflects the principle of *mutual respect*. Participants reflected a recognition that the patient is more than a body in decline, but as a person whos’ individuality and humanity persist even at the end of life and must therefore be respected. Ong et al. (2018) reported that nurses often turn to the physical domain of care particularly when patients are unconscious. Contrastingly, this study’s participants prioritised emotional connection, acting as facilitators of family presence and meaningful closure. By being emotionally present, fostering meaningful relationships and facilitating connection at the bedside, participants demonstrate that ethical care arises from emotional attunement and presence, manifesting the principle of *relational engagement* (Bergum, 2012).

Participants’ experiences of “bad deaths” within the ICU where characterised by when patients died alone, or suddenly or with their final wishes overridden,

scenarios which precisely contradict their efforts to give their patients a “good death”. The literature offers confirmation as in multiple studies participating nurses expressed distress at patients dying alone, recommending the nurses’ presence when families cannot attend (Efstathiou & Walker, 2014; Jang et al., 2018; Noome et al., 2016; Stokes et al., 2019). Family-centred ICU guidelines recognize family presence as essential for high-quality care, recommending that family members of critically ill patients in the ICU be offered open or flexible presence at the bedside (Davidson et al., 2017). This coincides with Jennifer’s advocacy for open visitation hours for families of EOLC patients (Section 4.2.2).

In sum, this subtheme confirms existing evidence that ICU nurses facilitate a “good death” for their patients by prioritising physical comfort and relational presence (Efstathiou & Walker, 2014; Noome et al., 2016; Stokes et al., 2019) whilst simultaneously challenging accounts where emotional care tends to be given less importance due to patients being unconscious (Ong et al., 2018).

5.3.3 Navigating Power Hierarchies

In this subtheme nurses reflected on their experience of navigating the medico-centric decision culture in the ICU where their impact on EOLCDM is contingent on the consultants and where they must often initiate involvement themselves to have their voice heard. This is consistent with the reviewed literature, in which several studies reported nurses being excluded from the decision-making process, with physicians often making decisions independently without consulting nurses, despite their bedside knowledge of the patient and their family (Billal et al., 2022; Holms et al., 2014; Kisorio & Langley, 2016; Noome et al., 2016; Ong et al., 2018; Rafii et al., 2015; Velarde-Garcia et al., 2016). This subtheme resonates deeply with the Relational Ethics principle of *environment*. By limiting nurses’ meaningful

contribution in the decision-making process, this medical power hierarchy illustrates how the institutional environment shapes ethical agency. By involving themselves, their act of advocacy becomes a form of ethical resistance in an environment which prioritises medical authority. Evidence indicates that exclusion from the decision-making process results in feelings of frustration and moral distress among nurses. A concept analysis of ICU nurses' autonomy found that restricting nurses' autonomy undermines their ability to act on their professional judgment and values, eventually leading to reduced job satisfaction and erosion of collaborative care (Taleghani et al., 2023). This is comparable to findings of this study, which demonstrated how this power imbalance limits nurses' moral agency and makes them feel they must hold back their opinions as they may be deemed less significant compared to those of physicians. In a mixed-methods study investigating moral distress among ICU nurses, Prompahakul et al. (2021) found that nurses experienced significant moral distress within strong hierarchical organizations. Similarly, McAndrew et al. (2018) linked nurse-physician power imbalance to hierarchical structures which prioritise medical values over nursing values, thus hindering the nurses' advocacy role in care decisions. Within this hierarchal structure, physicians may marginalise nurses' views, which is associated with moral distress among ICU nurses (Morley et al., 2022). Viewed through the Relational Ethics principle of *uncertainty*, in the ICU, uncertainty is inherent in clinical situations, however it is also present when nurses' experiential knowledge and emotional awareness of their patients' needs are undervalued, and power dynamics mediate whose interpretation of care is prioritised. Despite these barriers, participants described how they dealt with this hierarchy-instilled uncertainty by

making suggestions during ward rounds and quietly advocating for comfort measures.

A growing body of evidence demonstrates that inclusion of nurses in ICU EOLCDM improves quality of care. Literature investigating family experiences of EOLC in the ICU reported greater satisfaction with care among relatives when nurses were involved in family conferences and decision-making, emphasizing how nurses helped them get their points across to physicians and assisted them in the decision-making process (DeSanto-Madeya & Safizadeh, 2017; Wu et al., 2016).

As demonstrated by the literature, when nursing input is formally integrated into decision pathways, care plans are more likely to be value-concordant and consistent, resulting in a better EOLC experience for patients, families and healthcare teams. Therefore, investigation into initiatives to formally involve nurses in the decision-making process is needed.

5.4. CARRYING THE WEIGHT OF END-OF-LIFE CARE

Collectively, participants' accounts shared a common theme, namely that providing EOLC and witnessing grief and death spilled into their personal life, impacting them psychologically and emotionally, and eliciting shifts in their identity and perspective.

5.4.1 When it Hits Home

From their accounts of providing EOLC, participants experienced greater emotional vulnerability particularly when EOLC patients were young or had life circumstances which somehow resonated with their own. This was well documented in appraised studies where nurses reported experiencing significant emotional impact when caring for young patients. In Kisario and Langley (2016)

and Rafii et al. (2015), nurses described caring for young patients as emotionally and psychologically challenging for them. Similarly, Ong et al. (2018) described experiencing grief when their patients passed away, especially when they had formed an emotional connection with them or when the patient was still young. In Kiziltepe and Koc (2021), nurses reported that when caring for dying patients, they would empathize deeply with them and their family, imagining themselves or their families in their situation. This resonates deeply with this study participant's first-hand experiences of the deep empathetic identification they experience when watching young patients die and witnessing their grieving families. Jennifer's description of "reliving" past losses and grief succinctly and poignantly illustrates how the impact of particular cases can infiltrate insidiously into nurses' personal life.

Beyond this study, broader evidence explains why these cases may "hit home". In a review about nurses' exposure to patient trauma and their emotional responses, Missouridou (2017) found that repeated exposure to death and witnessing grief could result in secondary traumatic stress (STS) among nurses which could in turn trigger intrusive memories and paranoia, precisely the reactions described by the participants of this study. Similarly, Levi et al. (2020) found that ICU nurses are more predisposed to experiencing post-traumatic stress disorder (PTSD) due to the nature of their work. In Jang et al. (2018) and Kiziltepe and Koc (2021), nurses reported that frequently encountering death had made them reflect on their mortality and that of their loved ones. This is consistent with participants' reflections on mortality and the fragility of life as a direct impact of providing EOLC.

Furthermore, participants reflected on how working in the ICU and caring for dying patients had impacted their perspective on life, with participants reporting feeling

more appreciative of their life and their health. In a quantitative study that investigated the attitudes of ICU nurses caring for critically ill patients, Aktar et al. (2023) emphasised the importance of ICU nurses having an optimistic approach when caring for critically ill patients to alleviate feelings of emotional exhaustion and burnout.

To sum up, critical care nurses do not simply witness and provide EOLC; they internalize it, intensifying meaning and care. However, this heightens psychological risk through emotional exhaustion, stress and moral strain. Their experiences and commitment to being emotionally present, even when this exposes their own vulnerabilities, reflect the Relational Ethics principle of *relational engagement*. Participants' identification with patients, feelings of grief and lingering emotional impact illustrate how relational closeness can blur the boundary between the professional and personal self, leading to a shared emotional experience and deep moral connection. The findings of this study indicate the need to attend to the emotional and psychological impacts of EOLC on ICU nurses through structured support to sustain the people who make dignified dying possible.

5.4.3. Coping in Practise

Participants of this study utilised a variety of coping strategies to help them cope with the emotional demands inherent in EOLC ranging from emotional distancing to maintaining a work-life balance to humour and peer support.

Megan's stance on becoming "immune" to patient death, Simons' ability to "switch on and off" and maintain an "invisible block" and Jennifers' efforts to "shut off her mind" and leave work issues at work exemplified a deliberate and calibrated emotional distance meant to keep them functioning effectively in emotionally charged EOLC encounters. These findings are consistent with multiple studies

which have reported nurses utilising emotional distance as a way of coping. In Jang et al. (2018), Kiziltepe and Koc (2021) and Velarde-Garcia et al. (2016), nurses reported becoming less sensitive towards patient deaths over time and avoided forming close relationships with patients. Findings of this current study extend this literature in that participants distinguished between functional boundary setting and avoidance/dissociation by emphasizing that the emotional distance they maintained did not desensitise them but rather served as self-protection to remain present and effective at the bedside. Indeed, participants insisted that the quality of compassionate care they provided and the relational quality with patients and families was not compromised by these boundaries. This nuance is particularly significant as literature has linked avoidance/dissociative coping to higher risk of burnout, lower job satisfaction and poorer nurse-patient relationship quality (Lee et al., 2019; Tsouvelas et al., 2022). Moreover, in a grounded theory study about clinical empathy, Tan et al. (2021) found that cognitive empathy together with professional boundaries help to preserve compassion while protecting healthcare workers' mental wellbeing, precisely the strategy described by the current study participants. These coping strategies can also be interpreted through the Relational Ethics principle of *embodied knowing*. The deliberate emotional boundaries that participants maintain illustrate an embodied attempt to balance presence with protection. Through their lived experiences and encounters with death, nurses have embodied an awareness of how to regulate their emotional engagement by maintaining enough distance to protect their wellbeing without compromising the quality of compassionate care they provide. The conscious distinction nurses make between functional detachment and emotional distancing highlights how nurses carefully calibrate their emotional involvement in a way that allows them to remain

ethically and relationally connected whilst protecting themselves from emotional vulnerability and exhaustion.

Another coping mechanism mentioned by participants was self-care by maintaining a work-life balance. Jennifer and Megan emphasised engaging in leisure activities and travel and enjoying life as a way of coping, resonating with Stokes et al. (2019), where nurses emphasised the importance of engaging in self-care outside of work as essential to sustaining quality care.

