Grieving quietly whilst navigating the journey: The impact of managing end-of-life conversations on nurses working in adult general wards

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Table of Contents

LIST OF MODELS, FIGURES AND CHARTS

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ABSTRACT

Background

The management of end-of-life conversations in hospital settings has been discussed and debated for more than a decade, with commentary being raised by the government, national bodies, and regulators (DoH 2008, 2009, 2017; PHSO, 2015; CQC, 2016). Many studies have evidenced the way in which this can be improved in specialist settings; however, there is a dearth of empirical evidence in general wards where most hospitalised patients die (ONS, 2021).

Aim

The aim of this study was to explore the impact managing end-of-life conversations has on nurses working in adult acute general (non-specialist) inpatient wards.

Method

A constructivist grounded theory approach was used (Charmaz, 2014), with data collection occurring in four district general hospitals in the East of England. Purposeful and theoretical sampling recruited a total of eleven registered nurses. Data were collected using semi-structured interviews, which were audio recorded, transcribed verbatim and were analysed using the constant comparison method on the NVivo QSR system.

Findings

Five theoretical categories were co-constructed from the data to explain the processes of managing end-of-life conversations and their subsequent impacts. The categories of **walking the path with the dying, walking the path with the grieving, battling time, becoming lost** and **finding the way** form the substantive theory of **Navigating**

the Journey (Grieving Quietly), which evidences the cyclical and complex paths nurses take during each patient or familial interaction. Positive or negative impacts were predicated by the accessibility or lack of internal and external resources and time.

Conclusion

The proposed substantive theory of Navigating the Journey (Grieving Quietly) offers an insight into multiple microprocesses that occur when nurses enter conversations with the dying and the grieving. Further work is required to ensure that nurses have ready access to practical resources, meaningful education and supervision that will enable them to best succeed such journeys.

1. CHAPTER 1 – INTRODUCTION AND BACKGROUND TO THE STUDY

‘How people die remains in the memory of those who live on’ (Dame Cicely Saunders, 1989, p624)

1.1. Introduction

This thesis explores the impact on nurses working in adult general wards in the acute hospital setting when they are involved in communicating with patients at, or near, the end of their lives. This study specifically focusses on those conversations which occur within the last days and weeks of life of the patient. The research also explores the impact on nurses involved in communicating with patients’ loved ones and family members at this crucial time, and the ongoing conversations which follow bereavement.

Nurses are intrinsically involved in the care of the dying as part of their professional practice; however, this study specifically focusses on the process of communication rather than the physical care provided. For the purposes of this study communication relates not only to prognostic and diagnostic conversations such as ‘breaking bad news’, but also all surrounding conversations that are focussed on supporting both the patient and their family during the final weeks, days, and hours of a patient’s life. In addition, end of life communication also extends beyond death, where nurses are involved in ongoing conversations with the bereaved, who may require additional information, support, and care in the days and weeks following a death.

The research considers the impact of multiple conversations with the dying and the grieving on nurses and proposes a substantive theory to better understand this. The environmental context within which such conversations occur is in adult acute general (non-specialist) inpatient wards. These wards also provide support for patients who are receiving curative treatments. The patients who are at the end-of-life, and their families, are being cared for by the same nurses, at the same time.

Within this chapter the researcher will present the national picture pertaining to mortality in hospitals in the United Kingdom, and an overview of the standards of care expected for end-of-life by the Department of Health and Social Care and other national bodies, with a specific focus on those areas related to communication. Published concerns regarding effective communication with the dying and their families will also be highlighted to enhance the reader's understanding of why the focus of this research is required.

Furthermore, the impact of how the SARS-CoV-2 (COVID-19) pandemic has influenced end-of-life communication, which occurred whilst the research study was being conducted, will be explored. Clarification will be provided as to where this study is situated in time and place; thereby offering the relevant contextual placement for the reader's understanding.

The chapter will conclude with a presentation of the overarching purpose of the study, its objectives and relative significance.

1.2. The national picture

In 2018, over 500,000 people died in England and Wales (Office of National Statistics (ONS), 2021), and of those 46% died in hospital. Prior to the outbreak of the SARS-CoV2 (COVID-19) virus in 2020, most people were recorded as having died from dementia, frailty, chronic obstructive pulmonary disorder, heart disease and cancer (ONS, 2021). It is recognised that many people who die in hospital receive excellent care; however, for some this has not been the case. Concerns have been raised in relation to end of life care, which include insufficient provision of pain relief, failing to support a preferred place of death, a lack of co-ordinated care, and issues surrounding communication (Department of Health (DOH), 2008). Acute hospitals have been tasked historically by Her Majesty’s Government, through the publication of national frameworks, to ensure that patients and those close to them receive clear information, have opportunities to discuss their wishes, and are supported throughout the dying phase (Department of Health, 2009).

Despite such goals being set, supported by associated national guidance and framework development on the expected standards of care quality (National Institute of Health and Care Excellence (NICE), 2011; NICE, 2017), concerns continue to be raised about the level and quality of communication being provided to patients and their families and carers. Such concerns have been highlighted within national reports, which have shown the inconsistencies in practice delivered by healthcare professionals (Parliamentary and Health Service Ombudsman (PHSO), 2015).

Whilst there has been recent evidence to show that the number of conversations regarding end of life have increased in hospitals (Healthcare Quality Improvement Partnership (HQIP), 2016), patients and families have continued to share experiences where such conversations have not felt open, honest, or sensitive in their nature. This has subsequently led to negative experiences for families, and patients have been unable to make decisions about their end-of-life care choices (Care Quality Commission (CQC), 2016).

1.3. Communication challenges

The challenges of being involved in conversations about end-of-life care have been recognised for the past decade (National End of Life Care Programme (NEoLCP), 2011). To support healthcare professionals feel more confident in communicating about end-of-life care, strategies were developed to provide on-going training and supervision for healthcare professionals, in order for them to become more effective and supportive communicators (NEoLCP, 2011). Indeed, online training developed by Health Education England to provide a set of core competencies to support consistency in education delivery was developed. The aim of the education was to support patient choice and improve the quality of end-of-life care (Department of Health, 2017).

However, as outlined in national reviews of end-of-life care provision, the time needed to have meaningful and effective communication has not been consistently prioritised to minimise feelings of pain, anger, guilt and resentment by patients and their families (Neuberger et al, 2013).

1.3.1. Nursing communication during end-of-life care

Effective communication forms part of the Code of Conduct for all nurses, midwives, and associated practitioners, with the expectation that all will communicate clearly and effectively, whilst supporting patients in their decision-making and ensuring that their wishes are known (Nursing & Midwifery Council, 2018). Following Neuberger et al's (2013) review into the Liverpool Care Pathway, with some key findings focussed on poor communication, it was recognised that a new way to support the dying and their carers was required (Leadership Alliance for the Care of Dying People, 2014). However, despite recommendations for change being in place for some time, the need to ensure that nursing staff have been made aware of their responsibilities in this regard has remained (Merlane & Cauwood, 2020).

As noted earlier, death occurs regularly in hospitals and, for some nurses, they will experience death and dying many times in their professional careers (Zheng et al, 2018). Nurses' continued exposure to death and dying may have both positive (Zheng et al, 2015) or negative effects (Cefik & Kav, 2013; Peterson et al, 2010a; Peterson et al, 2010b). The outcome of these effects has been seen to be dependent upon whether nurses have had sufficient resources in place to deal with sometimes emotionally complex encounters with patients and their families (Burgess et al, 2010).

Most of the published literature relating to end-of-life conversations has occurred within specific settings, such as oncology, critical care, palliative care, and paediatrics. However, it is recognised that more patients die in general acute ward settings, as documented by the primary causes of death from national statistics (ONS, 2021). Therefore, the researcher has focussed on acute (non-specialist) adult wards as a research setting. The nursing profession was identified as the proposed researched staffing group, as it is recognised that in general acute wards nurses are more readily available to spend time with patients and families. This is due to the nature of medical teams' accessibility and patterns of working across multiple locations in hospital. This has been evidenced by the researcher's engagement and involvement with general inpatient wards over two decades in either clinical practice or leadership roles across multiple hospital Trusts in London and the East of England.

As will be shared in the following chapter, a review of the literature has highlighted relatively few high-quality academic papers which consider the impact of end-of-life communication specifically, outside the specialised settings mentioned above. Therefore, a doctoral level study exploring this aspect of clinical practice is proposed to have the potential to contribute to the existing knowledge base.

As a senior nurse working in the National Health Service for over twenty years, with clinical expertise in specialised end-of-life care settings (critical care, and organ donation services), and working in senior roles with leadership responsibilities for the professional practice of nursing, the researcher understands that the priority for exploring the potential impact such conversations has on nurses is never more pressing. By developing new knowledge, the research findings and associated theory constructed from the data are offered as having the potential to positively impact pre- and post-registration clinical practice curricula design. In addition, it is also proposed that the recommendations from this study will prompt a review of resources that are needed by nurses in their practise and, as importantly, it is offered that the voices of nurses are heard as part of future developments in policy. The need is greater than ever before given the unprecedented impact that COVID-19 has had on all healthcare professionals, who have needed to work in circumstances never thought imaginable.

1.4. SARS-CoV-2 (COVID-19): the impact on healthcare professionals in the provision of end-of-life care communication

SARS-CoV-2, commonly referred to as COVID-19 or COVID, was first genetically confirmed in China in January 2020, with the World Health Organisation declaring the respiratory virus a Public Health Emergency of International Concern (PHEIC) in March 2020 (Mayland et al, 2021). With the advent of increased deaths occurring in hospital settings, changing patterns of mortality were witnessed, caused by illnesses both related to COVID-19 and those which were not (Bone et al, 2020).

Over the past two years rapid changes have been made to end-of-life care protocols for those patients who were hospitalised, primarily caused by the restrictions placed on visiting for family members (Feder et al. 2021; Strang et al, 2020). This resulted in communication between families and dying patients being disrupted, which was known to have significant consequences, not only for the patient, due to a sense of isolation, but also for family members, leading to complicated grief, depression, and anxiety (Gesi et al, 2020). For patients, the sense of loneliness was compounded by the depersonalisation of staff having to wear personal protective equipment (PPE), particularly for those who were frail, diagnosed with a dementia, or for those who had communication difficulties (Selman et al, 2020).

For nurses working throughout the COVID-19 pandemic the increase in workload evidenced further challenges in communication between healthcare professionals, patients, and their families about goals of care, prognoses, and joint decision-making (Sanders et al, 2020). In recent published research it has been identified that for nurses the focus on physical care formed the basis of communication with patients, with difficulties emerging for them to combine both psychosocial with physical care (van Belle, 2020). A provisional explanation for this difficulty arising during COVID-19 is presented as being caused by the uncertainty of how the virus would affect patients as knowledge and understanding developed (Mayland et al, 2021).

Additionally, communication with families has been increasingly pressurised, due to situations rapidly changing, combined with a lack of resources available for staff to support patients and families engage in meaningful and emotionally laden conversations (Rubinelli et al, 2020), particularly towards the end of life. The rapidity of change which has occurred over the past two years has shown to have significantly increased stress levels for nurses, who were already working in operationally challenged environments (Fernandez et al, 2020).

The inability of nursing staff to work in an environment where patient, family and healthcare professionals could communicate with each other, the incomparable increase in rates of death and the level of uncertainty led to changes in outcomes for the grieving and the bereaved (Downar & Seccareccia, 2020; Mayland et al, 2020). The ever-changing balance that healthcare professionals were required to find to care for patients, whilst also protecting their own families and loved ones has been proposed as creating a sense of dissonance, leading to the development of moral distress for some (Bakewell et al, 2020; Greenberg et al, 2020).

Moral distress is identified as a phenomenon experienced by healthcare professions when they know what the right thing to do is, but the constraints caused by institutions or external situations make it practically impossible to follow the perceived right course of action (Jameton, 1984). For nurses in all clinical settings this state has been exacerbated by witnessing heightened family suffering and being unable to provide the best care due to constraints out with their control. Such constraints have included national restrictions to visiting in hospitals, the use of Personal Protective Equipment impacting on the ease of communication, and the movement of patients in hospital based upon their COVID-19 status, to mitigate the risk of transmission of the virus to others (Wiener et al, 2021).

Despite these constraints nurses and other healthcare professionals have undertaken tasks which focussed on what patients and families have considered the most important, such as ensuring that no-one died alone and, wherever possible, that staff would communicate with patients and families to support them at the end-of-life (Mitchinson et al, 2021). However, it is not yet clear whether such efforts were wholly successful.

Within the context of this research study, it was felt important to recognise the unique issues which have arisen due to the COVID-19 pandemic, and to acknowledge how this has impacted the study directly. The researcher has worked in the National Health Service throughout the pandemic, providing senior leadership support to nursing teams across multiple sites and within two healthcare organisations, with particular focus on infection prevention and control, overseeing visiting restrictions, and the delivery of end-of-life care.

Within the research process itself, data collection had been completed prior to the pandemic affecting healthcare services in the United Kingdom, as the researcher had established a point of theoretical saturation (in accordance with the Grounded Theory approach, which will be explained in greater detail in Chapter 3). In addition, due to the impact that COVID-19 was expected to have on healthcare workers across the country, and indeed the world, in consideration of research timelines and completion of the planned aspect of the research study, it was decided that no further data collection should be undertaken, due to the potential psychological impact that reliving recent experiences could have on participants and the researcher.

In addition, the potential impact of bias on the research was recognised as part of the reflective processes undertaken by the researcher. Being exposed, even remotely, to the high numbers of death, and by being responsible for the development of support systems for families who were bereaved, it was recognised that this may have a potential significant influence on the research process. Therefore, to safeguard the authenticity of the study and the participants who had already contributed, it was noted that the study would remain true to the specifics of time, highlighting that any findings related specifically to the impact on nurses prior to the pandemic. Furthermore, it was important to understand the potential bias that the pandemic would have on the analytic process. The rigorous use of a reflective journal enabled the researcher to identify when this was beginning to occur, and action could be taken to minimise this from happening. However, as will be seen in later chapters, there is a clear transferability of the findings to the post-pandemic era.