Other coping mechanisms mentioned by participants were peer support and humour. Kevin's account of "*laughing and joking around*" and "*cheering each other up*" positioned coping as a collaborative endeavour, congruent with Ong et al. (2018), who found that nurses reported seeking guidance from their seniors, humour and peer support as ways of coping. Similarly, Endacott et al. (2016) emphasized the importance of accommodating colleagues' emotional needs, including speaking up when they are emotionally unable to care for an EOLC patient. Alanzi (2024) reported how ICU nurses viewed working as a team as a coping strategy to help reduce stress related to workload and strengthen relationships among team members.

The findings of this current study support Cohen and Wills's (1985) buffer hypothesis which posited that social support could alleviate the negative impacts of stress and improve psychological resilience. Moreover, Dean and Major's (2008) study found that nurses often employed humour to reframe distressing situations and mitigate its negative effects. Ultimately, these coping strategies reflect how nurses attempt to sustain emotional presence and compassionate care by preserving their own emotional integrity, amid repeated exposure to death and grief. Study

participants' accounts exposed a gap between the emotional and psychological demands of EOLC and the available support, perceiving formal support as insufficient and poorly fitted to ICU realities. These findings mirror those in Billal et al. (2022), Endacott et al. (2016), Holms et al. (2014), Jang et al. (2018) and Kiziltepe and Koc (2021), in which nurses reported a lack of administrative support and called for better support systems. Nurses of the current study clearly articulated a preference for peer-based, unit-embedded support initiatives, such as group talk sessions and an onsite specialised psychologist. This emphasis aligns with evidence presented by both Berchtenbreiter et al. (2024) and Ng et al. (2023) who found that team-based support strategies, such as group debriefs and reflective rounds, may be more sustainable in high-acuity settings rather than ad-hoc referrals alone.

Findings of this study therefore highlight the need for investment in staff well-being initiatives that validate emotional experiences and make psychological support more ingrained in work culture. Support strategies could include team building exercises in a social setting, debriefing and reflective sessions, promoting time away from the ICU and promoting an open communication environment (De Brasi et al., 2022; Galea, 2014; Williams et al., 2022).

5.5 CARE BEYOND THE PATIENT

Participants in this study considered caring for the families of patients at the end of life central to their role. However, this was not without its challenges, with participants reflecting on this aspect of care as one of the most delicate and challenging tasks when providing EOLC.

5.5.1 Supporting Families

According to Wilkin and Slevin (2004) caring for family members of patients in the ICU includes listening, providing information and offering reassurance. Across all

accounts, participants described having a dual role - attending to the patient's comfort whilst also supporting families and tending to their emotional needs by offering reassurance and guidance, providing information and facilitating meaningful final moments. This commitment to supporting families directly exemplifies the *mutual respect* principle, where nurses recognise that the emotional needs and dignity of families of dying patients also deserve acknowledgment. By keeping them informed and offering reassurance, nurses ensure that families are guided through the complex dying process in the ICU, illustrating that ethical care is grounded in human empathy. These findings are in line with several other studies in which care for families was considered a crucial aspect of holistic EOLC. Efstathiou and Walker (2014) emphasized that supporting families was as important as caring for patients, a stance supported by participants of this study.

Contrastingly, in their studies Kisario and Langley (2016), Kiziltepe and Koc (2021) and Ong et al. (2018) reported that nurses did not always have the time to engage with families, with nurses suggesting the need for specialised personnel on the ward to provide families with the needed support. By contrast, participants of this current study claimed ownership of family support, and while some admitted that heavy workloads did sometimes interfere, they all emphasized prioritizing family care, affirming their belief in the possibility of enacting relational ethical care even within institutional constraints. Here the principle of *environment* becomes evident, as the medically driven ICU together with time constraints and competing clinical priorities, sometimes limit nurses' capacity for deep family interactions.

Participants in this study emphasized supporting families particularly by providing them with information and guiding them through the EOLC process. In a study

exploring the experiences of families of EOLC patients in the ICU, family members reported receiving regular information about the patient as one of their most important needs (Kisario & Langley, 2016). Indeed, studies have identified adequate communication as a crucial detriment of family satisfaction during EOLC in the ICU (Chen et al. 2019). In Efstathiou and Walker (2014), Kisario and Langley (2016) and Noome et al. (2016), nurses reported involving families in the care of patients such as during bathing as a way of helping the families feel closer to their loved ones. Participants in the current study did not report actively involving families in the care of patients; however, participants mentioned acting as the link between the families and the medical team, thus involving them in the decision-making process. Davidson et al. (2012) described that not involving families in the care of their loved ones could lead to feelings of sadness, depression and post-intensive care syndrome among family members. Further research is therefore warranted to investigate nursing practices that support families in having meaningful and positive end-of-life experiences in the ICU. Nurses who established open, supportive nurse-family relationships reported experiencing more confidence, lower anxiety and a greater satisfaction in their role (Adams et al., 2015). Similarly, participants in the current study also reported positive feelings and a renewed sense of purpose in caring for families, particularly when feeling otherwise helpless in changing the patient's outcome. Viewed through the Relational Ethics Theory, this sense of fulfillment arises from the reciprocal nature of *relational engagement*, where caring for others not only brings comfort to the patients and their family but reaffirms the nurses' own moral identity as a caregiver (Bergum 2012).

5.5.2 Communication as Care

In this subtheme nurses acknowledged their vital role in family communication, recognizing this aspect of EOLC as crucial for the family's experience yet one of the most challenging aspects for the ICU nurse.

Literature has emphasized the importance of effective communication skills of healthcare providers particularly within the sensitive realm of EOLC (Chen et al., 2019). Families of patients admitted to the ICU are at risk of developing major depressive disorders, acute stress, anxiety and post-traumatic stress (Shirasaki et al., 2024). Studies investigating family needs and experiences during EOLC in the ICU have cited communication as one of the highest rated needs of families, helping to improve understanding and acceptance of the situation and mitigate their stress and grief.

Participants highlighted how they employed effective communication techniques when communicating with families of patients such as using clear and simple terminology, repeating explanations and recognizing varying levels of health literacy among relatives in order to adjust explanations accordingly. These communication skills and techniques chime with similar strategies cited in Velarde-Garcia et al. (2016) and Noome et al.'s (2016) studies that underscored the importance of clear communication by explaining medical information in simple terms to facilitate understanding and align families' expectations with the patient's prognosis, as opposed to doctors' use of medical jargon, hindering understanding and decision-making (Endacott et al., 2016). In the current study nurses highlighted their role as intermediaries between the family and doctors, acting as translators and information brokers. These strategies illustrate the enactment of the principle

of *mutual respect*, as nurses' communication practices respect families' need for clarity and honesty in these critical moments.

Through their experiences, participants of this study highlighted that communication is not only about conveying information but an emotionally sensitive process. Jennifer stated that how information is given can have a significant impact on how families process difficult news. This is supported by Endacott et al. (2016), in which nurses emphasised timely and clear communication with families highlighting how this is crucial to help them manage expectations and emotional stress. Moreover, Arianto et al. (2022) and Velarde-Garcia et al. (2016) linked family's unrealistic expectations to poor communication, emphasizing that careful framing and ensuring understanding is crucial to align family expectations with the patients' realistic prognosis.

Participants strongly emphasized adopting a cautious approach when sharing information with families out of fear of being misinterpreted and blamed. Some participants expressed reluctance to speak with relatives opting for the doctors to speak to them first. Megan's comment about biting her tongue and Jennifer providing only superficial information correlates with the findings of Kisario and Langley (2016), who reported nurses hesitating about what to disclose with families as they feared being blamed, referring them to the doctors instead. Similarly, in Ong et al. (2018) nurses admitted that their communication with families was suboptimal, as they opted to share limited information to avoid inciting anger. In a study exploring family ICU experiences, Noome et al. (2016b) reported how nurses would give the families technical information without interpreting the meaning, thus raising unrealistic expectations. Moreover, nurses who felt inadequately prepared to provide information to families tended to give them meaningless and

vague information (Adams et al., 2011). Both Jennifer and Megan expressed feeling unprepared to communicate and deal with distressed family members. The principle of *uncertainty* is evident here, as nurses must face the ethical dilemma between being honest and protecting themselves from blame in emotionally charged communication with limited preparation for such scenarios.

Participants also reflected on the frustrating impact of interprofessional communication breakdown, which could lead to misleading information and mixed messages, thus potentially instilling false hope. Consequently, participants highlighted the importance of consistency when communicating with families. Similarly, Holms et al. (2014) reported frequent communication breakdowns between doctors, nurses and families resulting in inconsistencies in EOL decisions and conflicting messages. Endacott et al. (2016), Velarde-Garcia et al. (2016), Jang et al. (2018), Stokes et al. (2018) and Velarde-Garcia et al. (2016) all emphasized the importance of honest and transparent communication so that families can prepare themselves properly for the death of their loved one. Kevin's comment about feeling complicit when hearing doctors giving misleading information is congruent with multiple studies, which expose deceptive information and false hope being given to patients and families as morally distressing to ICU nurses (Andersson et al., 2022, Morley et al., 2022, Prompahakul et al., 2021).

The findings of this study highlight the important role ICU nurses play in family communication and support and show how nurses can in fact set the tone for families' experiences in the ICU. To enhance support and communication with families, further investigation is warranted into what families perceive as supportive nursing behaviours, nurses' perceptions of enablers and obstacles to their support of families and the way nurses engage in interactions and communication with

families. Such research could help clarify nurses' roles and responsibilities in providing supportive communication and inform strategies for supporting families in EOLC.