1.5. Purpose of the study

The study’s purpose is to generate a substantive theory that represents the impact that end-of-life conversations has on nurses working in adult general (non-specialist) inpatient wards in the acute care setting in England. The study was conducted across multiple sites within the East of England to develop a theoretical understanding of end-of-life communicative work for nurses within adult acute general ward settings. The findings are reviewed alongside extant literature to identify similarities and differences as well as new aspects of co-created interactions. The findings and associated theory is presented to offer nurses, leaders, and educators a greater understanding of how undertaking such conversations impacts nurses’ well-being, and how this may affect their interactions in similar situations in the future when working in adult acute general (non-specialist) inpatient wards.

1.6. Research study questions and objectives

The research questions posed are:

1. What is the impact of managing end-of-life conversations on nurse working in acute adult general (non-specialist) wards?’

2. What are the actions and interactions that nurses engage in when managing end-of-life conversations?

The objectives of the study are, from the nurses' experiences, and within the context of the United Kingdom healthcare setting:

1. To explore and describe the social processes, interactions, and experiences of engaging in end-of-life conversations with patients and those close to them, and how these impact on nurses working in adult acute general wards.

2. To identify the factors that facilitate or inhibit such experiences by nurses being positively or negatively perceived.

3. To develop a co-created substantive theory that supports healthcare professionals and organisational leaders gain a deeper understanding of the complexities of communicating with patients and their families at the end of life, and what resources are needed to do so successfully.

4. To understand the place of the substantive theory within the context of other relevant theoretical literature

5. To outline recommendations that focus on the need for easy access to resources for nurses that will support managing such conversations in a way that provides the best possible outcome for all those involved. Such resources should support individual staff beyond pre-known and commissioned education and training.

1.7. Need and significance of the study

This study is significant now more than ever. As the COVID-19 global pandemic has had such an impact on the frequency and form of mortality across the world, changes must be made to the support offered to the healthcare workforce. Hospitals require a workforce that is skilled to an advanced level of communication to support patients and families (Currin-McCulloch et al,2021). In addition, the importance of providing our healthcare professionals with the resources they need to continue to deliver care, which enhances the well-being of patients and their families, whilst minimising the impact of distress, unresolved grief and burnout in our clinical teams cannot be ignored (Mitchinson et al, 2021).

As will be shown in the following chapter, the dearth of international research studies, and those set within the United Kingdom context, which examine nurses' experience in depth when engaging in end-of-life conversations will be evidenced. The impact of such conversations is proposed as not being well understood, and the potential long-term consequences for staff working closely with the dying and the grieving within this context have not been explored sufficiently.

The results of this study will be meaningful and significant for nurses, nurse leaders, those with responsibility for education programmes and health and care well-being programmes, so strategies to support staff in the coming months and years can be developed. In addition, the findings of this study are timely to emphasise what is needed to support current work practices and those staff who have seen an immeasurable increase in the challenges to meet the needs of patients and those close to them at the end of life. It is proposed that the findings will make a new contribution to the understanding and knowledge of the reality of working in these environments.

By doing so it is offered that this research will have a positive impact on the care provided to patients, the education and support offered to enhance the resources available to nursing teams. It is therefore proposed that said findings have the potential to influence education programmes, clinical practice standards, organisational support structures and future policy. Such influence is anticipated to support nurses, allow their voices to be truly heard, and ultimately minimise unwanted variation in the care afforded to patients and those close to them, at such a vital time in their life journey.

1.8. Conclusion

This research aims to understand the impact of end-of-life conversation on nurses working in adult general (non-specialist) inpatient wards in the acute care setting in the England. It aims to understand the detail of said impacts through the development of a co-created substantive theory. This theory will highlight the complexities involved in communicating with patients and families at the end-of-life, and the external and internal resources required to successfully achieve a mutually beneficial end point.

This chapter has provided the reader with the national context for developing the research study, the link to nursing practice and communication during end-of-life care, and the rationale for the setting in which the research study has been conducted.

In addition, the impact of the COVID-19 pandemic has been explored, providing the reader with an understanding of where this study is situated in time, and to provide the professional context of the researcher. Acknowledgement of the specific issues regarding end-of-life communication during the COVID-19 pandemic have also been explored.

Finally, the purpose, objectives and significance of the study have been presented for the reader, recognising the potential for transferability of the findings in this research into the post-Covid era.

In the following chapter, the extant literature pertaining to this study will be reviewed, with an associated analysis of the studies, which align to the research purpose as identified above.

2. CHAPTER 2 – LITERATURE REVIEW

2.1. Introduction

This chapter provides a summary and analysis of the extant literature related to the identified research aims. The first aim of this literature review is to set out the broader context of the study, examine the research methods employed and critically appraise those studies which have examined the impact of end-of-life conversations on nurses. The second aim of the review is to synthesise the state of knowledge in relation to said conversations.

Literature reviews support the case for a proposed study and enhance it because they provide a useful secondary source of data and allow for questions to be asked of them. In addition, a literature review enhances theoretical sensitivity, contributes to the process of theoretical sampling, and offers a way to validate a developing theory (Aveyard et al, 2016).

2.2. Grounded Theory and Literature Reviews

Those who follow a traditional (Glaserian) Grounded Theory approach do not undertake a literature review until later in the research process (Glaser, 1998). However, the researcher recognised that preliminary scoping work was required to meet the obligations of the research proposal submission guidelines, and to scope the feasibility of this study with due consideration to any identified gaps in the extant literature.

During initial scoping work recent academic writing focussing specifically on the impact of end-of-life conversations on nurses in the general acute environment in England was found to be sparse. The researcher used the ECLIPSE search strategy (Wildridge & Bell, 2002), to provide a level of specificity needed to explore extant studies related to the research question. Only one article was found, a literature review (McCourt et al, 2013), which further identified three UK-based studies (Hopkinson et al, 2003; Jack et al, 2003; O'Hara, 2011). Upon review it was identified that none looked specifically at the impact of managing end-of-life conversations on nurses' emotional well-being or professional practice, but rather focussed on the impact of the Liverpool Care Pathway. The findings justified the rationale for the study aiding the contribution of new knowledge (Chiovitti & Piran, 2003). It also provided the justification to move the proposed topic under study forward by understanding how the subject had been researched to date (McMeniman, 2006).

Through a review of potential approaches to study, the researcher identified that a Constructivist Grounded Theory (CGT) approach would be the most appropriate methodology to explore the topic proposed. With further detail provided in the next chapter regarding this methodological approach it was felt important to highlight the following at this point in the thesis. The proponents of CGT recognise that the data and subsequent theory are co-constructed by the researcher and participants, and are influenced by the researcher's values, interactions, position, and location (Charmaz, 2008a, 2008b, 2009; Mills et al, 2006a, 2006b).

The CGT approach assumes multiple realities and associated perspectives on those realities, which are mutually constructed through interaction and are therefore subject to redefinition (Bryant & Charmaz, 2007; Charmaz, 2008a, 2008b, 2009, 2014). It is proposed that in relation to literature, constructivist grounded theorists support the recognition of prior knowledge, theoretical preconceptions, and subject them to rigorous scrutiny (Thornberg, 2012). Such scrutiny and associated synthesis will be shared within this chapter.

In addition, for those undertaking a grounded theory method (GTM) study, a systematic literature review is recommended to be undertaken on multiple occasions during the study's life cycle. Employing constant comparative analytic techniques with existing literature, as well as with the empirical data, and through the application of evidence-based coding processes, theoretical developments will progress (Charmaz, 2014). This offers researchers the opportunity to recognise the convergence and divergence of a study's analysis and findings against leading works. A systematic literature review also offers the reader an avenue to explore such works and situate the context of the co-constructed theory alongside said theories and research.

For the purposes of this study, and by remaining true to the key methods of a GT approach to research through constant comparison, the researcher undertook repeated reviews of the literature throughout the life cycle of this study. The initial systematic literature review was conducted shortly after completing initial coding within the first two interviews in September 2019, and subsequent reviews completed in January and September 2020, during the development of more focussed codes, and again in April 2021 as the dimensions of the core categories and development of theory was co-constructed. By doing so this ensured that any new research published was surfaced, and thereby added rigour to the overall methods of research design.

A pre-existing knowledge of theories related to grief (Papadatou, 2000; Stroebe & Schut, 1999, 2010), also allowed the researcher the opportunity to consider how they could be used to progress the analysis (Dunne, 2011), which shall be evidenced in the discussion chapter (Chapter 5). Additional literature searches were undertaken to identify specific theories related to professional grief, nursing communication theory and nursing theory which included physical, communicative, and spiritual components of care.

2.3. Search method and critiquing framework

The systematic literature review was undertaken through database searches, hand searches of published literature and reviewing their associated reference lists. For any internet searches required to identify resources from national government and nursing bodies, the primary search engine used was ‘Google’ and ‘Google Scholar’.

2.3.1. Primary databases and search strategy

The primary databases used for the literature search were Medline, the Cumulative Index of Nursing and Allied Health Literature (CINAHL Complete), APA PsycINFO, and Web of Science.

Having given due consideration to the various tools available to search for the relevant literature, including SPICE and SPIDER (Cooke et al, 2012; Methley et al, 2014), and having used ECLIPSE as part of the scoping work (Wildridge & Bell, 2002), the researcher determined to use the PICO(T) search tool for the ongoing systematic literature review. PICO(T) has traditionally been used for quantitative studies; however, terminology was developed for qualitative studies and was found to be appropriate (Fineout-Overholt & Johnston, 2005). The rationale for using PICO(T) was twofold; firstly, the terminologies developed were felt to be the 'best fit' for the study (Aveyard et al, 2016) and PICO(T) offered a robust approach for a more comprehensive search to be undertaken. Whilst ECLIPSE, SPICE and SPIDER have been recognised for having greater specificity they were found to deliver a less comprehensive result overall (Cooke et al, 2012; Methley et al, 2014). This was evidenced as more studies were identified using this tool, as shown below. The full search strategy and key search terms using PICO(T) is provided at **Appendix A.**

2.3.2. Inclusion Criteria

- No time frames were employed for data related to the subject matter
- Studies were required to either be originally published, or later translated into, English
- Only articles which included a focus on end-of-life conversations experienced by nursing staff were considered. These included studies involving multiple healthcare professionals and, in some cases, informal carers of patients
- Original articles and studies needed to evidence a contribution to new knowledge in the field being investigated

2.3.3. Exclusion Criteria

- Articles which were focussed solely on intensive care units, emergency departments, oncology wards/units, hospices, palliative care units, paediatric units, or community settings
- Articles which held no evidence of nursing involvement as participants in the study
- Articles containing no empirical data or containing insufficient description of methodology and instruments were excluded

Following a systematic review of all the papers identified (Moher et al, 2010) (a PRISMA flowchart is provided at **Appendix B –** accessed at www.prisma-statement.org/statement.htm), the final number of papers identified were as follows, and are summarised at **Appendix C**:

- Eight qualitative studies
- Two descriptive survey studies

2.4. Contextualising the study: End-of-life conversations in the acute inpatient ward setting

The literature review was undertaken to understand the body of existing knowledge regarding nurses' involvement in undertaking, or being involved in, end-of-life conversations with patients and those close to them, and the impact of doing so. Its purpose was to identify potential issues, challenges and barriers that impact on nurses' practice or emotional well-being, or a description of identified strategies that supported them in practice. Only three studies were found to be specific to the impact of having end-of-life conversations on nurses alone (termed 'breaking bad news' or 'communication issues'); therefore, during the full review of texts, concepts were broadened to include those of coping with caring for dying people, staff and carer communication within a multi-disciplinary context, and communication and decision-making within the context of goals of care at the end-of-life.

The quality of all papers has been considered prior to inclusion in the literature review, with a focus on transparency and openness (Walsh and Downe, 2006), and by using the QARI Tool published by the Joanna Briggs Institute (2014) (an example of the tool is found at **Appendix D)**. However, a pragmatic approach led to the inclusion of all the studies identified following the use of the critical appraisal tool, as it has been proposed that unprompted judgement versus the use of the tools is not evidenced to be a deficient approach when agreeing the quality of studies (Dixon-Woods & Shaw, 2007). Indeed, it is argued that checklists should not replace thought and judgement (Burls, 2014), and therefore the researcher used the QARI tool as an 'aide memoire' to consider the strengths and weaknesses of the studies' design (Aveyard et al, 2016).

One key point to note is that for all the qualitative studies (n=8), which involved methods of observation or interviewing, there is a paucity of reflexivity seen. The positions of the research teams or individual researchers responsible for interviewing participants, and how this may impact their interaction with them, and the subsequent potential influence on the studies is not clear. This is highlighted as an important factor for qualitative research design (Tong et al, 2007).

2.5. Synthesising the data – the constant comparative analysis method

As has been described earlier in this chapter, the researcher committed to undertake a constructivist grounded theory (CGT) approach to answer the research questions focussing on the actions and interactions undertaken by nurses, and the impacts experienced, when managing end-of-life conversations. The constant comparative analysis method is widely recognised as one of the key processes when undertaking a grounded theory study (Glaser & Strauss, 1967; Corbin & Strauss, 2014; Charmaz, 2014). This approach has also been recognised as a way to analyse and synthesise qualitative and mixed-method literature (Aveyard et al, 2016).

Through the process of coding and the subsequent development, naming and comparison of themes in the literature, a sense of confidence in the convergence of some stable or meaningful data can be evidenced (Lincoln & Guba, 1985). This is achieved through the interrogation of the findings of empirical studies, employing a back-and-forth review until the set of themes developed is robust (Thomas & Harden, 2008). Indeed, the utilisation of this approach has been proposed to encourage a reviewer to be increasingly reflexive, whilst maintaining the interpretive properties of the empirical studies (Kearney, 2001). However, caution is also given to using the constant comparative approach to the synthesis of data, as it does not provide advice on the appraisal of studies for inclusion. Due to the nature of the grounded theory method being identified to conduct a variety of types of analysis, the development of this approach as an accepted and trusted way to synthesise empirical studies is yet to be fully accepted (Dixon-Woods et al, 2004, 2005).

However, based upon a review of the different methods to approach the synthesis of evidence, the researcher determined that the constant comparative method was congruent with this study's design, and the opportunity for greater reflexivity during the synthesis of data has been used, to minimise researcher influence on thematic development. The thematic analysis is presented at **Appendix E**.

2.5.1. Avoiding the conversation

One of the strongest themes identified from the analysis of the literature is the concept of 'avoiding the conversation', with a particular focus on communication of prognoses being identified by nurses as the purview of the medical profession (Dosser & Kennedy, 2012). This is also noted by Caswell et al's (2015) study, through their triangulation of staff and carer interviews, and non-participant observation. It was observed that nursing staff do not make eye contact with families/carers, thereby preventing an opportunity to engage in conversation – although this finding was not evidenced as being triangulated with staff or carer participants.

A consideration of the wider geographical and associated cultural context when managing end-of-life conversation forms another basis for 'avoiding the conversation'. Within two papers presenting the Canadian context for end-of-life communication it is evidenced that the overarching premise of saving lives 'at all costs' leads to conversations regarding death becoming problematic and uncomfortable

(Kryworuchko et al, 2016). Indeed, the concept of undertaking end-of-life conversations focusses on proposed goals of care and is shared as ‘dreaded’ by both doctors and nurses, as it is felt that the therapeutic relationship can be broken, with the cultural taboo of discussing death and dying being breached (Nouvet et al, 2016).

This view is supported by Rejnö et al (2017) with participants in their Swedish study identifying the reluctance of being the bearer of bad news to family members. The findings of their study reveal that some nurses will not review potentially negative diagnostic results, so they are not placed in a position of having to withhold information but are rather in a state of ignorance. Moreover, within the Canadian context it is noted that commencing such conversations will only be considered when all curative treatments have been offered and when death is considered imminent – identified as delaying the conversation (Nouvet et al, 2016). It is offered by the researcher that this is, in fact, avoidance of the opportunity to have a meaningful conversation with patients and/or those close to them.

Additionally, within an Australian context role confusion impacts nurses sharing test results, with role blurring predicating potentially inappropriate disclosures of information, and thereby causing distress to patients, families, and nurses (Kerr et al, 2020). Where avoiding the conversation is noted as a key theme, minimising distress to patients and/or those close to them is identified as a key determinant for this action, in addition to protecting self from emotional harm. The concept of protecting self is also explored when the theme of avoiding the conversation is not identified; rather a theory of coping and protecting self are posited as a set of unconscious strategies to cope with the dying patient (Hopkinson et al, 2005).

2.5.2. Coping

It is fully recognised that coping with the dying is a stressor for nurses (Field & Copp, 1999). Coping has historically been associated with responding to stress, with the evaluation of strategies being found to be either positive or negative, when considered within the context of the health and well-being of nurses (Tyler & Ellison, 1994). It is recognised that caring for the dying can have an impact on nurses both in and out of their work environment, with the potential to affect relationships with others (Wilson & Kirshbaum, 2011). Moreover, for those who have closer relationships with patients who have died, the effects of grief-related symptoms can be greater, which include both physical and emotional impacts, and an associated effect on work performance (Rickerson et al, 2005).

In contrast, the impact of how nurses cope when caring for the dying when they are at the beginning of their careers evidences the need for meaningful relationships with colleagues as a key strategy to help the act of caring and subsequent coping. Additionally, receiving feedback on care from families to help understand their professional practice is also recognised as being important (Hopkinson et al, 2005).

Having access to sufficient resources is also a key determinant in the ability of nurses to cope when working with the dying, particularly when the types of death can lead to previously sufficient resources being suddenly overwhelmed (Dosser & Kennedy, 2012). To accommodate such situations, experiential learning with colleagues is identified as an approach for nurses to develop their skills to better care for the dying; however, formal education is not considered to have significant benefit (Hopkinson et al, 2005). This position is also noted by other studies in the review, with the development of new and different education frameworks proposed as a key recommendation for future practice (Dosser & Kennedy, 2012; Kerr et al, 2020).

The development of a model of a ‘translucent web’ for coping theoretically evidences how newly qualified nurses use a series of strategies to cope when working with dying (Hopkinson et al, 2005). Such strategies include being able to control the amount of involvement they have with the dying and families, providing personal comfort to the dying and revising their opinions of an ideal way to die based upon their ongoing experiences. Whilst this exploratory study only focusses on newly qualified nurses with clinical experience of less than three years, the potential transferability of the findings and associated theory are plausible, as will be evidenced in the findings chapter of this study.

2.5.3. Battling time

Time is a constant that can never be underestimated. The third key theme which was developed from the synthesis of the literature surrounds the challenges with time. The issues relating to time are varied for nurses, including a lack of time to prepare, to debrief following a conversation, or indeed managing the time when attempting to negotiate competing priorities with other patients in the ward environment (Warnock et al, 2010). The challenge of being able to release time to communicate with relatives is replicated across the studies, irrespective of the individual geographical and healthcare system contexts (Dosser & Kennedy, 2012; Kryworuchko et al, 2016; Warnock et al, 2017; Kerr et al, 2020).

The sense of feeling ‘time-poor’ is clearly defined, although it is noted that this can also occur when delaying tactics to engage in conversations have been employed by nurses, intimating a cause-and-effect scenario. This results in the subconscious fears of nurses becoming realised, with delaying actions being driven by an underlying sense of lacking power to lead conversations. This then leads nurses to change the timings of conversations with families, which can become rushed (Kryworuchko, 2016). Moreover, concerns emerge for nurses that not having enough time to engage in meaningful conversation can lead to a negative impact in them being able to develop trusting and open relationships (Caswell et al, 2015; Kerr et al, 2020).

For the studies in the literature review that did not identify time as a key challenge when engaging in end-of-life conversations, it is acknowledged that their foci preclude this being considered. The research aims of these studies relate to other concepts, such as ‘truth-telling’ (Rejnö et al, 2017) and coping theory (Hopkinson et al, 2005). In addition, it is proposed that the methodological approaches, such as a mixed-methods survey focussed on end-of-life stroke care, minimises the opportunity to gain a deeper understanding of this area of practice (Doubal et al, 2018).

2.5.4. Managing the Journey

The overarching theme identified within the review was that of ‘managing the journey’. Within this theme, sub concepts were identified, such as providing information, managing difficult situations, feeling the emotions, and supporting the family.

For some nurses managing the journey leads to positive outcomes professionally and personally, gaining satisfaction that they can help patients and relatives prepare for the future (Warnock et al, 2010). This is achieved when adequate resources are available so that the level of support and information needed to meet the information needs of those being cared for are met (Hopkinson et al, 2005). However, this is not always achieved, which can lead to feelings of frustration. This is, in part, proposed as being caused by the paradigm of acute nursing care focussing on physical care needs rather than a parity of attention given to communication to support psychosocial issues (Dosser & Kennedy, 2012).

However, it is identified in other research contexts that the nurses' communication roles are clear. They interpret the information provided by medical colleagues, to be understood in a way that is meaningful (Caswell et al, 2015). In addition, nurses are also required to prepare the way for patients or family members prior to medically led conversations. This is, in part, deemed to be needed as the healthcare system under study is identified as not fully embracing earlier palliative conversations in the acute care setting (Kryworuchko et al, 2016).

Providing information as part of managing the journey is key to developing trusting relationships and gaining deeper understandings of family dynamics (Rejnö et al, 2017). However, this can sometimes morph into a more protective role, with assumptions being made that certain information should not be shared in case of causing harm. The perceived success or failure of being able to manage journeys is compounded by external variables out with nurses' controls, such as the type of death (sudden versus expected), the means of communication with families (over the telephone rather than face to face) or the challenges of being able to gain a deeper understanding of familial contexts, such as agreements with plans of care and understanding relationship hierarchies (Warnock et al, 2017; Doubal et al, 2018; Kerr et al, 2020).

When engaging in these multiple processes nurses become sensitised to the emotionally laden aspects of managing end-of-life conversations, coded as ‘feeling the emotions’. Circumstances which lead to this occurring include situations where the emotions of patients and families are so acute that nurses are required to control their own involvement to protect themselves from increasing personal distress (Hopkinson et al, 2005). This is particularly prevalent when nurses are required to enter an environment where disagreements or heated discussions with medical colleagues have already occurred (Kryworuchko, 2016), or when a diagnosis or prognosis is not accepted by either the patient or family members (Warnock et al, 2017; Kerr et al, 2020).

Alternatively, nurses may not provide full disclosure of the next steps in the journey, should they perceive patients or relatives as not yet being emotionally ready to hear details. Whilst this paternalistic response is not something advocated within the United Kingdom healthcare setting, it is presented as an accepted approach within a Swedish context; however, this cannot be verified as a transferable finding as the limitations of the study were identified as relating to one healthcare setting only (Rejnö et al, 2017).

2.5.5. Lacking Confidence

The confidence of nurses engaging in end-of-life conversations is shared as being variable, with some not feeling ready to discuss aspects of care, for fear of ‘saying the wrong thing’ and not having the confidence to deliver the message (Caswell et al, 2015). The fear of neither providing a clear message nor having the skills to confidently engage in such conversations is further compounded when entering emotionally charged environments, which can lead to greater challenges as described above (Doubal et al, 2018; Kerr et al, 2020). This is particularly prevalent when all parties do not agree with the plans of care (Kryworuchko et al, 2016; Nouvel et al, 2016). Such situations can then lead to feelings of guilt and distress when the nurses’ lack of resources are perceived to lead to familial disagreements, and tensions increasing between professionals and families during communication at the end-of-life (Warnock et al, 2017). This is particularly acute in situations when nurses have not been able to intervene to support planned communication as agreed with relatives (Warnock et al, 2010).

Moreover, feeling uncertain about patients being identified as ‘end-of-life’ can lead to a further lack of confidence, by nurses not being able to engage in conversation with patients or their families in case this is an incorrect assumption on the part of the those involved (Nouvet et al, 2016). This position is further compounded by concerns that any assumption about the depth of information to be provided to patients or families can lead to an over-sharing of prognostic information, again leading to a deterioration in the trusting relationships previously formed (Dosser & Kennedy, 2012). These worries and concerns across all settings are identified as leading to a sense of low confidence in engaging in end-of-life conversations.

2.5.6. Wanting support

The theme of ‘wanting support’ was noted as part of the analysis of the papers reviewed. Support is needed by some nurses during the process of communication itself, through seeking the involvement of others when making decisions, so they can professionally cope with the dying process (Hopkinson et al, 2005). For others support takes the form of needing education and training in communication skills, specific to end-of-life, that go beyond the traditional offering (Dosser & Kennedy, 2012; Warnock et al, 2017; Doubal et al, 2018; Kerr et al, 2020). Moreover, the education support needed by nurses is multidisciplinary in nature, to avoid silo working that causes low confidence levels (Kryworuchko et al, 2016). Consideration of supervision for clinical staff is also a recognised need for professionals, although it is interesting to note that this is only referenced as being appropriate for medical staff (Kryworuchko et al, 2016). No other mention of supervision is referred to in any of the studies analysed.

2.6. Gaps in knowledge

Whilst the key themes identified within the context of the systematic literature review evidence an alignment with this study’s findings, some key areas are proposed as not having been considered prior to this study.

Most importantly there is no evidenced exploration of the shifts and changes in approach which occur both consciously and unconsciously for nurses when engaging with patients and families in conversation surrounding the acute end-of-life phase. The ‘microprocesses’ which are evidenced in the findings of this study are posited as not being explicitly considered in the studies found as part of the systematic literature review.

Furthermore, the complexity of the emotional work required when communicating with the dying or the grieving is also proposed as not being evidenced in the studies reviewed, nor is there any exploration of the wider context of dialogic interaction occurring ante, intra and post-mortem.

Finally, it is offered that only one of the studies offer any understanding of the post communicative work which is undertaken by nurses to protect themselves (Hopkinson et al, 2005), so they are able to function professionally and without detriment to the other patients in their care, many of whom require ongoing curative treatment and support.

Therefore, it is proposed that others cannot clearly understand the full impact of having multiple conversations with patients and/or their families from the studies found. It is presented that the findings of this research will help to address those gaps.

2.7. Conclusion

This chapter has provided a synthesis of the substantive literature using the constant comparative method, following the deployment of a robust search strategy (PICO(T)), which determined the total number of papers for review and the use of a critical analysis tool to ratify and corroborate their inclusion.

The synthesis has highlighted that several themes exist which focus on the process of engaging in end-of-life conversations in the adult general (non-specialist) inpatient ward setting. However, the findings have shown a paucity of depth of understanding of the impact that such conversations can have on nurses. Whilst there is evidence of nurses lacking confidence, there is no definitive knowledge supplied that considers the nuances of interacting with patients and families through conversation, and how this shapes individuals' practice and future decision-making.

Whilst recommendations identified are consistent in the development of education programmes, as has been evidenced from the introductory chapter, decades of education programmes being proposed and developed have yet to see a sustained improvement in experience for the grieving. Additionally, no evidence has been identified to support a consistent improved experience for nurses engaging in this communicative and emotionally laden work.

Having completed the literature review, the following chapter will justify and explore the chosen research methodology (Constructivist Grounded Theory), and address the design of the study, the process of analysis, the vital importance of reflexivity and research governance requirements.