5.6 END-OF-LIFE CARE IN CURATIVE SPACE

In this theme nurses reflected on various aspects associated with the way the ICU operates, which has an impact on their experience of providing EOLC and caring for dying patients and their families, ranging from the physical and technological environment of the ICU to the lack of systemic structures in place to help nurses provide quality EOLC in the ICU.

5.6.1 The ICU – A Restless Space for Dying

This study's participants recognized the existing misalignment between the ICU environment and the needs of dying patients and their families. The ICU is primarily designed to provide life-sustaining care and is therefore a hectic environment characterised by noise, bright lights and equipped with extensive life-supporting equipment (Price, 2023). Participants in this study perceived the ICU environment as inappropriate to provide EOLC as it posed challenges related to their ability to provide their patients and families with a peaceful and dignified death. These challenges to the provision of adequate EOLC also featured prominently in an extensive body of literature (Endacott et al., 2016; Holms et al., 2014; Kiziltepe & Koc 2021; Velarde-Garcia et al., 2016). Participants cited measures they took to make the environment more comforting for both the patient and their family - including removing unnecessary equipment, turning off monitor alarms and closing curtains for privacy. Similarly, Efstathiou and Walker (2014) reported attempts by nurses to create an intimate environment to reconnect the patient with their family in the final stages of life. Moreover, participants in this

current study expressed frustration at the lack of privacy imposed by the structural layout of the ICU, with participants describing that their only option would be to draw the curtains when patients are in the open bedded area. Nurses felt better when EOLC patients were placed in a single room, as this allowed nurses to permit more visitors at the bedside in a private, peaceful space. This is supported by Holms et al. (2014), who emphasised the need for quiet spaces and private areas to provide dignified EOLC within the ICU. A participant's frustration at the lack of private spaces and potentially traumatising involvement in other patients' death was also reported by Ransie et al. (2012), who found that nurses favoured the privacy offered by single rooms as it limited patient and family exposure to death. In the local ICU there are a limited number of single rooms (n=5), which are often reserved for patients with a compromised immune system or those with a contagious multi drug-resistant organism. Participants recounted how patients receiving EOLC were sometimes transferred to a quieter ward setting however the act of transferring a patient at the end-of-life could be more distressing to the patient and their family and might not be achievable if the patient is too unstable (Puntillo et al., 2001).

This subtheme aligns strongly with the Relational Ethics principle of *environment*, illustrating how the physical context influences nurses' capacity to provide dignified EOLC, prompting them to create a more comforting and intimate space for patients and their families. Findings of this study have therefore underscored the need for more private spaces for both patients and families within the local ICU to enhance privacy and their overall experience of EOLC. Moreover, further research is needed to gain a greater understanding of the impact of the ICU environment on the provision of EOLC.

5.6.2 Seeking Structure in Systemic Uncertainty

In their accounts participants underscored the need for formal structures to better support and guide them in providing quality EOLC.

Participants in this study were highly critical of the unstructured provision of EOLC within the ICU, which was exacerbated by frequent rotations of attending ICU consultants and consequently, constant changes in care plans. Nurses perceived this to be a barrier to the provision of seamless EOLC as it resulted in a fragmented and inconsistent approach to care. Participants felt that integrating formal EOLC guidelines could help improve the quality of EOLC provided. This finding is supported by Holms et al. (2014), who proposed an integrated EOLC pathway in the ICU as they felt that it provided clearer guidance and communication among HCP, thus facilitating a dignified death for their patients. Several benefits have been associated with the establishment of such pathways with the End-of-Life Care Strategy document in the UK recommending the integration of EOLC pathways in all acute settings (UK Department of Health, 2008). Moreover, according to Chapman (2009), integrating a formal EOLC protocol could potentially help shift the “death denying” culture within the ICU. Nurses expressed how an EOLC protocol could potentially allow them to have more autonomy and confidence when discontinuing non-beneficial interventions (Holms et al., 2014). This achievement of autonomy chimes with the present study’s findings. This was also supported by Velarde-Garcia et al. (2016) where nurses reported that a lack of ICU specific guidelines hindered their confidence and ability to provide quality care for dying patients.

Jennifer pointed out that while ICU specific EOLC guidelines could provide a helpful framework, it must not replace individualized care. In fact, Coombs and

Long (2008) cautioned that without robust implementation and education, an EOLC protocol could deteriorate into a box-ticking exercise. According to the Leadership Alliance for the Care of Dying People (2013), HCPs must understand the philosophy behind EOLC and associated care pathways. In doing so, nurses are able to better attune to the unique needs and individuality of each patient (Neuberger, 2013).

Participants in this study also expressed a lack of formal preparation particularly for the psychological and communicative demands of EOLC, expressing how they sometimes experienced feelings of uncertainty and inadequacy particularly when supporting and communicating with families. This lack of training and education in EOLC was also reported in several other studies (Billal et al. 2022; Holms et al., 2014; Jang et al., 2018; Kisario & Langley 2016; Kiziltepe & Koc 2021; Ong et al. 2018). In that respect Jang et al. (2018) found that participating ICU nurses linked their emotional stress to low confidence in delivering EOLC, attributing it to not being adequately prepared to manage EOLC in their nursing education. This current study found a reliance on experiential learning as participants expressed gaining more confidence in speaking to and supporting families through experience rather than formal training. However, in their study investigating doctor-patient communication, Cantwell and Ramirez (1987) demonstrated that experience alone cannot be relied upon. Studies have demonstrated that communication skills can in fact be taught. Indeed, an extensive body of evidence has demonstrated that communication skills training could improve nurses' experiences of providing EOLC in the ICU. Investigating the impact of a communication skills training programme on the mental health of ICU staff, Holmberg et al. (2024) found lower perceived stress related to communication situations among HCPs. Similarly, Asadi

et al. (2023) found that higher self-compassion and a more positive attitude towards EOLC were reported among ICU nurses with EOLC training.

Consequently, the findings of this study underscore that formal training in EOLC, particularly in communication skills and family support is needed to help nurses build confidence and adequately manage the dying process in the ICU.

In bringing these insights together, this study returns to its aim of exploring how ICU nurses experience and make sense of providing EOLC. Across the four themes, a coherent experiential narrative emerges: nurses' strong *moral commitment* to advocating for a dignified death becomes intertwined with the *emotional burden* of caring for dying patients in a highly technical environment. This sense of responsibility extends *relationally* beyond the patient to families, where nurses navigate complex emotional and communicative demands. Finally, these experiences are shaped and, at times, constrained by wider *systemic and hierarchical structures* that influence what nurses feel able to enact in practice. Together, these themes illuminate the ethical, emotional, and relational dimensions of EOLC in the ICU and demonstrate how nurses strive to uphold patient-centred values within organisational contexts that can both support and limit their intentions.

5.7. Strengths and Limitations

The strengths and limitations of this research project are presented in this section.

5.7.1. Study Strengths

A major strength of this study is that it is the first local study aimed at exploring the experiences of critical care nurses providing EOLC in the Maltese ICU, thereby generating new knowledge which could potentially improve nurses' experiences and the provision of EOLC in the local critical care setting.

To enhance study credibility and transferability, a thorough account of the methodological approach was provided together with an in-depth data collection and a rigorous analytical process to strengthen the study's trustworthiness.

Moreover, an IPA approach, underpinned by phenomenology, double hermeneutic and idiography, allowed the researcher to gain an in-depth understanding of participants' experiences.

The researcher's "outsider" position given her inexperience of working in the ICU functioned as a strength as it reduced dual-role tensions. Moreover, participants tend to explain in greater detail with someone outside their specialty, encouraging participants to articulate taken for granted aspects of EOLC. Furthermore, not being a colleague to participants could have helped make them more comfortable in giving honest answers, as acknowledged by one of the participants.

5.7.2. Study Limitations

Being a novice researcher could have caused certain methodological imperfections. However, the guidance and attentiveness of their academic supervisor were key to conducting a systematic and rigorous research process.

The transferability of the findings is naturally bounded, owing to the study's small sample of nurses from a single ICU. This small sample reflects IPA's idiographic focus which prioritises deep insight into individual experiences rather than broad representativeness (Smith et al., 2022). While findings are not intended to be generalised, their transferability is supported by the presentation of a clear and transparent audit trail and rich contextual detail, allowing readers to judge the applicability of the findings to other settings.

The researchers' position as an "outsider" could also be considered a limitation as not being an intensive care nurse may have limited her understanding of ICU norms and context of care. To address this, the researcher engaged in reflexive practice by maintaining a journal, sought peer debriefing from an ICU-experienced colleague external to this study and anchored interpretations in verbatim excerpts.

5.8. Conclusion

These participants' experiences show that nurses highly value their role of humanising the dying experience for their patients and their family, even within a space centred around cure and recovery. Their experiences reveal EOLC as an intimate weaving of clinical skills and emotional presence and expose the frictions that shape EOLC in the ICU. Critical care nurses strive to navigate the operational realities of the ICU to provide value-concordant, patient-centred EOLC. At its core, their experience is defined by a sustained commitment to undertake the deeply human task of guiding and accompanying each patient to a good death. In the following and final chapter, a summary of the whole study is presented, along with recommendations for further research, practice and education.

Chapter VI

Conclusion

6.1. Introduction

This chapter presents a comprehensive summary of the research study.

Recommendations drawn from the study findings for future research, education, practice and management are also provided.

6.2. Summary of the Study

This study sought to explore and interpret how critical care nurses make sense of providing EOLC in the ICU. It also set out to gain an insight into the emotional and psychological impacts caring for dying patients has on critical care nurses as well as exploring coping strategies they engage in. Another objective of this study was to explore and understand critical care nurses' relationships and communication with families of dying patients. Finally, this study sought to explore the need for strategies to support critical care nurses when providing EOLC.