3. CHAPTER 3 – THE GROUNDED THEORY RESEARCH METHODOLOGY

3.1. Introduction

This chapter considers the research methodology and methods that have been adopted for this study, following a review of research paradigms. It describes the journey through which the specific version of Grounded Theory has been determined, after consideration of Glaserian (or classic), Straussian and Constructivist (Charmaz) Grounded Theory approaches. The chapter further considers specific issues relating to theoretical saturation, purposive and theoretical sampling, and explores the ways in which data have been collected and subsequently analysed. The chapter will also consider how the researcher has evidenced a state of reflexivity, including the reflexive interview process and analysis of the data, to enhance the rigour of the study.

Importantly, within the context of qualitative research, and specifically considering the emotive topic being researched, an exploration of how the study was ethically approved is shared. As noted previously, this study's purpose is to explore the impact of end-of-life care conversations on nursing staff working in adult general (non-specialist) acute wards, and to gain a deeper understanding of how such experiences and interactions can affect individual nurses, their practise, and the wider team and profession.

In conclusion, this chapter outlines the criteria used to ensure academic rigour, including the concepts of credibility, auditability, originality, and usefulness.

3.2. Qualitative Research

Research paradigms provide researchers with world views for all approaches to the study of society (Grix, 2010). Such views offer both ontological and epistemological positions. Ontology explores the constitution of the nature of reality (Blaikie, 2000); whilst epistemology allows claims to be made about how knowledge can be gained, as well as the interaction between the enquirer and what is yet to be known (Grix, 2010). Within the context of the philosophies of social and human sciences, three main paradigms exist – positivism, post-positivism and interpretivism. Whilst it is argued that these positions can overlap, as interpretivism has also been described as post-positivism, it remains distinct in its approach to research (Grix, 2010). The two main 'traditions' of research which have championed either the positivist (and post-positivist), or interpretive paradigms are referred to as quantitative and qualitative research (Robson & McCartan, 2016).

Quantitative research can be described as a research strategy that emphasises the quantification of data collection and subsequent analysis, which has a deductive approach to the relationship between theory and research through the testing of said theories. It has incorporated the practices of the natural scientific method and positivism, and views social reality as an objective and external reality (Bryman, 2016).

Conversely, qualitative research is explained as a research approach to understand and explore the meanings groups or individuals give to a social or human problem, involving the use of emerging questions and procedures. Data are analysed inductively, building theory from incidences to more general themes, with a focus on how individuals interpret their social world. Therefore, social reality is a constantly changing property of individuals' construction (Creswell, 2014).

3.3. The Grounded Theory Method

The Grounded Theory Method (GTM) is identified as a qualitative approach that seeks to distil issues of importance for specific groups of people. It aids creating meaning about those issues through the analysis of data and modelling of theory (Mills et al, 2006a, 2006b). It is offered that the methods and procedures within GTM can be applied to help explore meanings and beliefs that underpin the actions that people take, whilst examining aspects of behaviour that can be determined as either rational or non-rational (Corbin & Strauss, 2015).

3.3.1. Historical development of the Grounded Theory Method

Barney Glaser and Anselm Strauss (1967) developed GTM as a response to the paradigmatic dominance of positivist and quantitative survey-style approaches to social science research in the United States (Clarke et al, 2017). Glaser & Strauss (1967) did not advocate any specific ontology or epistemology within their seminal work, something for which criticism has been raised (McCann & Clarke 2003a, 2003b). However, others have identified a variety of proposed ontologies and associated epistemologies with GTM since Glaser and Strauss's seminal work (Morse et al, 2016; Charmaz, 2014; Bryant & Charmaz, 2007; Clarke et al, 2017; Strauss & Corbin, 1990; Strauss & Corbin, 1998; Corbin & Strauss, 2015).

Glaser and Strauss defined GTM as a way in which theory development occurs using rigorous qualitative methods for inquiry (Annells, 1997a). Theory generated from data is considered to have greater use than those deduced from a priori assumptions (Glaser & Strauss, 1967).

3.3.2. Taking separate paths – the divergence of the Grounded Theory Method

Due to differing ontological and epistemological beliefs, variations in GTM emerged. Glaser, who has been recognised as developing many principles of classic grounded theory (Charmaz, 2014) followed a critical realist ontology, assuming an external reality through which discoveries could be made, and subsequently recorded by neutral observers (Charmaz, 2000). Glaser also aligned to a positivist epistemology, which drove the purpose of GTM to be one that yielded theories leading to further research, thereby validating the 'fit' of a provisional theory (Annells, 1997b).

Contrastingly, Strauss (alongside Juliet Corbin, with whom he worked extensively on the further development of GTM) was noted as not accepting a pre-existing reality (Strauss and Corbin, 1998) and that his (and Corbin's) ontological position was relativist (Mills et al, 2006a). However, other views of Strauss and Corbin's ontological position are shared. Annells (1996, 1997a, 1997b) and Charmaz (2000) both assert that Strauss & Corbin remained within the realist ontological camp, with a post positivist epistemological lens, as 'giving voice' to respondents through accurate representation was key, whilst acknowledging that participants' view of reality may conflict with the researchers (Strauss and Corbin, 1998).

The lack of original clarity on the ontological and epistemological basis for GTM may have been due to the divisions in thought on the generation of knowledge and truth (McCann & Clarke, 2003b). Importantly, the differences in GTM can be seen through the variation of epistemological emphases on the use of induction, abduction, deduction, and verification in theory generation (Heath & Cowley, 2004). The differentiation between the emergence of theory from the data, as expressed by Glaser (1978, 1992, 1998) and the discovery of theory, as outlined by Strauss (1978) and Strauss and Corbin (1990, 1998) evidence the crystallisations of differing epistemological and methodological positions.

Despite the difference noted above, key areas of GTM are aligned to support researchers in their inquiry. As noted by Annells (1997b), GTM in any version is best suited for an inquiry with a focus on social interactions, processes, and structures. GTM also focusses on theory development in relation to issues which are important for people (Mills et al, 2006a).

3.3.3. Symbolic Interactionism

Grounded theory is borne from symbolic interactionism, which highlights the importance that symbolic meanings, words, clothing, gestures, and artifacts have for people as they interact with one another (Cutliffe, 2000). It is presumed that one can only understand human action and interaction through the exchange of meaningful communication and symbols – therefore, humans are acting with each other, rather than being acted upon (Lumen Learning, no date - accessed 12 November 2017). Symbolic interactionism does not deny the existence of social structures; however, it is argued that people construct and reproduce these (Charmaz, 2014). Herbert Blumer (1969) outlined the three main principles upon which symbolic interactionism rests:

- People act towards things based on the meaning that said things have for them
- The meanings of things arise from social interactions that people have with each other
- The meanings of things are modified through an interpretive process by people as they encounter things

Charmaz (1980) further extends this position with the following propositions:

- Meanings are interpreted through communication and shared language
- The way in which meanings are mediated in social interaction are distinguished by a continually emerging, processual nature
- The process of interpretation becomes explicit when people's meaning and/or actions become problematic, or their situations change.

3.3.4. Philosophy – American Pragmatism

Symbolic interactionism is a product of American Pragmatism, developed through the works of James, Dewey, Cooley, Peirce, and Mead (Heath & Cowley, 2004). American Pragmatism is a philosophical belief which proposes that an ideology or proposition is true if it works satisfactorily. It also proposed that unpractical ideas should be rejected (McDermid, no date - accessed 12 November 2017). Within this philosophy theories require a level of utility through their problem-solving abilities, and if this can be evidenced then said theory should remain. However, there always remains the possibility that the theory can be replaced by another which has greater utility than the one in existence. As importantly, the principle of 'so what?' sits centrally to ensure that any argument for, or against, a generation of theory makes a practical difference, for if not then it should be subsequently forgotten (Bryant, 2009).

In alignment with an ontologically relativist and epistemologically interpretivist position, pragmatism as a philosophy is proposed as a way for experience to be interpreted, beliefs to be interpreted to generate action, and action (in turn) to be interpreted to generate belief (Morgan, 2014).

An alignment of philosophy, ontology, and epistemology to the proposed methodology evidences how GTM offers an approach to help researchers understand, through rich description and interpretation, systems of behaviour under study. By rigorous application of methods, a substantive theory can be developed that is grounded in data that have been systematically gathered and analysed (Cutliffe, 2000).

3.3.5. Development of Grounded Theory following the Constructivist Turn

Constructivism proposes that everyone mentally constructs the work of experience through cognitive processes, which differs from social constructionism, which has a more clearly defined social focus (Young & Colin, 2004). A constructivist approach to GTM identifies key tenets that link to its pragmatic and symbolic interactionist heritage, whilst shifting the focus to a more clearly defined relativistic ontology and interpretive epistemology (Charmaz, 2017).

Within Constructivist Grounded Theory (CGT) social reality is constructed, is multiple and processual. Moreover, the researcher's position, perspective, interaction, and power (or lack of) is as much a part of the research reality as that of the participants (Charmaz, 2014). CGT recognises the temporality of findings, which is argued as not having been fully considered in other versions of GTM (Charmaz, 2000). Specifically, what is explored through the research process is related to that location, time and set of circumstances (Mills et al, 2006b); therefore, it cannot be replicated or generalised. However, it is acknowledged that findings may be transferable to other similar situations (Charmaz, 2014).

CGT acknowledges that the researcher is bound to the co-creation of the research findings and subsequent theory. Therefore, they are required to scrutinise how their views and preconceptions of the world impact the research process (Charmaz, 2014; Clarke et al, 2017). Corbin (& Strauss posthumously) (2015) has recognised and acknowledged the influence that the constructivist view has had upon their own position, confirming that concepts and theories are constructed through the research process to aid knowledge co-construction. The importance of how 'self-reflection' (or reflexivity) is key to ensuring that the researcher is aware of how they can influence the process of research, and how it influences them is supported (Corbin & Strauss, 2015). The process of reflexivity shall be explored further in the chapter.

CGT proposes that the previously considered norm of hierarchy between researcher and the participant is not possible, as the interaction between both generates the co-construction of meaning in that moment (Mills et al, 2006b). CGT has been critiqued at length by Glaser (2012), postulating it being closer to Qualitative Data Analysis (QDA) rather than GTM; however, despite such views there is a nuanced congruence of the actual methods used, such as constant comparative analysis, coding frameworks and the development of theory.

Within CGT there is recognition of the potential impact power has on the research itself. Power-laden differences (such as age, gender, language ability, experience, professional background, ethnicity) within the research process, particularly when undertaking interviews are evident (Bondi, 2003). Researchers must be mindful of potential power differences, to mitigate against oppression and exploitation (Yates, 2013). Therefore, it is vital that ethical considerations are fully explored to ensure appropriate care of participants is achieved. The ways in which the researcher ensured the care of participants was achieved is discussed further in this chapter.

3.3.6. The rationale for choosing Constructivist Grounded Theory for this study and the link to philosophy

The purpose of this study is to understand systems of behaviour which exist when nurses are involved in end-of-life care conversations with patients or relatives. By identifying and analysing the actions and beliefs which shape the basic social processes at play when such interactions and experiences occur has led to a deeper understanding of why they are varied, and often not seen or recognised by the participants themselves.

Through the lens of symbolic interactionism and its alignment with the epistemological position of CGT, the interpretation of the complex communicative episodes and their associated symbolic meanings which are formed during the last days of life between nurses, patients and families are offered as being significant. It is proposed that by considering such encounters in this way the interpretations that are made by participants and the researcher, which form the co-creation of their realities at that time and in that space can best be co-constructed into a substantive theory. By rigorous application of the research methods employed through a CGT approach, a deeper understanding of the myriad of social, structural and psychological processes deployed during an individual interaction or following the cumulative impact of multiple interactions can be reached.

The purpose of this study has been to gain a deeper understanding of these interpretations and the impact that they have on nurses who continually engage in this dialogic process. Therefore, it is offered that using a CGT methodology, underpinned by a symbolic interactionist approach and a pragmatic philosophy, a level of clarity on how actions and interactions shape meaning and belief for nurses when communicating with the dying and the grieving will develop through the co-construction of theory to support understanding and actions to aid for future practise.

3.4. Reflexivity

Reflexivity has been associated as a crucial strategy for the development of knowledge through qualitative research (Berger, 2015), which focusses on the exploration of topics that include concepts, motivations, and beliefs (Parahoo, 2014). Researchers who undertake qualitative studies do not do so from an objective position of observation, due to their own positions within the worlds they study (Frank, 1997). Therefore, by engaging with reflexivity the quality and credibility of qualitative research can be enhanced (Patton, 1999). Schwandt (2001) identifies reflexivity as:

- ‘*the process of critical self-reflection on one’s biases, theoretical predispositions, and preferences’*
- an acknowledgement that *‘the enquirer is part of the setting, context and social phenomenon he or she seeks to understand’*
- *‘a means for critically inspecting the entire research process’*

Therefore, the process of reflexivity requires a thoughtful, conscious awareness of self within the research process (Finlay, 2002) without becoming overly narcissistic or self-indulgent (Bishop & Sheppard, 2011). To do so risks silencing the voice of the participants and obscuring their experiences (Hall & Callery, 2001). By turning the research lens back on oneself, it allows the researcher to take responsibility for their place within the research process, and how this may affect the participants being researched (Berger, 2015).

The way in which researchers construct the world, use language, ask questions, and decide which lens they will filter the information they have gathered to make meaning from it, ultimately impacts the way the findings and the conclusions of the study are reached (Kacen and Chaitin, 2006).

Specifically, within the context of this research study, which can be identified as sensitive research (due to the nature of the subject in question), potential threats to both participants and the researcher exist (Lee, 1993). Asking participants to describe and provide detail about their experience relies on providing some revelations which are personal and emotional, which can leave both participants and the researcher feeling cautious and vulnerable (Rolls & Relf, 2006). For this study, the researcher was very mindful of their ethical responsibilities, and the need to ensure where they sat within the research process was explored fully. This was to bring to light any potential emotions which could impact the perception and interpretation of the data (Drew, 1989).

Ultimately reflexivity is proposed to understand one's actions and values when undertaking research, by being able to view one's own beliefs in the same way that the beliefs of others are viewed (Seale, 1999).

3.4.1. Researcher assumptions

As has been explored in the previous chapter, the concept of the researcher being a 'tabula rasa' (blank slate) (Glaser, 1978) is deemed not possible within CGT, or that other research should be dismissed until after a study is completed. CGT supports previous research being considered that aligns to the topic under study (Charmaz, 2014), whilst cautioning that to do so does not stifle creativity or ‘strangle the theory’. Previous studies can influence the research process and should be subject to rigorous critical analysis to ensure that the CGT researcher is sensitive to different positions and thereby takes nothing for granted; a position of ‘theoretical agnosticism’ (Henwood & Pigeon, 2003; Thornberg, 2012).

As the researcher has worked in the sphere of end-of-life care for most of their clinical career, in addition to having responsibility for leading end-of-life care programmes of work within hospitals, it has not been possible for them to adopt a position of ‘tabula rasa’. However, by maintaining distance from more recent research studies during the initial stages of the research process they have ensured that they did not allow previous knowledge to impact their ability to enter the research field with an open mind. Additionally, the position within which they entered the interviewing process was key to ensure that existing knowledge and experience did not impact participants’ comfort to share their experiences.

As a practitioner/researcher, with experience of managing end-of-life conversations within a speciality environment (adult intensive care and organ donation), it would not be possible for the researcher to undertake robust research without being able to scrutinise their own values and views on how such conversations could or should occur. This could only be achieved through reflexivity throughout the research process (Ritchie et al, 2014). The axiological position of CGT is value-laden, and therefore associated attention must be given to the intrinsic and extrinsic values of the researcher and participants to ensure an ethically appropriate study is undertaken.

3.4.2. The researcher’s position

The dichotomy of being either an ‘emic’ insider researcher – as a nurse with experience of working in end-of-life care, or as an ‘etic’ outsider – as a doctoral student researcher from university was considered, recognising the clear challenges that both positions can bring (Bonner & Tolhurst, 2002; Young, 2005).

An insider perspective risks losing a sense of objectivity and thereby making assumptions based upon prior knowledge and experience (DeLyser, 2001). In addition, insider researchers can become too close to the culture, which can prevent provocative questions being raised to challenge research methodology, design, or results (Merriam et al, 2001), otherwise known as ‘going native’. However, techniques are offered to assist the insider researcher, such as maintaining research journals (Lincoln & Guba, 1985), peer debriefing (Greene, 2014) and reflexivity to question perceptions and expose biases that can be contextualised and power-driven (Bourdieu & Wacquant, 1992).

Conversely, an outsider perspective can lack access to research participants, and a lack of capacity to appreciate experiences that are highlighted as key challenges to achieving a robust study; outsiders may be unable to understand or accurately represent the experiences of their participants. This is of particular importance when the research conducted focuses on those who may be vulnerable or marginalised (Hayfield & Huxley, 2015; Bridges, 2001). In these cases, such researchers should address said distances between themselves and their participants in an ethical way, so that their research is sensitive, and it enhances the participants' lives, in addition to the understanding of communities and the public (Sixsmith, Boneham & Goldring 2003).

As an alternative to the binary insider/outsider position of a researcher, a 'hybrid' position has been proposed (Reed & Procter, 1995). A hybrid researcher is one who undertakes a study into the practice of other practitioners and is familiar with that research area (McGhee et al, 2007). The positions of insider, hybrid and outsider are argued as not being polarised but exist on a continuum, which the researcher can traverse during the research process (Reed & Proctor, 1995). As a clinician with knowledge of the study area but without clinical involvement for some time, the hybrid position best aligned to the researcher's situation within the research process.

The risk of becoming more strongly associated with the research participants during the data collection and analysis process, leading to a stronger 'insider' position was noted as a potential risk; however, it was identified that the 'outsider' perspective of reviewers would help mitigate potential bias (Brunero & Lamont, 2012).

Moreover, the use of reflexive memos post-interview and during coding helps researchers understand the social interactions between the participants and themselves (Birks & Mills, 2015). Memos assist the capture of potential analytic ideas, and act to elaborate on processes, assumptions, and actions covered as part of coding the data (Charmaz, 2014). However, the researcher determined that the process of memoing would be insufficient and so undertook a reflexive interview in addition to the rigorous use of memos and a reflective journal.

3.4.3. The reflexive interview

To further explore perceived existing biases early, and to gain a deeper understanding into personal history, professional biography, and methodological stance (Allen, 2004; Brunero & Jeon, 2015), a reflexive interview was undertaken. In research supervision sessions it was noted that some assumptions included whether the participants and the researcher would consider the role and responsibilities of a nurse involved in end-of-life conversations similarly, or whether they would share the same professional language and meaning (Finlay, 2002).

A reflexive interview allows the exploration and understanding of assumptions and can be compared to telling a story (Lear et al, 2018); with the words and meaning held within the interview used as sources of rich qualitative reflexive data to add to a study's design. This process also ensures rigour, thereby meeting the requirements of reliability and trustworthiness (credibility, transferability, dependability, and conformability) (Lincoln & Guba, 1985). In addition, the story can expose any potential bias, whilst also allowing the researcher to explore past events (Downing et al, 2013) to highlight any potential ethical issues that have not yet been realised (Denzin, 2001).

3.4.3.1. Purpose of reflexive interview

The first reason to undertake a reflexive interview was to expose any biases that were unseen from clinical experiences, so the researcher could be consciously aware of these during the interviews and subsequent analysis of data. The only way to explore these biases was to become the 'researched', using the interview tool as a pilot participant in the research study itself, and then subsequently analysing the data. To enhance the credibility of analysis a reviewer undertook a separate analysis so the triangulation of results could be discussed.

By undertaking this reflexive interview, a deeper understanding of ‘self’ and the intrinsic values, morals and drivers which had influenced the choosing of this research topic were unearthed. Some of the reasons were unexpectedly painful as a sharing of being bereaved formed part of the interview process. Through the process of analysis, unconscious assumptions which had the potential to impact the researcher’s ability to truly hear the narratives of participants were unearthed (Rolls & Relf, 2006).

By exposing these safely, the researcher could understand their own professional learning, and how this had shaped a professional ‘self’. Indeed, the dawning of meeting more than one ‘self’ had begun and recognising that these multiple selves had the potential to either support or create tension within the research process was a key revelation. A personal concept of a ‘good conversation’ or ‘bad conversation’, when looked at through the lens of each of these selves was highlighted as a potential influence on the research process.

Secondly, the interview instrument needed to be tested, as semi-structured interviews were planned with participants as the method of data collection. Interviews attend to research participants and support the construction of theoretical analyses (Charmaz, 2014). Questions should encourage participants to reflect on their experience during the interview, with clear attention paid to language and discourse (Charmaz, 2009), whilst not being too rigid to prevent the exploration of experience. Therefore, the testing of the instrument prior to conducting interviews with participants was key, allowing for the modification of the tool where necessary, thereby increasing its refinement.

3.4.3.2. Impact of the reflexive interview

As part of the process of undertaking the reflexive interview the interviewer (a colleague with experience in conducting interviews) was able to feed back to the researcher some of the challenges with the initial questions, an overuse of medicalised jargon rather than plain English, which allowed for further development of the research tool. Moreover, the interviewer was able to share their experience of using the tool, the emotional effort that was required to fully engage in the process, so that the researcher was better prepared to undertake the interviews.

The reflexive interview was coded following the precepts of Constructivist Grounded Theory (Charmaz, 2014), by initial coding constructed using gerunds and ‘in vivo’ codes, ensuring that the analysis was grounded in the data. Following this process focussed coding was undertaken to help determine the adequacy and conceptual strength of the initial codes. In addition, the interview was used as a tool to determine whether the researcher’s experiences of managing end-of-life conversations, albeit within the context of specialist environments (intensive care units as a nurse and as a transplant co-ordinator) were aligned to those of the research participants. However, the output of the analysis of the interview confirmed the potential tensions that existed within the identified ‘selves’ in the research process, as described in a proposed model (**Model 1**).

Model 1: The influences of 'self' on the research process

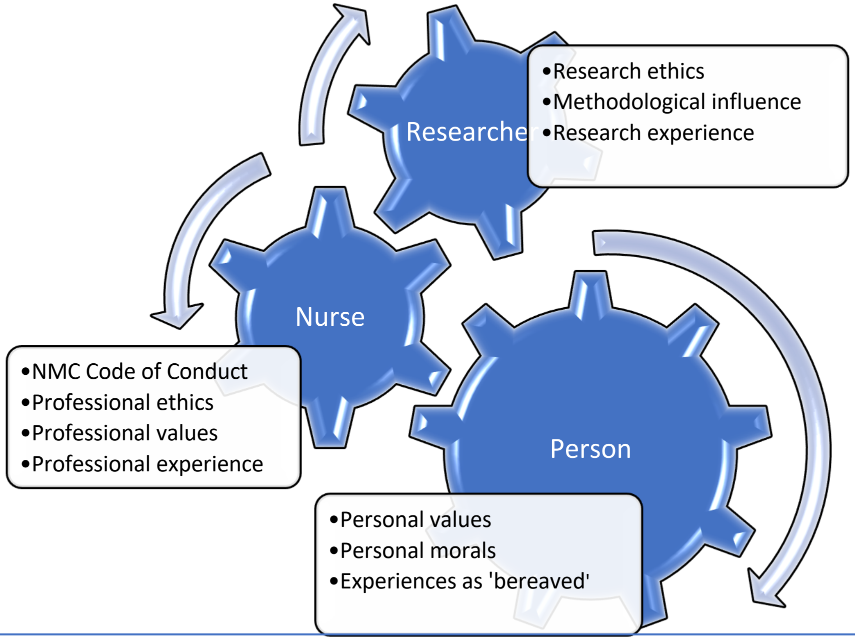
Disharmony

Conflict

Control

Silencing participants' voices

Reduced transparency



Harmony

Congruence

Co-construction

Representing participants' voices

Enhanced transparency

The benefit of developing a model supported the researcher identifying when and how tensions were arising during the research process. A research journal was maintained not only to record methodological and analytical thoughts post-interview, but to reflect on any potential impact that emerging tensions between the ‘selves’ could have on the process of co-constructing data, with the model being used to help better identify any risks to delivering an authentic and rigorous study. This has aided the continual process of reflexivity without becoming self-absorbed (Arber, 2006).

Furthermore, the model helped working through the impact of being a researcher in a time of great global upheaval, to deliver a substantive Grounded Theory which aligns to the theoretical and philosophical underpinnings of a CGT approach.

Understanding the following three selves outlined the drivers which could fall into conflict:

- Self as person – intrinsic morals and values that have developed from childhood to adulthood and the experiences of bereavement are influential in the consideration of ‘good’ or ‘bad’ experiences.
- Self as nurse – professional values and ethics based upon clinical practice and management experience within the context of end-of-life care – being able to empathise with patients and relatives as part of ‘good’ nursing practice that is underpinned by professional regulatory requirements.
- Self as researcher – cognisance of undertaking ethical research that ensures the experience for participants is one that is beneficial and does not negatively

impact upon their life. A drive to meet the requirements of doctoral level study and delivery of a research project that contributes to the body of knowledge.

The tension between being a practitioner and researcher is recognised as common amongst those undertaking qualitative research, with reflexivity being adopted to ease said tensions, particularly if undertaking research with patients. (Wilde, 1992; Frank, 1997; Chesney, 2001; Holloway & Wheeler, 2002; Colbourne & Sque, 2004; Brunero & Jeon, 2015).

As noted above, through using the model as a point of ongoing reflection the three selves worked in harmony to conduct a research study that focussed on the co-construction of experience and associated theory. Previously unexplored biases could have impacted the way in which interviews were conducted, and so great care needed to be taken (Lear et al, 2018). It was also apparent that through engaging in a reflexive interview and developing a personalised reflexive model for ongoing use enhanced theoretical sensitivity to the data, whilst the researcher's professional background enhanced communication with the participants (McGhee et al, 2007).

Should the researcher not have undertaken the process of the reflexive interview and subsequent analysis, internal conflict may have developed as the 'selves' battled each other, seeking control of the research process overall (control was a key category from the analysis of the reflexive interview). This would have had the potential to suppress the voices of the participants, and thereby lead to a lack of transparency for the reader, which may have impacted the study's credibility.

Not entering a 'therapeutic space' with participants was key, due to the potential emotional burden undertaking such interviews could have on the participant and researcher. Such burdens can potentially result in feelings of unease, discomfort, and emotional pain (Rolls & Relf, 2006), particularly when researching death and dying (Lee, 1993). To alleviate such burdens being able to offer a safe space where participants felt comfortable and could share their experiences has been of paramount importance to conducting an ethical study. This has been supported by offering participants the opportunity to debrief post interview, and to provide feedback to the researcher. In addition, the researcher has sourced supervision from research and clinical supervisors to ensure that they remain mindful of the impact conducting a study of this nature can have on others, and themselves.

The following section of this chapter will now evidence how the process of gaining ethical approval for the study was achieved.

3.5. Gaining Ethical Approval

Prior to commencing the study, ethical approval was sought and gained from the University of Essex Ethics Committee, and the Health Research Authority (HRA). (**Appendices F & G**). Key to gaining ethical approval from the HRA was to provide clear evidence of the safeguards in place to minimise any risk to participants as part of their contribution to the study.