To meet the aim and objectives of this study, a qualitative phenomenological approach guided by IPA was employed. Individual, semi-structured interviews with four purposively selected participants were conducted. Following an in-depth analysis of participants' accounts aligning with the principles underpinning IPA as outlined by Smith et al. (2022), four GETs emerged together with their respective subthemes. These are presented in Table 6.1 below.

Table 6.1- Resulting GETs and Subthemes

| |
|--|
| <p>GET 1: SHAPING THE DYING PROCESS</p> <ul style="list-style-type: none">i. Advocacy in End-of-Life Careii. Crafting a Good Deathiii. Navigating Power Hierarchies |
| <p>GET 2: CARRYING THE WEIGHT OF END-OF-LIFE CARE</p> <ul style="list-style-type: none">i. When it Hits Homeii. Coping in Practice |
| <p>GET 3: CARE BEYOND THE PATIENT</p> <ul style="list-style-type: none">i. Supporting Familiesii. Communication as Care |
| <p>GET 4: END-OF-LIFE CARE IN A CURATIVE SPACE</p> <ul style="list-style-type: none">i. The ICU – A Restless Space for Dyingii. Seeking Structure in Systemic Uncertainty |

This study underscored how participating ICU nurses made sense of and found meaning in caring for dying patients. Across their testimonies, participants viewed themselves as advocates for their patients, acting as the patients’ voice when absent, facilitating a good death centred on comfort and dignity, and serving as key players within a hierarchy where they must navigate limited formal authority to align care with what matters to their patients. Through their rich, idiographic accounts,

participants elaborated on the practicalities of EOLC, such as symptom control and environmental manipulation, while articulating their deeply held moral values underpinning and shaping their vision of care. Their humanistic view on death and dying challenges the curative focus within the ICU, showing how nurses actively shape the dying process. This, however, is not without its burdens and sacrifices. Participants' experiences illuminated the emotional and psychological toll providing EOLC has on nurses. Participants described how cases which resonated with their own life circumstances and where younger patients were involved left a deep emotional and psychological impact on them, triggering moments of vulnerability and existential reflection. However, as a direct result of providing EOLC and witnessing death, nurses developed a deeper appreciation for one's life and health, underscoring the dual impact of EOLC work. Nurses engaged in different coping strategies ranging from maintaining emotional boundaries to humour and peer support to help them keep functioning effectively in the face of death, trauma and grief. Across accounts, participants viewed institutional formal support as lacking and insufficient, highlighting a gap between the emotional demands of EOLC and available support. Nurses expressed the need for ICU-embedded psychological resources and support strategies such as group-based initiatives. In line with the objective of exploring nurses' interactions and experiences with families of patients receiving EOLC in the ICU, participants' accounts illustrated how nurses prioritised family support as a central part of their role in EOLC. By providing reassurance and facilitating meaningful closure between them and the patient, nurses demonstrated an understanding that death is a shared experience shaped by both patient and family needs. Participants' accounts also captured how nurses view communication as a form of care, achieved by simplifying complex information, ensuring understanding,

and preventing harm caused by misinterpretation and false hope through consistent and clear discourse. Participants also concurred that these supportive actions are not simply practicalities in EOLC but a way of restoring a sense of purpose when patients' outcomes are beyond their control. In the final theme, participants described how they experienced and interpreted caring for the dying within a curative, technology-dense space, citing the environmental and technological tensions they must deal with. Furthermore, participants identified systemic gaps, including the absence of ICU-specific EOLC guidelines and limited preparation in order to be well equipped to meet the psychological and communicative demands of EOLC. To bridge these gaps, participants underscored the pressing need for clear guidelines and training to ensure safe, patient-centred, and confident practice. Overall, the findings of this study captured the practicalities, personal impacts, and systemic constraints that, together, shape and define nurses' lived experiences of providing EOLC in the ICU.

6.3 Recommendations for Education and Training

- Participants expressed a lack of formal preparation in EOLC and felt uncertain, particularly regarding family support and communication, explaining how such skills were often learnt through trial and error rather than structured training. Therefore, EOLC and communication skills education and training should be integrated into intensive care training programmes to improve efficacy and confidence and mitigate occupational stress. Furthermore, more emphasis on palliative and EOLC should be placed in nursing student curriculums to better equip nurses for the practical and emotional demands of this aspect of nursing.

- To mitigate interprofessional misalignment and communication breakdowns, multidisciplinary team-based training sessions targeting communication and care planning should be incorporated into critical care training.
- Participants highlighted how a lack of knowledge among families often led to misinterpretations and delays in EOLC provision. More emphasis on EOLC education and awareness is needed at the national level, with health authorities and public health department policymakers ensuring that information about EOLC is available to the public. Educating the community about end-of-life planning could potentially alleviate decision-making challenges during patients' final moments.

6.4. Recommendations for Practice and Management

- Given the emotional and psychological demands of EOLC as evidenced by participants' experiences, adequate institutional support systems are needed. Participants unanimously agreed on the urgent need for a more proactive psychology department with an onsite specialised psychologist. Moreover, group talk sessions and debriefs among colleagues should be integrated into ICU routines.
- As mentioned by one of the participants, team-building activities and social events outside of work can also provide support to nurses, allowing them to meet with colleagues and share struggles and concerns outside the work environment.
- To improve patient and family end-of-life experiences, ICUs ought to implement noise-control practices and environmental-hygiene measures. In the event the local ICU undergoes renovations, more private spaces and single rooms ought to be considered.

6.5. Recommendations for Future Research

- Accounts by patients and their families of their experiences in the ICU may reveal unique care requirements that may not be immediately apparent to critical care nurses. Further investigation into patients' and families' perceptions and experiences of EOLC in the ICU is crucial, since they are primary stakeholders in care.
- A deeper exploration of nurses' perception and understanding of their role in EOLDM is important to help identify barriers and facilitators to their formal integration in decision-making processes. Moreover, further research is warranted on how the formal inclusion of nurses in EOLDM impacts care trajectories and patient/family perceptions.
- The feasibility of the implementation of ICU-specific EOLC guidelines should be investigated, and its implications examined.

6.6. Personal Learning and Development

Conducting this research study has been a significant personal learning journey. As a novice researcher, I became acquainted with and learnt about many research designs in the process of selecting a design aligning with my research aim and objectives, eventually leading me to Phenomenology and IPA. Conducting a phenomenological study has allowed me to gain knowledge, skill and confidence in designing and conducting sensitive interviews and refining my communication skills in order to gain rich, insightful data. Moreover, I developed analytical skills pertaining to IPA, which allowed me to gain a deeper insight and interpret participants' experiences. Through this research project, I have strengthened core research skills, such as comprehensive literature searching and critical appraisal, while also deepening ethical sensitivity around consent and confidentiality in research. Personally, I found

the process of collecting and analysing data the most challenging and time-consuming aspect of the project; however, this also taught me the importance of proper time management, background reading and perseverance. The overall process was highly rewarding and enriching, as it equipped me with the requisite skills to conduct my first qualitative research study.

6.7. Conclusion

The primary mandate of the ICU is cure and recovery; however, as an increasing number of critically ill patients approaching death are admitted to the ICU, comfort-focused care must be integrated into the ICU's curative focus. The findings of this study illuminate how ICU nurses experience and make EOLC work in a setting built for cure by advocating for fulfilling patients' wishes, facilitating dignified deaths, and supporting families while resiliently bearing the emotional weight of this labour and dealing with hierarchy and technology. To sum up, these insights deepen understanding of nurses' lived experiences and inform strategies and interventions that can deliver more value-concordant, consistent and compassionate EOLC in the ICU.

References

- Abela, J. (2025). Maltese doctors and their views on end-of-life issues. *Malta Medical Journal*, 37(3), 6–13.
- Adams, J. A., Bailey Jr, D. E., Anderson, R. A., & Docherty, S. L. (2011). Nursing roles and strategies in end-of-life decision making in acute care: A systematic review of the literature. *Nursing Research and Practice*, 2011, 527834. <https://doi.org/10.1155/2011/527834>
- Adams, A., Mannix, T., & Harrington, A. (2017). Nurses' communication with families in the intensive care unit: A literature review. *Nursing in Critical Care*, 22(2), 70–80.
- Adu, P. (2019). *A step-by-step guide to qualitative data coding*. Routledge.
- Ahmed, S. (2024). The pillars of trustworthiness in qualitative research. *Journal of Medicine, Surgery and Public Health*, 2, 100051. <https://doi.org/10.1016/j.glmedi.2024.100051>.
- Akinosoglou, K., Schinas, G., Almyroudi, M. P., Gogos, C., & Dimopoulos, G. (2023). The impact of age on intensive care. *Aging Research Reviews*, 84, 101832.
- Aktar, S., Pandey, V., & Kumar, A. (2023). Attitude of nurses caring for critically ill patients admitted in the ICUs of AIIMS Hospital, Jodhpur. *Journal of Education and Health Promotion*, 12, 125.
- Alanazi, N. H. (2024). Intensive care unit nurses' experiences in caring for end-of-life patients in Saudi Arabia: A qualitative study. *International Journal of Environmental Research and Public Health*, 21, 931.
- Alruwaili, M., & Abuadas, F. H. (2023). Professional autonomy among nurses in Saudi Arabian critical care units. *BMC Nursing*, 22, 224. <https://doi.org/10.1186/s12912-023-01390-x>
- Andersson, M., Nordin, A., & Engström, A. (2022). Critical care nurses' perceptions of moral distress in intensive care during the COVID-19 pandemic: A pilot study. *Intensive and Critical Care Nursing*, 72, 103279. <https://doi.org/10.1016/j.iccn.2022.103279>
- Arianto, A. B., Trisyani, Y., & Emaliyawati, E. (2022). Nurses' experiences of ethical dilemmas at the end-of-life care in the intensive care unit. *The Soedirman Journal of Nursing*, 17(3), 112–116.
- Bach, V., Ploeg, J., & Black, M. (2009). Nursing roles in end-of-life decision making in critical care settings. *Western Journal of Nursing Research*, 31(4), 496–512.