As outlined in the UK Policy Framework for Health and Social Care Research (HRA, 2017) it was key that this study followed all the principles relating to health and social care research. The primary principle is that the safety and well-being of individuals supersedes the interests of society or science. Research which is determined to be ethical must ensure that the rights of humans are protected, ensuring that studies focus on doing good (beneficence), do no harm (non-maleficence) and ensure that participants are autonomous in their decision-making. This can only be achieved by maintaining participants' confidentiality, being always fair and truthful with them, and ensuring that consent to the study is informed.

In addition to gaining ethical approval, all research sites were contacted to gain Research Department approval. Participant consent forms, information sheets, contact information, site posters, proposed email communication, researcher curriculum vitae, Disclosure and Barring Service statements were all submitted, prior to research passport completion. No participants were contacted until all necessary research site requirements were fulfilled.

The following section of the chapter will now focus on the methods used to collect data for the study.

3.6. Data Collection

To support this study, the settings that the research was conducted in, including sampling and recruitment, in addition to how data were collected from the following sources (between July and December 2019) are described:

- Semi-structured interviews

- Memoing
- Diagrams and conceptual models

3.6.1. Research sample, setting and recruitment

Nurses who had experience of managing end-of-life conversations in acute adult general inpatient wards were recruited for this study. The nurses came from four hospital sites across the East of England. All the hospital sites were District General Hospitals and participants were required to have experience of the phenomenon under investigation.

Following ethical approval the researcher made initial contact through formal letters to the Chief Nurses at the sites, which requested an opportunity to discuss the research with them **(Appendix H)**. The meeting provided an opportunity to discuss the objectives of the study, and information to be shared through internal communications channels within the hospitals, to reach the relevant staff with experience (**Appendix I)**.

Staff were then invited to contact the researcher directly, to ascertain their suitability for inclusion in the study. Once participants contacted the researcher, an information sheet was shared with them (**Appendix J**), and then a subsequent discussion was had to confirm their willingness to participate in the study.

The researcher would then travel to a location that was comfortable for the participant, and a consent form was completed (**Appendix K)** in person, followed by an opportunity to ask any additional questions prior to the interview being undertaken. It was highlighted to participants that they could withdraw consent at any point in the process, and their data would not be used should they do so.

3.6.2. Inclusion criteria and selection of research participants

The following inclusion criteria were developed for participant inclusion into the study:

1. Registered nurses who had experience of managing end of life conversations
2. Registered nurses who had this experience whilst working in an adult inpatient ward environment (non-cancer, non-critical care, non-paediatric, non-palliative care team role)
3. Had not been recently bereaved to ensure re-traumatisation was minimised
4. Completed the written consent form thereby enabling them to participate in the study

Initially, purposive sampling was used to ensure that there was a rich description of events, and that the experience of the nurses having these conversations could be understood (Bryman, 2016). However, as the data were being analysed using the constant comparative technique, and categories began to emerge, the researcher began to theoretically sample (Glaser & Strauss, 1967) to recruit further interview participants.

3.6.3. Theoretical Sampling

A researcher decides what data to collect next and where to find them, during the process of collecting, coding, and analysing data (Glaser & Strauss, 1967; Corbin & Strauss, 2015). Therefore, the process of theoretical sampling is used to include participants with different levels of experience, allowing for a richer description and exploration of comparative groups, thereby aiding the generation of theory, and is controlled by theory itself. This occurrs until the state of theoretical saturation is reached, when no new insights of information are collected from participants, and the categories identified are complete (Bryant & Charmaz, 2007; Charmaz, 2014; Glaser & Strauss, 1967). Within the context of this study, the sample size of 11 participants was determined by theoretical saturation.

The researcher undertook focussed coding to assist the development of connections and to address any unanswered questions within the dimensions of the core categories under development. It was recognised during the coding and memo-writing processes that there were gaps within the dimensions of key focussed codes. Recognising that participants with greater experience and more senior roles offered a deeper level of experience of communication with the dying and the grieving, theoretical sampling was undertaken to interview senior level staff to better comprehend the dimensions and interconnectedness of the focussed codes under development. This process assisted the finalisation of incomplete dimension, and the relationships between the categories became clear, thereby aiding the co-construction of the theory.

3.6.4. Theoretical saturation

As mentioned in the initial chapter theoretical saturation was reached following the conclusion of the eleventh interview. Theoretical saturation is proposed when no new codes are found (Urquhart, 2013) and when no new theoretical insights or properties are identified which further develop the emerging grounded theory (Charmaz, 2014).

Within the context of this study the constant comparative approach, supported by discussions with reviewers regarding the properties and dimensions of the core categories underpinning the generation of the proposed substantive grounded theory, enabled the researcher to recognise that the repetition of existing codes was evident at the point of the tenth interview being analysed. However, through the process of theoretical sampling, and by identifying participants who had experiences in different sub-specialty and role, the eleventh interview was convened; however, no new dimensions or codes were found and following a further discussion the point of saturation was agreed. During ongoing comparison and final coding checks no new data emerged and the researcher was confident in their position of saturation.

3.6.5. Research Interviews

Purposeful interviews are undertaken which focus on the co-construction of the participants' realities but are neither untheorized nor uncritical endorsements of personal narratives (Atkinson & Silverman, 1997).

Data were collected through semi-structured interviews which took place between July and December 2019. Eleven face-to-face interviews were undertaken which ranged between 45 minutes to 70 minutes, with an average interview time of 55 minutes. In total over 10 hours of recorded interviews were transcribed verbatim (Brinkmann & Kvale, 2015). All participants were interviewed at their place of work, but in an office away from the clinical environment.

The interviews were open-ended to provide consistency of the main concepts for each interview (Corbin & Strauss, 2015). Within the context of the GTM the purpose of interviews is to allow the researcher to develop theoretical concepts of the topic under study, and thereby develop a theory grounded in the data through the interview process (Brinkmann & Kvale, 2015). Importantly for CGT theorists, the purpose of the interview is to ensure sufficient attention to language and engaging in discourse with participants allows them to reflect on their experiences during an interview that will allow the advancement of the construction of theory (Charmaz, 2014).

An interview guide was used by the researcher, which was informed by the reflexive interview, discussions with reviewers, and adapted following the reflexive interview process, and following the first two interviews with participants (**Appendix L**). Such changes supported the researcher in eliciting nuances of experience that would help deepen theoretical development, ensuring that taken-for-granted language was followed up. Furthermore, the interview questions were used more as an aide memoire during the interview process itself, as the importance of spending sufficient time with participants prior to commencing the interview enabled a sense of psychological safety to be developed, leading to an interview which focussed on conversation and knowledge co-construction.

Following each interview, the researcher constructed a memo outlining the new concepts identified in the interview, thereby preventing a loss of rapport during the interview process through notetaking. Many of the participants thanked the researcher at the end of the interview for the opportunity to explore their experiences and reflect on some of the challenges they had faced during end-of-life conversations. For some it was the first time they had been able to do this in depth.

3.7. Undertaking constant comparative data analysis

Grounded theory methods specify analytic strategies, specifically the constant comparative method (Glaser & Strauss, 1967). The researcher undertook simultaneous analysis of data from the interviews transcribed, literature and research memos. The analysis formed the development of codes and categories. Coding allows researchers to see new perspectives on the material and focus further data collection, leading to new understandings and directions (Charmaz, 2014). Through the generation of action codes (gerunds), the abstraction of data to a conceptual level, rather than descriptive can be achieved. The process of coding within this study was through initial and focussed coding, followed by theoretical coding processes.

3.7.1. Qualitative Data Analysis Software (QDAS)

The coding was undertaking using the QDAS programme NVivo (versions 11 & 12). NVivo provides a series of tools to assist researchers in the process of qualitative data analysis (Jackson & Bazeley, 2019). For the purposes of this study, the ability to consider the coding process graphically and visually supported the researcher in a great depth of understanding of the dimensions associated with the codes as they were constructed in the data, and the relationships that were forming between them.

3.7.2. Substantive (open and focussed) coding within the research process

Careful word-by-word and line-by-line coding was undertaken by the researcher to ensure that there was relevance within the analytic process (Charmaz, 2014). This careful coding process allowed the researcher to not unduly bias the data, and to allow for differing perspectives to be formed. The use of 'in vivo' codes (Glaser & Strauss, 1967) enhanced the participants' exact words. By undertaking this process, the opportunity for comparison of the differences and similarities within and across interviews was achieved. The open coding produced over 1000 codes within the data. Through ongoing constant comparative analysis between the codes, and across the incidences and experiences of participants, initial codes were absorbed rapidly into broader codes, which offered the greatest clarity of the social processes and structures being constructed by the participants, and better reflected an abstraction of what was happening for the participants when engaging in conversations, and the subsequent impacts upon them. A significant reduction in the number of codes occurred over a seven-month period, whilst data were collected, transcribed, and analysed.

The focussed coding process revealed multiple dimensions and properties that supported a deeper understanding of their interconnectedness, and the way in which their interdependencies represented both the unconscious and more conscious microprocesses of the participants. The opportunity for abstraction became greater during focussed coding and allowed the researcher to move towards theoretical coding and ultimately the development of the theory (Charmaz, 1995).

3.7.3. Theoretical coding

The constructivist approach to coding ensures the centrality of the researchers' interactions with participants through the analysis of data, as well as ensuring that they continue to reflect on what and how they think when shaping the data (Charmaz, 1990). In addition, the theoretical analysis of the data ultimately shares a tale of people, social processes, and the situations within which they occur. Ultimately, the theoretical coding process supports further conceptualisation of the substantive codes constructed to develop a theory that will integrate theoretical findings into a cohesive whole (Glaser, 1978).

Whilst other approaches to GTM include the use of pre-determined 'coding families' (Glaser, 1978), the CGT position argues that the process of substantive analysis will indicate the types of theoretical codes that should be used, following their utility to support the construction of knowledge through integration being identified (Charmaz, 2014).

As can be evidenced at **Appendix M**, the co-construction of the theoretical and supportive substantive categories has formed the key vehicle through which others can understand the intricacies of end-of-life conversations between nurses, patients and families, and the subsequent impacts that can occur.

Throughout the process of constant comparative analysis and coding processes, memos were also written to capture the ongoing construction of findings and theory development.

3.7.4. Memos

When writing memos, the researcher was able to recognise how and why the experiences of the participants were influencing the research process and exposing previously unknown biases and assumptions (Corbin & Strauss, 2015). Furthermore, the memoing process evidenced an auditable trail of the researcher's thoughts and offered a record of new lines of inquiry to explore through theoretical sampling and interviews (Saldaña, 2016). As known to all those who undertake GTM, writing memos is an integral and vital part of theory development as without memos an emerging theory could be commented as being unoriginal and superficial in development. An example of a theoretical memo during the later stages of the coding process is offered below entitled 'Signposting the Way' – recorded on 3 June 2020:

> *I am trying to consider here what is going on for the nurses when they interact with the families.*
>
> *Initially I was looking at the processes between the nurse and the family in a variety of different contexts, and my realisation is that this is more than just answering questions, it feels as though the nurses are signposting the path that the family will take. They do this in different ways, as seen in the initial coding.*
>
> *But what is the impact of being the sign poster? There is something about the tightrope that is walked and developed over years of experience......some of these skills are very practical in nature, such as explaining the protocol, providing*

information, responding to questions and explaining what is happening. Within this 'doing work' there are subtler interactions at play, which include providing options, creating a sense of involvement for the family - what are the boundaries for doing this? The variations that exist in the participants comes through from experience in managing these conversations. The second part of this work is the 'sensing'.

These codes are beginning to coalesce into something more profound and I am feeling humbled by the way these nurses are making fast unconscious decisions about when, how, and where to take these actions through communication.

When this is happening it does not only occur during the process of dying but also after the death, there continues to be a signposting for the families to resolve concerns, questions and also to help move families forward in their grieving processes.

3.7.5. Diagrams and Conceptual Models

Diagrams and conceptual models support categories as they develop, and the relationships that exist between them in a visual format (Clarke et al, 2017). As detailed earlier in the chapter, the basis of the analysis for this study aligns with a CGT approach, that has an emphasis on both meaning and action, underpinned by a pragmatist philosophy which focusses on understanding of social processes and interactions (Charmaz, 2014).

The methods undertaken in this study, through semi-structured interviews, constant comparative analysis, and rigorous coding (open, focussed, and theoretical) have been utilised to develop a substantive theory from the research findings by elevating the substantive codes into a theoretical form that supports an analytic story that is coherent (Glaser, 1978). To do this the researcher used diagrammatic forms throughout the process to organise the ideas and, more importantly, the relationships between them.

An initial concept model was created during the open and focussed coding processes, which became more developed as further interviews were conducted following theoretical sampling. The model was informed by the data, constructed codes and through ongoing memoing as part of the analytic process. By developing a visualisation of analytic concepts and categories, a greater understanding of the interactions and social processes that the participants were intrinsically involved in was constructed from the data.

It was also recognised that any theory developed was an interpretation and co-construction of meaning, which was bound to geographic location, time, and space. In addition, the researcher acknowledged the range of variation between and within the interpretations of the participants. Importantly, the purpose of any proposed substantive theory must have credibility, originality/auditability, resonance, and usefulness whilst evidencing a representation of the participants' voices and views through the analytic process (Charmaz, 2014).

The following section of this chapter outlines how methodological rigour has been considered to provide a credible theory.

3.8. Methodological Rigour

The strategies identified within GTM for undertaking a rigorous approach to knowledge (co)construction have been identified as follows (Charmaz, 2008a):

- Minimise wherever possible preconceived ideas about the research problem within the data
- Simultaneously collect and analyse data so that there is continuous development
- Be open to the variation of explanations and understanding of the data
- Ensure a focus on data analysis to construct middle-range theories

These methods are identified as part of the way in which all versions of GTM can provide a systematic and interpretive way to aid theory development grounded in data, leading to further explanation, guidance, and aids to practice (Breckenridge, 2009).

Charmaz (2014) provides further clarity on what is required to ensure that there is rigour to the application of undertaking a CTG study, as follows:

- Ensuring that constant comparative analysis and collection is an interactive process
- The analysis of data focusses on actions and processes (not structure and themes)
- The development of conceptual categories is drawn from data

- Utilising systematic data analysis to develop inductive abstract categories
- The development of theory construction is emphasised instead of a description of applying current theories
- Actively seeking variation in the processes or categories that are being studied
- Focus on developing a category instead of attempting to cover a whole topic

As discussed, GTM is an approach to undertaking qualitative research that helps explore an area of study with the purpose of generating theory to aid practice. It is recognised that the traditional hierarchy of evidence (Sackett et al, 1996) places qualitative studies towards the bottom of evidence value; however, it is argued that said hierarchy is often utilised for many aspects of inquiry, when it was originally designed for critiquing evidence to support effective treatment decisions (Aveyard & Sharp, 2013).

If research is focussed on understanding the experience of patients or staff to aid practice then this hierarchy is not practical to utilise and another should be identified (Noyes, 2010). Therefore, it is beholden upon those wishing to critically appraise research relevant to the question posed to utilise an appropriate methodology.

Within the context of socio-political changes, the Care Quality Commission (2016) have highlighted the importance of patient experience as part of their regulatory scrutiny. Further metrics to ensure staff experience is explored is also being utilised (CQC, 2016). Therefore, the alignment of undertaking a study which understands the impact of such interactions with patients is timely. It will evidence organisations involved taking an active interest in the improvement of services through research, to support staff, and thereby potentially positively impact retention, and ultimately improve standards of care. Moreover, given the recent radical impact that COVID-19 has had on healthcare systems across the world, the importance of communication, particularly at the end-of-life, has never been starker.

Within the field of GTM research Beck's (1993) criteria for demonstrating rigour has been utilised to assure research has been robustly undertaken (Cooney, 2011; Chiovitti & Piran, 2003). Moving away from a positivistic quantitative paradigm for rigour (internal validity, external validity, reliability, objectivity), the following criteria for judging qualitative research are identified:

- Credibility – whether the study presents a faithful description so that those who have experienced this would recognise it as their own
- Auditability – ensuring that a comprehensive record of methodological decisions has been maintained
- Fittingness (also known as transferability) – the research can demonstrate that the findings/theory would have meaning to others in similar situations

To highlight research praxis between the pragmatist philosophy which underpins GTM and CGT methods application, Charmaz (2014) adds that 'usefulness' is an important category to incorporate when determining the rigour of a CGT study. Does the analysis offer interpretations that people can use in their everyday worlds? This ensures that the 'so what' question can be answered.

As will be seen through the findings and discussion chapters of this study, rigour has been achieved through the consideration of a credible study, which evidences a clear methodological approach to the development of theory. It is postulated that this study will have meaning to others, particularly due to the impact of COVID-19 and the subsequent increased incidence of mortality in healthcare settings. Finally, it is believed the substantive theory has use in healthcare settings today, as it provides a way for others to view the impact of end-of-life conversations on nurses working in adult inpatient wards.

3.9. Conclusion

This chapter has provided the reader with an overview of the chosen methodology for this study – CGT. Through an exploration of the associated philosophy, ontology, epistemology and methodology, a consistent and credible approach to the study and substantive theory development has been evidenced. The methods used to collect data, analyse them, and help co-construct a substantive theory are offered for consideration, which aligns to the GTM approach to research, with a justification for specifically following a CGT approach.

The importance of reflexivity being incorporated into the study design to minimise influence and bias on the process has been explored. The specific use of a reflexive interview has been shared with the associated developed model of three ‘selves’ being identified as potential enablers or confounders of the research process itself.

Following a descriptor of how ethical approval was gained and ongoing ethical responsibilities have been shared, an exploration of how rigour can be applied to this study has been provided for the reader.

In the following chapter, the findings of the research study will be shared, evidencing the process of constant comparative analysis, coding processes and the development of a substantive theory.

4. CHAPTER 4 – THEORY CONSTRUCTION – NAVIGATING THE JOURNEY (GRIEVING QUIETLY)

4.1. Introduction

The previous chapter provided the reader with an overview of the methodology proposed to seek the development of a theory to understand the research question posed. This chapter will now offer the analysis of the findings from the co-constructed data, using CGT methods.

4.2. Construction of the substantive theory

The substantive theory proposes a co-constructed interpretation of the social structural and psychological processes and problems occurring for nurses who are involved in end-of-life conversations, and the subsequent impacts these have. In this study it was identified that the continued impact of end-of-life conversations on participants emerged as a concept of *grieving quietly*. This concept was identified as a neutral state on a continuum experienced by the research participants as they undertook the process of *navigating the journey* with patients and relatives.

Dependent upon how well, or not, these social processes and interactions were received by patients and families, as perceived by the participants themselves, causes them to move along a continuum towards a state of *suffering silently* as a social psychological problem, or conversely, towards a reparative social psychological process of *reconstructing meaning*. The conditions which affected this state of being were influenced by the adequacy, or lack thereof, of internal and external resources available to the participants. The detail of the adequacy or insufficiency of said resources is detailed later in the analytic process; however, it is important to highlight at this point that the overwhelming influence identified by all participants is the basic social structure of time.

Importantly, the researcher wished to understand what predicated the movement on this continuum. Further analysis of the data provided a deeper understanding of the situated experiences of the participants. The contexts within which these interactions occurred were bound to place (both geographically and within the institutions in which they occurred), and time (prior to the Covid-19 pandemic affecting healthcare institutions globally), and therefore any generation of theory has been considered within these constructs and contexts. Quotes from the participants' interviews have been referenced to ensure a rich description of experience and evidence of the social processes occurring is shared and understood (Bryman, 2016).

To support the trustworthiness of the data and the analytic processes undertaken in this study, relevant supporting literature is used to extrapolate meaning from the findings, in addition to situating them against extant research as presented below. However, first it is important to share the key demographic information regarding the participants in the research.

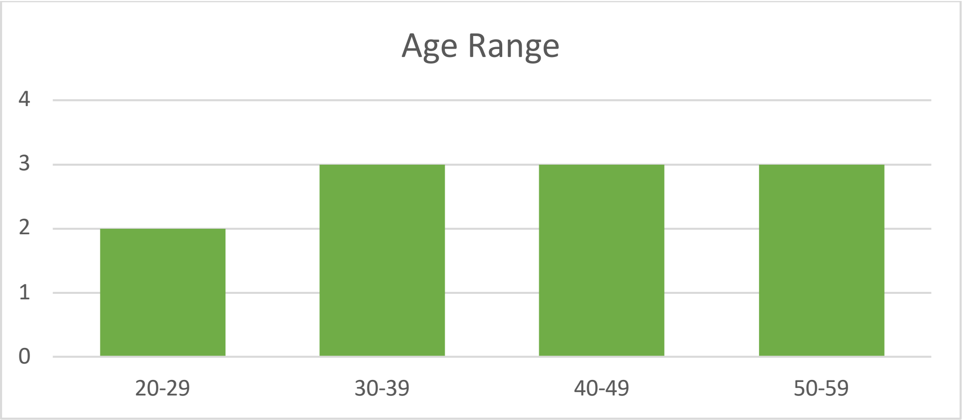
4.3. Demographic data of participants

The following information provides the reader with a detailed overview of the demographic information of the research participants who contributed to this study.

- All the participants were female, except one male nurse.
- Nine of the participants were White British and two were Southeast Asian
- All the participants worked in medicine sub-specialties, apart from one participant who worked in surgery.
- Two participants worked in hospital 1, four participants worked in hospital 2, three participants worked in hospital 3, and two participants worked in hospital 4.

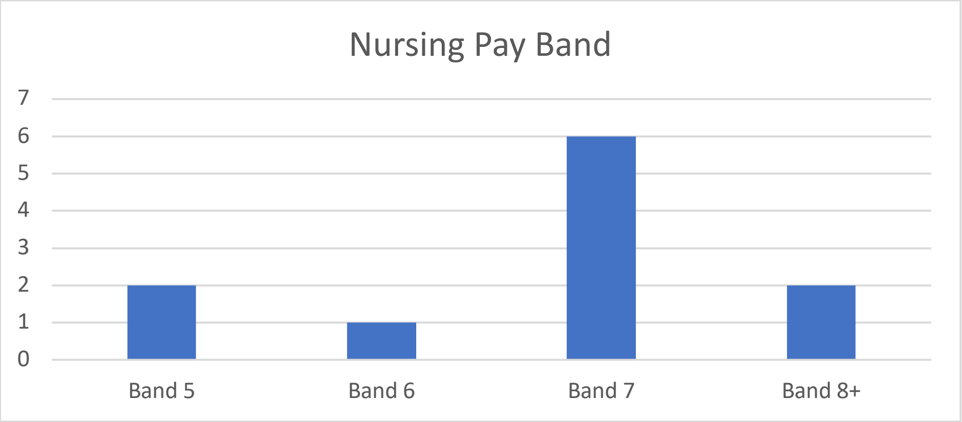
For other demographic data with wider representation, the results are offered graphically below:

Chart 1



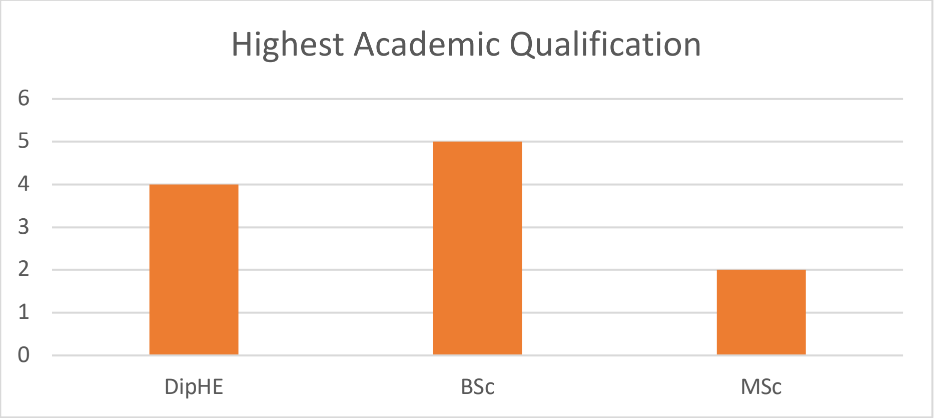
Participants' age ranges

Chart 2



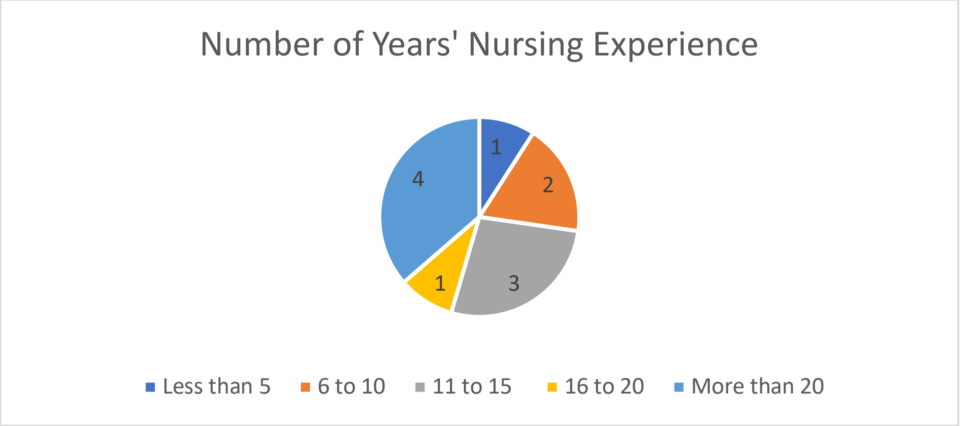
Participants' nursing bands (Agenda for Change pay scales)

Chart 3



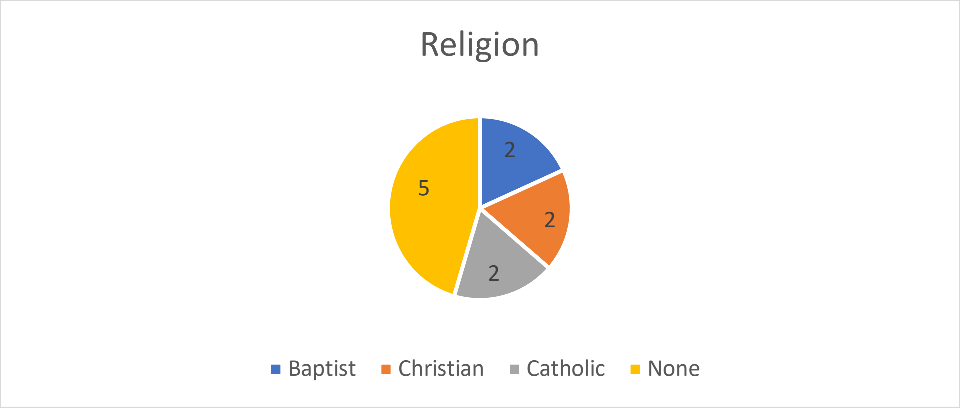
Participants' highest level of attained formal education