- Baldwin, J., Pingault, J.-B., Schoeler, T., Sallis, H., & Munafò, M. (2022). Protecting against researcher bias in secondary data analysis: Challenges and potential solutions. *European Journal of Epidemiology*, 37(1), 1–10. <https://doi.org/10.1007/s10654-021-00839-0>
- Baxter, P. E., & Jack, S. M. (2008). Qualitative case study methodology: Study design and implementation for novice researchers. *The Qualitative Report*, 13(4), 544–559.
- Benhabib, S. (1987). The generalized and the concrete other: The Kohlberg–Gilligan controversy and feminist theory. In S. Benhabib & D. Cornell (Eds.), *Feminism as critique: Essays on the politics of gender in late-capitalist societies* (pp. 77–95). Polity Press.
- Berchtenbreiter, K., Innes, K., Watterson, J., Nickson, C. P., & Wong, P. (2024). Intensive care unit nurses' perceptions of debriefing after critical incidents: A qualitative descriptive study. *Australian Critical Care*, 37(2), 288–294. <https://doi.org/10.1016/j.aucc.2023.06.002>
- Bergum, V. (2012). Relational ethics for nursing. In P. Storch, P. Rodney, & R. Starzomski (Eds.), *Toward a moral horizon: Nursing ethics for leadership and practice* (pp. 127–142). Pearson Education Canada.
- Bergum, V., & Dossetor, J. (2005). *Relational ethics: The full meaning of respect*. University Publishing Group.
- Bilal, M., Mukhtar, F., Kousar, S., Ghani, M., & Khan, M. H. (2022). Nurses' experiences in end-of-life care in an intensive care unit at a tertiary healthcare setting, Lahore. *Pakistan Journal of Medical and Health Sciences*, 16(8), 249–253.
- Boddy, C. R. (2016). Sample size for qualitative research. *Qualitative Market Research*, 19(4), 426–432. <https://doi.org/10.1108/QMR-06-2016-0053>
- Boland, A., Cherry, M. G., & Dickson, R. (2017). *Doing a systematic review: A student's guide* (2nd ed.). SAGE.
- Booth, A. (2016). Searching for qualitative research for inclusion in systematic reviews: A structured methodological review. *Systematic Reviews*, 5, 74. <https://doi.org/10.1186/s13643-016-0249-x>
- Bratcher, J. R. (2010). How do critical care nurses define a “good death” in the intensive care unit? *Critical Care Nursing Quarterly*, 33(1), 87–99. <https://doi.org/10.1097/CNQ.0b013e3181c8e2d7>
- Bruce, A., Beuthin, R., Schick-Makaroff, K., Sheilds, L., & Molzahn, A. (2016). Narrative research evolving: Evolving through narrative research. *International Journal of Qualitative Methods*, 15(1), 1–6.
- Cantwell, B., & Ramirez, A. (1997). Doctor–patient communication: A study of junior house officers. *Medical Education*, 31, 17–21.

Capuzzo, M., Volta, C., Tassinati, T., Moreno, R., Valentin, A., Guidet, B., ... Rhodes, A. (2014). Hospital mortality of adults admitted to intensive care units in hospitals with and without intermediate care units: A multicentre European cohort study. *Critical Care*, 18(5), 551.

Critical Appraisal Skills Programme (2024). *CASP systematic review checklist*. <https://casp-uk.net/casp-tools-checklists/systematic-review-checklist/>

Critical Appraisal Skills Programme (2024). *CASP qualitative checklist*. <https://casp-uk.net/casp-tools-checklists/qualitative-studies-checklist/>

Chapman, S. (2009). The Liverpool Care Pathway: “Tick box” approach not encouraged. *International Journal of Palliative Nursing*, 15(9), 420–421.

Chen, C., Michaels, J., & Meeker, M. (2019). Family outcomes and perceptions of end-of-life care in the intensive care unit: A mixed-methods review. *Journal of Palliative Care*, 35(3), 143–153.

Christensen, M., & Liang, M. (2023). Critical care: A concept analysis. *International Journal of Nursing Sciences*, 10(3), 403–413.

Clancy, M. (2013). Is reflexivity the key to minimising problems of interpretation in phenomenological research? *Nurse Researcher*, 20(6), 12–16.

Coffey, A. (2018). *Doing ethnography*. SAGE.

Cohen, S., & Wills, T. (1985). Stress, social support, and the buffering hypothesis. *Psychological Bulletin*, 98(2), 310–357. <https://doi.org/10.1037/0033-2909.98.2.310>

Conte, H., Dorell, A., Wedin, E., & Eckerblad, J. (2023). In their absence: Intensive care nurses’ experiences of communicating and supporting relatives from a distance. *BMC Nursing*, 22, 421.

Coombs, M., & Long, T. (2008). Managing a good death in critical care: Can health policy help? *Nursing in Critical Care*, 13(4), 208–214.

Corbin, J., & Strauss, A. (2007). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (3rd ed.). SAGE.

Creswell, J. W. (2009). *Research design: Qualitative, quantitative, and mixed methods approaches* (3rd ed.). SAGE.

Crombie, I. K. (2022). *The pocket guide to critical appraisal* (2nd ed.). Wiley-Blackwell.

Davidson, J. E., Jones, C., & Bienvenu, J. (2012). Family response to critical illness: Postintensive care syndrome–family. *Critical Care Medicine*, 40(2), 618–624. <https://doi.org/10.1097/CCM.0b013e318236ebf9>

Davidson, J., Aslakson, R., Long, A., Puntillo, K., Kross, E., Hart, J., ... Curtis, R. (2017). Guidelines for family-centered care in the neonatal, pediatric, and adult ICU. *Critical Care Medicine*, 45(1), 103–128.

De Brasi, E. L., Giannetta, N., Ercolani, S., Gandini, E., Moranda, D., Villa, G., & Manara, D. F. (2021). Nurses' moral distress in end-of-life care: A qualitative study. *Nursing Ethics*, 28(5), 614–627.

Dean, R. A., & Major, J. E. (2008). From critical care to comfort care: The sustaining value of humour. *Journal of Clinical Nursing*, 17(8), 1088–1095.
<https://doi.org/10.1111/j.1365-2702.2007.02090.x>

Denzin, N. K., & Lincoln, Y. S. (Eds.). (2011). *The SAGE handbook of qualitative research* (4th ed.). SAGE.

DeSanto-Madeya, S., & Safizadeh, P. (2017). Family satisfaction with end-of-life care in the intensive care unit: A systematic review of the literature. *Dimensions of Critical Care Nursing*, 36(5), 278–283.

Efstathiou, N., & Clifford, C. (2011). The critical care nurse's role in end-of-life care: Issues and challenges. *Nursing in Critical Care*, 16(3), 116–123.
<https://doi.org/10.1111/j.1478-5153.2010.00438.x>

Elpern, E. H., Covert, B., & Kleinpell, R. (2005). Moral distress of staff nurses in a medical intensive care unit. *American Journal of Critical Care*, 14(6), 523–530.

Endacott, R., Boyer, C., Benbenishty, J., Ben Nunn, M., Ryan, H., Chamberlain, W., ... Ganz, F. (2016). Perceptions of a good death: A qualitative study in intensive care units in England and Israel. *Intensive and Critical Care Nursing*, 36, 1–9.

England, N. H. S. (2013). *Leadership Alliance for the Care of Dying People: Engagement with patients, families, carers and professionals*.
https://www.engage.england.nhs.uk/consultation/care-dying-ppl-engage/supporting_documents/lacdpengage.pdf

Faenza, D., Trapani, J., & Bonello, M. (2022). Maltese nurses' and doctors' perceptions on palliative care in critical care settings: Qualitative findings from a mixed methods case study. *Nursing in Critical Care*, 27(S1), 20.

Fox, M. (2014). Improving communication with patients and families in the intensive care unit: Palliative care strategies for the intensive care unit nurse. *Journal of Hospice and Palliative Nursing*, 16(2), 93–98.

Galea, M. (2014). The progressive impact of burnout on Maltese nurses. *SOP Transactions on Psychology*, 1(1), 1–12.

Ghanad, A. (2023). An overview of quantitative research methods. *International Journal of Multidisciplinary Research and Analysis*, 6(8).
<https://doi.org/10.47191/ijmra/v6-i8-52>

- Giannetta, N., Villa, G., Bonetti, L., Dionisi, S., Pozza, A., Rolandi, S., ... Manara, D. F. (2022). Moral distress scores of nurses working in intensive care units for adults using Corley's scale: A systematic review. *International Journal of Environmental Research and Public Health*, *19*(17), 10640.
- Gundumogula, M. (2020). Importance of focus groups in qualitative research. *The International Journal of Humanities and Social Studies*, *8*(11), 299–302.
<https://doi.org/10.24940/theijhss/2020/v8/i11/HS2011-082>
- Health, U. D. (2008). *End of life care strategy: Promoting high-quality care for all adults at the end of life*.
https://assets.publishing.service.gov.uk/media/5a7ae925ed915d71db8b35aa/End_of_life_strategy.pdf
- Hinderer, K. A. (2012). Reactions to patient death: The lived experience of critical care nurses. *Dimensions of Critical Care Nursing*, *31*(4), 252–259.
- Holmberg, J., Rosendahl, I., Andersson, R., Kemani, M., Holmstrom, L., Öst, L.-G., & Wicksell, R. (2024). Improving mental health among intensive care unit staff with communication skills training. *Frontiers in Psychology*, *15*, 1454702.
- Holms, N., Milligan, S., & Kydd, A. (2014). A study of the lived experiences of registered nurses who have provided end-of-life care within an intensive care unit. *International Journal of Palliative Nursing*, *20*(11), 549–556.
- Jang, S., Park, W., Kim, H.-I., & Chang, S. (2018). Exploring nurses' end-of-life care for dying patients in the ICU using focus group interviews. *Intensive and Critical Care Nursing*, *52*, 3–8.
- Joanna Briggs Institute. (2020). Checklist for analytical cross-sectional studies. JBI.
<https://jbi.global/critical-appraisal-tools>
- Kaushik, V., & Walsh, C. A. (2019). Pragmatism as a research paradigm and its implications for social work research. *Social Sciences*, *8*(9), 255.
- Kisorio, L. C., & Langley, G. C. (2016). Intensive care nurses' experiences of end-of-life care. *Intensive and Critical Care Nursing*, *33*, 30–38.
- Kızıltepe, S. K., & Koç, Z. (2021). Intensive care nurses' experiences related to dying patients: A qualitative study. *SAGE Open Nursing*, *7*, 1–15.
- Korsah, E. K., & Schmollgruber, S. (2023). Barriers and facilitators to end-of-life care in the adult intensive care unit: A scoping review. *International Journal of Africa Nursing Sciences*, *19*, 100636.
- Latour, J. M., Fulbrook, P., & Albarran, J. W. (2009). EfCCNa survey: European intensive care nurses' attitudes and beliefs towards end-of-life care. *Nursing in Critical Care*, *14*(3), 110–121.

- Lee, T.-H., Tzeng, W.-C., & Chiang, H.-H. (2019). Impact of coping strategies on nurses' well-being and practice. *Journal of Nursing Scholarship, 51*(2), 195–204. <https://doi.org/10.1111/jnu.12467>
- Leung, L. (2015). Validity, reliability, and generalizability in qualitative research. *Journal of Family Medicine and Primary Care, 4*(3), 324–327.
- Levi, P., Patrician, P., Moss, J., Vance, D., & Montgomery, A. (2020). Post-traumatic stress disorder in intensive care unit nurses: A concept analysis. *Journal of Nursing Scholarship, 52*(5), 224–234. <https://doi.org/10.1177/2165079920971999>
- Lincoln, Y. S., & Guba, E. G. (2013). *The constructivist credo*. Left Coast Press.
- Lincoln, Y. S., Lynham, S. A., & Guba, E. G. (2011). Paradigmatic controversies, contradictions, and emerging confluences revisited. In N. K. Denzin & Y. S. Lincoln (Eds.), *The SAGE handbook of qualitative research* (4th ed.). SAGE Publications.
- McAndrew, N. S., Leske, J., & Schroeter, K. (2018). Moral distress in critical care nursing: The state of the science. *Nursing Ethics, 25*(5), 552–570. <https://doi.org/10.1177/0969733016664975>
- McGrath, C., Palmgren, P., & Liljedahl, M. (2018). Twelve tips for conducting qualitative research interviews. *Medical Teacher, 40*(9), 1002–1006.
- Mhaskar, R., Emmanuel, P., Mishra, S., Patel, S., Naik, E., & Kumar, A. (2009). Critical appraisal skills are essential to informed decision-making. *Indian Journal of Sexually Transmitted Diseases and AIDS, 30*(2), 112–119. <https://doi.org/10.4103/2589-0557.62770>
- Missouridou, E. (2017). Secondary posttraumatic stress and nurses' emotional responses to patients' trauma. *Journal of Trauma Nursing, 24*(2), 110–115.
- Morley, G., Bradbury-Jones, C., & Ives, J. (2022). The moral distress model: An empirically informed guide for moral distress interventions. *Journal of Clinical Nursing, 31*(9–10), 1309–1326. <https://doi.org/10.1111/jocn.15988>
- Neuberger, J., Aaronovitch, D., Bonser, T., Charlesworth-Smith, D., Cox, D., Guthrie, C., ... Waller, S. (2013). *More care, less pathway: A review of the Liverpool Care Pathway*. https://assets.publishing.service.gov.uk/media/5a75153340f0b6397f35d87d/Liverpool_Care_Pathway.pdf
- Ng, L., Schache, K., Young, M., & Sinclair, J. (2023). Value of Schwartz Rounds in promoting the emotional well-being of healthcare workers: A qualitative study. *BMJ Open, 13*, e064144. <https://doi.org/10.1136/bmjopen-2022-064144>
- Noble, H., & Smith, J. (2015). Issues of validity and reliability in qualitative research. *Evidence-Based Nursing, 18*(2), 34–36.

Noome, M., Beneken genaamd Kolmer, D. M., van Leeuwen, E., Dijkstra, B. M., & Vloet, L. C. (2016). The nursing role during end-of-life care in the intensive care unit: An integrative review. *Scandinavian Journal of Caring Sciences*, 30, 645–661.

Noome, M., Dijkstra, B. M., van Leeuwen, E., & Vloet, L. C. (2016). Exploring family experiences of nursing aspects of end-of-life care in the ICU: A qualitative study. *Intensive and Critical Care Nursing*, 33, 56–64.

Ong, K., Ting, K. C., & Chow, Y. L. (2018). The trajectory of experience of critical care nurses in providing end-of-life care: A qualitative descriptive study. *Journal of Clinical Nursing*, 27(1–2), 257–268.

Ozga, D., Wozniak, K., & Gurowiec, P. J. (2020). Difficulties perceived by ICU nurses providing end-of-life care: A qualitative study. *Global Advances in Health and Medicine*, 9, 1–7. <https://doi.org/10.1177/2164956120916176>

Page, M. J., McKenzie, J. E., Bossuyt, P. M., Boutron, I., Hoffmann, T. C., Mulrow, C. D., Shamseer, L., Tetzlaff, J. M., Akl, E. A., Brennan, S. E., Chou, R., Glanville, J., Grimshaw, J. M., Hróbjartsson, A., Lalu, M. M., Li, T., Loder, E. W., Mayo-Wilson, E., McDonald, S., Moher, D. (2021). The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *BMJ (Online)*, 372, n71. <https://doi.org/10.1136/bmj.n71>

Palinkas, L. A., Horwitz, S. M., Green, C. A., Wisdom, J. P., Duan, N., & Hoagwood, K. (2015). Purposeful sampling for qualitative data collection and analysis in mixed method implementation research. *Administration and Policy in Mental Health and Mental Health Services Research*, 42(5), 533–544. <https://doi.org/10.1007/s10488-013-0528-y>

Pan, H., Shi, W., Zhou, Q., Chen, G., & Pan, P. (2023). Palliative care in the intensive care unit: Not just end-of-life care. *Intensive Care Research*, 3, 77–82.

Park, Y. S., Konge, L., & Artino, A. R. (2020). The positivism paradigm of research. *Academic Medicine*, 95(5), 690-694.

Peters, L., Cant, R., O'Connor, M., McDermott, F., Hood, K., Morphet, J., & Shimoinaba, K. (2013). How death anxiety impacts nurses' caring for patients at the end of life: A review of literature. *The Open Nursing Journal*, 7, 14–21.

Peters, K., & Halcomb, E. (2015). Interviews in qualitative research. *Nurse Researcher*, 22(4), 6–10.

Pollard, C. L. (2015). What is the right thing to do? Use of a relational ethics framework to guide clinical decision-making. *International Journal of Caring Sciences*, 8(2), 362–368.

Price, A. M. (2013). Caring and technology in an intensive care unit: An ethnographic study. *Nursing in Critical Care*, 18(6), 278–288.

- Prompahakul, C., Keim-Malpass, J., LeBaron, V., Yan, G., & Epstein, E. G. (2021). Moral distress among nurses: A mixed-methods study. *Nursing Ethics, 28*(7–8), 1165–1182. <https://doi.org/10.1177/0969733021996028>
- Puntillo, K., Benner, P., Drought, T., Drew, B., Stotts, N., Stannard, D., ... White, C. (2001). End-of-life issues in intensive care units: A national random survey of nurses' knowledge and beliefs. *American Journal of Critical Care, 10*(4), 216–229.
- Rafii, F., Nasrabadi, A. N., & Karim, M. A. (2015). End-of-life care provision: Experiences of intensive care nurses in Iraq. *Nursing in Critical Care, 21*(2), 105–112.
- Ranse, K., Yates, P., & Coyer, F. (2012). End-of-life care in the intensive care setting: A descriptive exploratory qualitative study of nurses' beliefs and practices. *Australian Critical Care, 25*(1), 4–12.
- Ryan, L., & Seymour, J. (2013). Death and dying in intensive care: Emotional labour of nurses. *End of Life Journal, 3*(2), 1–9.
- Shao-Hua, C., Jun-E, L., Xiao-Yu, B., Peng, Y., & Shi-Xiang, L. (2021). Providing targeted psychological support to frontline nurses involved in the management of COVID-19: An action research study. *Journal of Nursing Management, 29*(5), 1169–1179. <https://doi.org/10.1111/jonm.13255>
- Shirasaki, K., Hifumi, T., Nakanishi, N., Nosaka, N., Miyamoto, K., Komachi, M. H., ... Otani, N. (2024). Post-intensive care syndrome-family: A comprehensive review. *Acute Medicine & Surgery, 11*(1), e939.
- Smith, J. A., & Nizza, I. E. (2021). *Essentials of interpretative phenomenological analysis*. American Psychological Association.
- Smith, J. A., Flowers, P., & Larkin, M. (2022). *Interpretative phenomenological analysis* (2nd ed.). SAGE.
- Stokes, H., Vanderspank-Wright, B., Bourbonnais, F. F., & Wright, D. K. (2019). Meaningful experiences and end-of-life care in the intensive care unit: A qualitative study. *Intensive and Critical Care Nursing, 53*, 1–7.
- Taleghani, F., Dehbozorgi, R., Babashahi, M., Monemian, S., & Masoumi, M. (2023). Analysis of the concept of nurses' autonomy in intensive care units: A hybrid model. *Investigación y Educación en Enfermería, 41*(2), e17. <https://doi.org/10.17533/udea.iee.v41n2e17>
- Tan, L., Le, M. K., Yu, C., Liaw, S. Y., Tierney, T., Ho, Y., ... Low, J. (2021). Defining clinical empathy: A grounded theory approach from the perspective of healthcare workers and patients in a multicultural setting. *BMJ Open, 11*(9), e045224. <https://doi.org/10.1136/bmjopen-2020-045224>

- Team, M. C. (2025, June 26). *MAPHM feedback to the public consultation on voluntary assisted euthanasia*. <https://maphm.org/2025/06/27/maphm-feedback-to-the-public-consultation-on-voluntary-assisted-euthanasia/>
- Todd, D., Booth, A., & Smith, B. (2021). Critical appraisal. *International Review of Sport and Exercise Psychology*, *15*(1), 52–72. <https://doi.org/10.1080/1750984X.2021.1952471>
- Tsouvelas, G., Kalaitzaki, A., Tamiolaki, A., Rovithis, M., & Konstantakopoulos, G. (2022). Secondary traumatic stress and dissociative coping strategies in nurses during the COVID-19 pandemic: The protective role of resilience. *Archives of Psychiatric Nursing*, *41*, 264–270.
- Tuffour, I. (2017). A critical overview of interpretative phenomenological analysis: A contemporary qualitative research approach. *Journal of Healthcare Communications*, *2*(4), 52.
- Utami, R. S., Pujiyanto, A., Setyawan, D., Naviati, E., & Rochana, N. (2020). Critical care nurses' experiences of end-of-life care: A qualitative study. *Nurse Media Journal of Nursing*, *10*(3), 260–274.
- Vanderspank-Wright, B., Fothergill-Bourbonnais, F., Brajtman, S., & Gagnon, P. (2011). Caring for patients and families at the end of life: Nurses' experiences during withdrawal of life-sustaining treatment. *Dynamics*, *22*(4), 31–35.
- Velarde-García, J., Pulido-Mendoza, R., Moro-Tejedor, M., Cachón-Pérez, J., & Palacios-Ceña, D. (2016). Nursing and end-of-life care in the intensive care unit. *Journal of Hospice and Palliative Nursing*, *18*(2), 115–123.
- Wang, X., & Cheng, Z. (2020). Cross-sectional studies: Strengths, weaknesses, and recommendations. *Chest*, *158*(1), S65–S71. <https://doi.org/10.1016/j.chest.2020.03.012>
- Wells, C., & Bressler, T. (2023). “Unaware and unprepared”: Experiences of critical care nurses providing end-of-life care. *Journal of Hospice and Palliative Nursing*, *25*(2), 105–113.
- Wenham, T., & Pittard, A. (2009). Intensive care unit environment. *Continuing Education in Anaesthesia, Critical Care & Pain*, *9*(6), 178–183.
- Wiegand, D. L., & Funk, M. (2012). Consequences of clinical situations that cause critical care nurses to experience moral distress. *Journal of Clinical Nursing*, *21*(9–10), 1368–1377.
- Wilkin, K., & Slevin, E. (2004). The meaning of caring to nurses: An investigation into the nature of caring work in an intensive care unit. *Journal of Clinical Nursing*, *13*(1), 50–59. <https://doi.org/10.1111/j.1365-2702.2004.00814.x>
- Williams, H. (2021). The meaning of phenomenology: Qualitative and philosophical phenomenological research methods. *The Qualitative Report*, *26*(2), 366–385.

Williams, S. L., VanDerWeele, L. J., Magana, E., & Abraham, S. P. (2022). The effects of counseling on intensive care unit nurses who have experienced traumatic events. *International Journal of Science and Research Methodology*, 23(2), 167–177.

Wu, H., Ren, D., Zinsmeister, G. R., Zewe, G. E., & Tuite, P. K. (2016). Implementation of nurse-led family meetings in a neuroscience intensive care unit. *Dimensions of Critical Care Nursing*, 35(5), 268–276.

Yardley, L. (2000). Dilemmas in qualitative research. *Psychology & Health*, 15(2), 215–228.

Appendices

Appendix A – Participant Information Sheet (PIS) and Consent Form



Participants' Information Sheet

Dear Participant,

My name is Rhys Azzopardi, and I am currently reading for a Masters in Nursing (Critical Care) at the University of Malta. As part of my course requirements I am conducting a research study entitled, “Critical Care Nurses’ experiences of caring for patients at the end of life”. The aim of this study is to explore the lived experiences of critical care nurses providing end-of-life care to adult patients in the local intensive care unit. Your participation in this study would help us gain a better understanding about the experiences of nurses providing end-of-life care within the complex critical care setting and the effects this has on them. Furthermore, all data collected from this research shall be used solely for the purpose of this study.

You are being invited to participate in two separate interviews exploring your experiences of caring for patients at the end of life. The first interview will take approximately 1 hour, while the second will take approximately 30 minutes, if necessary. Both interviews will be held at a time and place most suitable for you, either face to face or online, according to your preference. You are not obliged to answer all the questions and may withdraw from the study at any time without giving a reason. Furthermore, withdrawal from the study will not have any negative repercussions on you. Should you choose to withdraw, any data collected will be erased as long as this is technically possible (for example, before it is anonymised or published), unless erasure of data would render impossible or seriously impair achievement of the research objectives, in which case it shall be retained in an anonymised form. Unless you have any objections, interviews will be audio-recorded. No video recordings or photography will take place during the interviews. I can assure you that confidentiality will be maintained throughout the study and that your identity and personal information will not be revealed in any publications, reports or presentations arising from this research. All data collected will be pseudonymised meaning that the transcripts will be assigned codes and that this data will be stored securely

and separately from any codes and personal data. Collected data may only be accessed by the researcher. The academic supervisor/s and the 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 wish to enquire who accessed your data please contact my supervisor, Dr Ermira Tartari Bonnici via email on ermira-tartari.bonnici@um.edu.mt.

The coded audio-recordings, and transcripts will be stored on the researcher's personal computer that is password protected and in an encrypted format. Personal data shall be stored offline in an encrypted manner on an external hard disk. Any material in hard-copy form will be placed in a locked cupboard.

In the event that you feel distressed due to participation in the interview, the service of a healthcare professional, Ms Mariella Meachen, hospital psychotherapist will be available at no financial cost on your part. Ms Meachen may be reached via email on mariella.meachen@gov.mt or 79521344.

Participation in this study is completely voluntary and you are free to accept or refuse to take part without giving a reason. A copy of the information sheet and consent form will be provided for future reference. 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. Personally identifiable data will be deleted when it is no longer necessary, which should be by July 2025. Any subsequent anonymised data may be kept indefinitely.

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

Thank you for your time and consideration. Should you have any questions or concerns do not hesitate to contact me on 79823784 or by e-mail rhys.azzopardi.17@um.edu.mt or my supervisor Dr Ermira Tartari Bonnici on 23401168 or by email on ermira-tartari.bonnici@um.edu.mt.

Yours Sincerely,

Rhys Azzopardi

Researcher

79823784

rhys.azzopardi.17@um.edu.mt

Dr Ermira Tartari Bonnici

Research Supervisor

23401168

ermira-tartari.bonnici@um.edu.mt

Participants` Consent Form

I, the undersigned, give my consent to take part in the study conducted by Rhys Azzopardi. The purpose of this document is to specify the terms of my participation in this research study.

1. I have been given written and verbal information about the purpose of the study and all questions have been answered.
2. I understand that I have been invited to participate in two separate interviews, in which the researcher will ask questions to explore my experiences of providing end-of-life care to patients in the local intensive care unit.
3. I am aware that the first interview will take approximately 1 hour, while the second interview will take approximately 30 minutes. I understand that the interview is to be conducted at a time and place most suitable for me either face to face or online.
4. I am aware that this interview will be audio recorded and transcribed (written down as it has been spoken).
5. I am aware that the transcripts will be coded and that this data will be stored securely and separately from any codes and personal data.
6. I am aware that the researcher is the only person who has access to this data. The academic supervisor/s 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 I want to enquire who accessed my data, I may contact academic supervisor, Dr Ermira Tartari Bonnici via email on ermira-tartari.bonnici@um.edu.mt.
7. I am also aware that the coded audio-recordings and transcripts will be stored on the researcher`s personal computer that is password protected and in an encrypted format. My personal data shall be stored offline in an encrypted manner on an external hard disk. Any material in hard-copy form will be placed in a locked cupboard and kept until results are published.
8. I am aware that my identity and personal information will not be revealed in any publications, reports or presentations arising from this research.
9. I also understand that I am free to accept, refuse or stop participation at any time without giving any reason. This will have no negative repercussions on myself and that any data collected from me will

be erased. Data will be stored anonymously if it is impossible to delete (e.g. if it has already been anonymised).

10. I also understand that my contribution will serve to provide a valuable insight into the effects caring for patients nearing the end of life has on critical care nurses on a personal and professional level.
11. If I feel that the interview has distressed me in any way, Ms Mariella Meachen, hospital psychotherapist will be available to provide a service at no financial cost on my part. Ms Meachen may be reached via email on mariella.meachen@gov.mt or via phone on 79521344.
12. 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.
13. I also understand that personally identifiable data will be deleted when it is no longer necessary, which should be by July 2025. Any subsequent anonymised data may be kept indefinitely.
14. I will be provided with a copy of the information letter and consent form for future reference.
15. I have read and understood the points and statements of this form. I have had all the questions answered to my satisfaction, and I agree to participate in this study.

Participant: _____

Signature: _____

Online contact detail (if applicable): _____

Date: _____

Rhys Azzopardi

Researcher

79823784

rhys.azzopardi.17@um.edu.mt

Dr Ermira Tartari Bonnici

Research Supervisor

23401168

ermira-tartari.bonnici@um.edu.mt

Appendix B – Interview Guide

Q1. How long have you been a nurse and working in the Intensive Care Unit?

Q2. Can you describe your role and nursing practice when delivering EOLC?

Q3. What aspect of providing end-of-life care do you prioritise?

Q4. What aspects of caring for dying patients in the ICU do you find difficult or challenging?

Q5. How do you usually feel during and after providing end-of-life care?

Q6. How do you think that your role in providing end-of-life care and caring for dying patients affects you?

Prompt: Have you noticed any changes in how you approach your work or personal life?

Q7. In your opinion, what does a “good death” mean in the ICU?

Prompt: How do you provide this for you patients?

Q8. Can you share an experience where you felt the patient did not have a good death?

Prompt: How did this make you feel?

Q9. What has been your experience with family members of patients nearing the end of their lives in the ICU?

Q10. What personal coping strategies do you use engage in to cope with the emotional and professional challenges associated with providing end-of-life care?

Q11. What is your perception on institutional support strategies for nurses providing end-of-life care in the ICU?

Appendix C – Approval from the Faculty Research Ethics Committee (FREC)

FHS-2024-00361 Rhys Azzopardi External Inbox x



Research Ethics HEALTHSCI

5 Aug 2024, 14:46



Dear Rhys, FREC has reviewed the application in caption. Please address the following issues: URECA form Part 1(b) -kindly reword to state that interested parti



Rhys Azzopardi

6 Aug 2024, 09:26



Dear Prof Paulann Grech, Kindly find attached the requested documents for my FREC application FHS-2024-00361. As requested I have attached: - the participant in



Paulann Grech <paulanngrech@gmail.com>

to me, Research, Paulann, Ermira

9 Aug 2024, 06:01



Dear Rhys,

Thank you for the update. Your recent amendments have been reviewed and approval is granted on behalf of FREC.

Please make sure that the updated documents forwarded to FREC have also been uploaded on the URECA portal, without track changes.

You may continue with your data collection.

Good luck.

Best wishes,

Paulann



The status of your REDP form (FHS-2024-00361) has been updated to Approved Inbox x



form.urec@um.edu.mt

to me

Mon, 16 Sept 2024, 12:50



Dear Rhys Azzopardi,

Please note that the status of your REDP form (FHS-2024-00361) has been set to *Approved*.

You can keep track of your applications by visiting: <https://www.um.edu.mt/research/ethics/redp-form/frontEnd/>.

****This email has been automatically generated by URECA. Please do not reply. If you wish to communicate with your F/REC please use the respective email address.****

← Reply

→ Forward

Appendix D – CASP Checklist for Qualitative Research



CASP Checklist For Qualitative Research

| | |
|-----------------|--|
| Reviewer Name: | |
| Paper Title: | |
| Author: | |
| Web Link: | |
| Appraisal Date: | |

During critical appraisal, never make assumptions about what the researchers have done. If it is not possible to tell, use the “Can’t tell” response box. If you can’t tell, at best it means the researchers have not been explicit or transparent, but at worst it could mean the researchers have not undertaken a particular task or process. Once you’ve finished the critical appraisal, if there are a large number of “Can’t tell” responses, consider whether the findings of the study are trustworthy and interpret the results with caution.

| | |
|---|--|
| Section A Are the results valid? | |
| 1. Was there a clear statement of the aims of the research? | <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Can't Tell |
| <p><i>CONSIDER:</i></p> <ul style="list-style-type: none"> <i>what was the goal of the research?</i> <i>why was it thought important?</i> <i>its relevance</i> | |
| 2. Is a qualitative methodology appropriate? | <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Can't Tell |
| <p><i>CONSIDER:</i></p> <ul style="list-style-type: none"> <i>If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants</i> <i>Is qualitative research the right methodology for addressing the research goal?</i> | |
| 3. Was the research design appropriate to address the aims of the research? | <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Can't Tell |
| <p><i>CONSIDER:</i></p> <ul style="list-style-type: none"> <i>if the researcher has justified the research design (e.g., have they discussed how they decided which method to use)</i> | |
| 4. Was the recruitment strategy appropriate to the aims of the research? | <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Can't Tell |
| <p><i>CONSIDER:</i></p> <ul style="list-style-type: none"> <i>If the researcher has explained how the participants were selected</i> <i>If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study</i> <i>If there are any discussions around recruitment (e.g. why some people chose not to take part)</i> | |

| | |
|---|--|
| 5. Was the data collected in a way that addressed the research issue? | <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Can't Tell |
|---|--|

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*

| | |
|---|--|
| 6. Has the relationship between researcher and participants been adequately considered? | <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Can't Tell |
|---|--|

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*

Section B: What are the results?

| | |
|---|--|
| 7. Have ethical issues been taken into consideration? | <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Can't Tell |
|---|--|

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*

| | |
|---|--|
| 8. Was the data analysis sufficiently rigorous? | <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Can't Tell |
| <p><i>CONSIDER:</i></p> <ul style="list-style-type: none"> • <i>If there is an in-depth description of the analysis process</i> • <i>If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data</i> • <i>Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process</i> • <i>If sufficient data are presented to support the findings</i> • <i>To what extent contradictory data are taken into account</i> • <i>Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation</i> | |
| 9. Is there a clear statement of findings? | <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Can't Tell |
| <p><i>CONSIDER:</i></p> <ul style="list-style-type: none"> • <i>If the findings are explicit</i> • <i>If there is adequate discussion of the evidence both for and against the researcher's arguments</i> • <i>If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst)</i> • <i>If the findings are discussed in relation to the original research question</i> | |
| Section C: Will the results help locally? | |
| 10. How valuable is the research? | <input type="checkbox"/> Yes <input type="checkbox"/> No <input type="checkbox"/> Can't Tell |
| <p><i>CONSIDER:</i></p> <ul style="list-style-type: none"> • <i>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)</i> • <i>If they identify new areas where research is necessary</i> • <i>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</i> | |

APPRAISAL SUMMARY: *List key points from your critical appraisal that need to be considered when assessing the validity of the results and their usefulness in decision-making.*

| Positive/Methodologically sound | Negative/Relatively poor methodology | Unknowns |
|--|---|-----------------|
| | | |

Appendix E- CASP Checklist for Systematic Review



CASP Checklist: 10 questions to help you make sense of a Systematic Review

How to use this appraisal tool: Three broad issues need to be considered when appraising a systematic review 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. Systematic Review) Checklist. [online] Available at: URL. Accessed: Date Accessed.*

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Paper for appraisal and reference:

Section A: Are the results of the review valid?

1. Did the review address a clearly focused question?

| | |
|------------|--------------------------|
| Yes | <input type="checkbox"/> |
| Can't Tell | <input type="checkbox"/> |
| No | <input type="checkbox"/> |

HINT: An issue can be 'focused' In terms of

- the population studied
- the intervention given
- the outcome considered

Comments:

2. Did the authors look for the right type of papers?

| | |
|------------|--------------------------|
| Yes | <input type="checkbox"/> |
| Can't Tell | <input type="checkbox"/> |
| No | <input type="checkbox"/> |

HINT: 'The best sort of studies' would

- address the review's question
- have an appropriate study design (usually RCTs for papers evaluating interventions)

Comments:

Is it worth continuing?

3. Do you think all the important, relevant studies were included?

| | |
|------------|--------------------------|
| Yes | <input type="checkbox"/> |
| Can't Tell | <input type="checkbox"/> |
| No | <input type="checkbox"/> |

HINT: Look for

- which bibliographic databases were used
- follow up from reference lists
- personal contact with experts
- unpublished as well as published studies
- non-English language studies

Comments:

4. Did the review's authors do enough to assess quality of the included studies?

Yes

Can't Tell

No

HINT: The authors need to consider the rigour of the studies they have identified. Lack of rigour may affect the studies' results ("All that glisters is not gold" Merchant of Venice – Act II Scene 7)

Comments:

5. If the results of the review have been combined, was it reasonable to do so?

Yes

Can't Tell

No

HINT: Consider whether results were similar from study to study

- results of all the included studies are clearly displayed
- results of different studies are similar
- reasons for any variations in results are discussed

Comments:

Section B: What are the results?

6. What are the overall results of the review?

HINT: Consider

- If you are clear about the review's 'bottom line' results
 - what these are (numerically if appropriate)
- how were the results expressed (NNT, odds ratio etc.)

Comments:

7. How precise are the results?

HINT: Look at the confidence intervals, if given

Comments:

Section C: Will the results help locally?

8. Can the results be applied to the local population?

Yes

Can't Tell

No

HINT: Consider whether

- the patients covered by the review could be sufficiently different to your population to cause concern
- your local setting is likely to differ much from that of the review

Comments:

9. Were all important outcomes considered?

Yes

Can't Tell

No

HINT: Consider whether

- there is other information you would like to have seen

Comments:

10. Are the benefits worth the harms and costs?

HINT: Consider even if this is not addressed by the review, what do you think?

Yes

Can't Tell

No

Comments:

Appendix F – JBI Checklist for Cross Sectional Studies

Reviewer _____

Date _____

Author _____ Year _____ Record
Number _____

| | Yes | No | Unclear | Not applicable |
|---|--------------------------|--------------------------|--------------------------|--------------------------|
| 1. Were the criteria for inclusion in the sample clearly defined? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 2. Were the study subjects and the setting described in detail? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 3. Was the exposure measured in a valid and reliable way? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 4. Were objective, standard criteria used for measurement of the condition? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 5. Were confounding factors identified? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 6. Were strategies to deal with confounding factors stated? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 7. Were the outcomes measured in a valid and reliable way? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| 8. Was appropriate statistical analysis used? | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Overall appraisal: Include Exclude Seek further info

Comments _____ (Including _____ reason _____ for
exclusion) _____