Chart 4



Participants' years of nursing experience

Chart 5



Participants identified religious belief

4.4. The substantive theory of Navigating the journey (Grieving Quietly) to manage end-of-life conversations

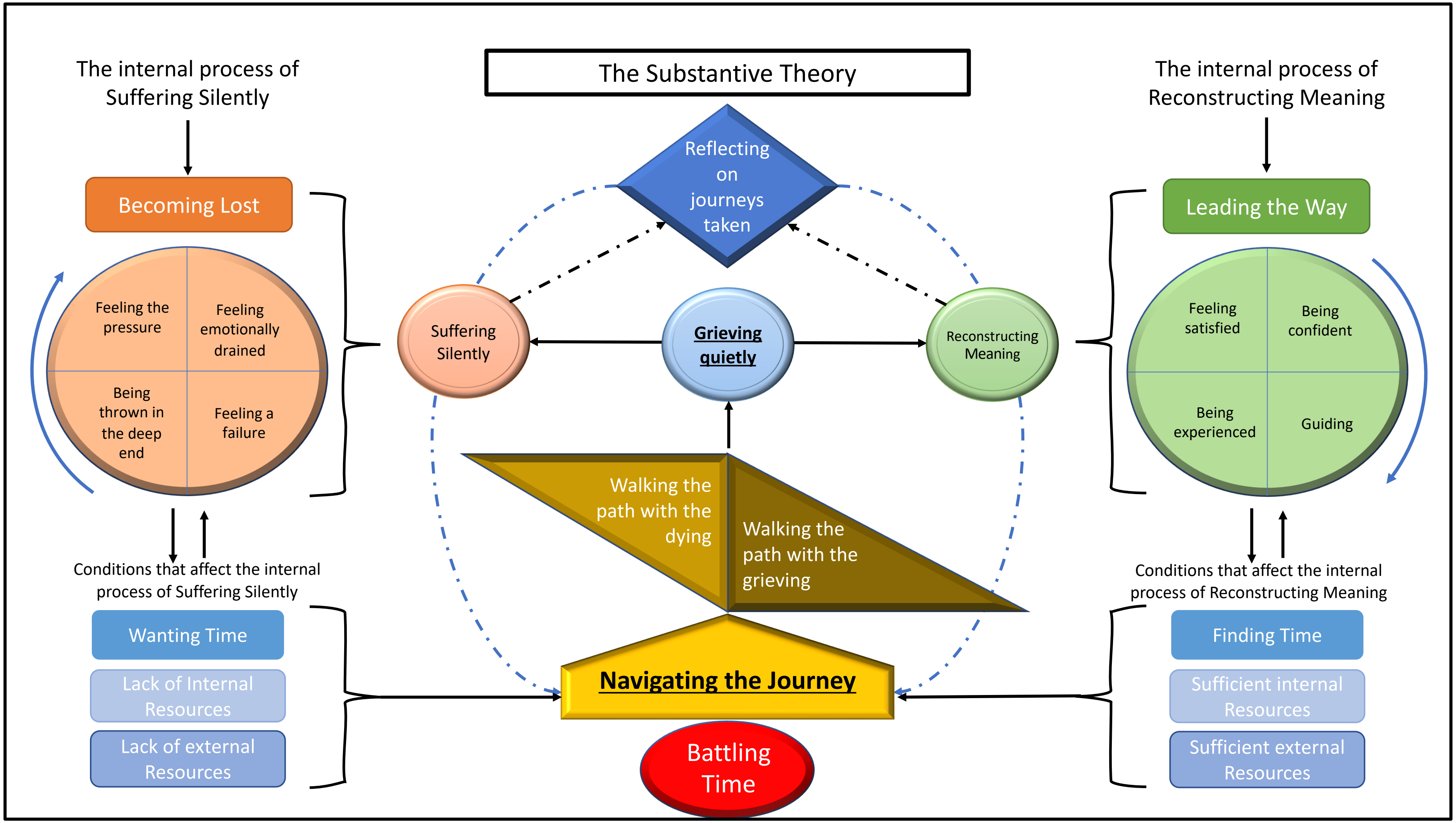
The theory of *Navigating the Journey* was developed to better understand how the research participants entered the social reality of the dying and the grieving through conversation and communication, to provide meaningful support and care. Whilst doing so one of the key theoretical categories of this theory proposes that when involved in the dialogic process, participants enter a state of *grieving quietly* – which is a neutral, internalised and normative position found on a continuum of impact.

The perception of success or failure in *Navigating the Journey* is predicated by the competing demands participants encounter whilst working with each patient and family, with participants making efforts to acquire sufficient internal and external resources to support the dying and the grieving in their respective journeys. This was a common challenge for all those who shared their experiences as the volume of resources required was identified as substantial. The primary social structural process to contend with for all participants was time.

The shared social structural problem for all participants was that of *becoming lost*, when resources were insufficient and demands would overwhelm them, subsequently moving on the continuum towards the social psychological problem categorised as *suffering silently*. Conversely, when resources were readily available, participants would enter the social structural process of *leading the way* for the dying and the grieving, and internally move towards the other end of the continuum to begin the social psychological process of *reconstructing meaning*, learning and reflecting, so they could prepare themselves for the next journey to be navigated.

Participants' abilities to move back along the continuum from the problem of *suffering silently* towards the process of *reconstructing meaning* were affected by the social structural processes at play which could influence their interactions with the grieving and the dying, either positively or negatively. The substantive theory of Navigating the journey (Grieving Quietly) is offered schematically at **Model 2**.

Model 2: The substantive theory of Navigating the Journey (Grieving Quietly)



The basic social structural process that participants were experiencing in this study was co-constructed as *Navigating the Journey*, when participants engaged in end-of-life conversations. The process of Navigating the Journey was explored by participants as both *walking the path with the dying* and *walking the path with the grieving*. The participants were attempting to successfully travel both paths, which had differing beginning and end points. Resource requirements for the dying and the grieving, and themselves, were varied and differed during each interaction.

When walking the path with the dying, participants articulated how they engaged with them by *supporting a 'good death'*, *advocating for the patient*, and *managing the dying person's journey*. Moreover, the participants would psychologically prepare for dealing with different deaths to maintain a sense of professional propriety, theoretically categorised as the social psychological state of *grieving quietly*.

Similarly, when walking the path with the grieving, the participants articulated a variety of different communicative strategies which included information giving, identified as *Signposting*, and through a nuanced interaction with the grieving by *understanding the context* and *walking in others' shoes*. Such interactions then enabled the participants to start smoothing the way for those close to the dying, with a clear goal highlighted to achieve the best possible outcome.

The most important social structural process which influenced the impact having such conversations had on participants was consistently recognised as time. Participants shared their continued attempts at *Battling Time*. Whether this was time to spend with the dying or the grieving, or time to process and heal from the experiences they had been involved in, this continual battle was experienced by all. Strategies for battling time included *assessing the caseload*, whilst *accepting the busyness* of the environments in which they worked to mitigate internal stressors. The ability to make decisions relating to time was varied, and depended on various other social structural processes, many of which were out with the control of the participants.

Such social structural processes which affected whether the participants moved along the continuum towards the social psychological process of reconstructing meaning or conversely the social psychological problem of suffering silently included the adequacy and availability of external resources to support navigating the journey successfully. Such resources were identified as being the level of support from other professionals, the ability to practically move the journey forward, such as onward placements for the dying, or identifying ways to support understanding for the grieving. In addition, the adequacy of internal emotional, psychological and experiential resources required to provide the care needed was varied, thereby impacting on participants' ability to best support families through communication and conversation. This then further impacted on participants' reserves or capacity to even consider *reflecting on the journeys* (they had) *taken*.

When conditions did not support participants gaining access to the resources needed, they would begin *feeling emotionally drained*, *feeling the pressure*, and consequentially *feeling a failure*, with some participants articulating how they felt '*being thrown in the deep end*'. The combination of these feelings led participants to move towards the social psychological problem of *suffering silently*. This state was timebound for some, with participants being able to move away from this end of the continuum to begin navigating another journey, although this was underpinned with feelings of worry about potential emotional exhaustion. For others such feelings remained prominent, leading to an ongoing concern of being involved in similar situations in the future.

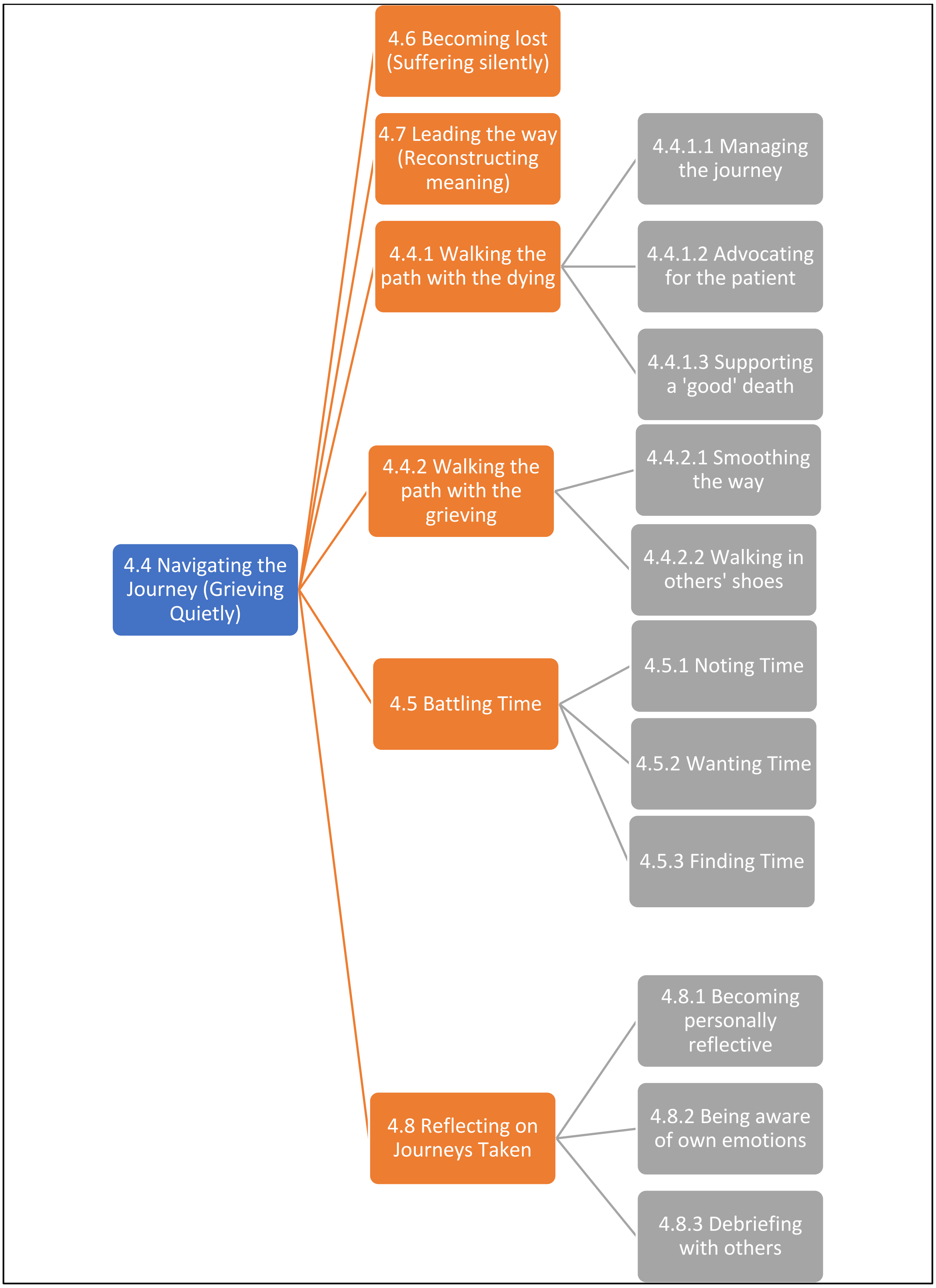
Conversely, the data revealed when conditions were met for participants to adequately access both internal and external resources to successfully navigate journeys, a sense of *being confident* to have meaningful conversations and *being experienced* in walking both paths were evident. From the data, it was highlighted that participants could manage the variation of such situations with confidence. These experiences of ‘being’ were shown to be the basis from which participants could engage in holistic social structural processes with the dying and the grieving, constructed as *guiding*. This ultimately led to a state of *feeling satisfied* in the level of support offered to the dying and grieving. This subsequently supported participants in moving along the continuum towards the co-constructed social psychological process of *reconstructing meaning*, most times utilising the social structural processes of *reflecting on the journey taken*. The reconstruction of meaning for the participants is evidenced as supporting them to replenish their internal reserves prior to *Navigating the Journey* for the next patient and those close to them.

It is important to note that these processes are neither linear, sequential, nor polarised in nature. Participants shared experiences of becoming stuck on the continuum and having to process episodes of communication later, with varied success. From the data it is evidenced that some cases still lingered in the memories and thoughts of participants. Moreover, the relationships developed with the grieving (and subsequently bereaved) lasted longer than the death of the patient in some cases. This placed a further challenge on the limited resources available to participants, as they continued to provide the best possible end-of-life care in an environment which manages both curative and palliative care processes.

In summary, the substantive theory has co-constructed the social reality of the participants as they begin Navigating the Journey for the dying and the grieving, and the meanings they associate with this. A state of grieving quietly was shared by all participants, whilst walking the path with the dying and walking the path with the bereaved. The grieving process is internalised by the participants and not often visible. Battling time is the biggest challenge for all, in addition to ensuring that sufficient internal and external resources are available when needed to provide the support required. Dependent upon the resources available participants either move along a continuum towards the social psychological problem of suffering silently or the social psychological process of reconstructing meaning. Some of the participants began reflecting on the journeys taken in order to prepare themselves for the next journey ahead, although this was not a process undertaken by all.

The detail of each core category is now presented in the following sections of this chapter. A schematic of the highest level of the coding tree is offered graphically below as Figure 1. The full coding schema can be found at **Appendix M.**

Figure 1: Coding Tree Diagram



4.5. Navigating the journey (Grieving quietly)

The main social structural process constructed from the analysis of the data was that of *navigating a journey* (through communication) with a patient and/or their family (referred to as ‘the dying’ and ‘the grieving’). Each participant’s process of navigation was unique, with every conversation or point of communication requiring the availability and accessibility of internal and external resources to reach a mutually recognised desired end point. Navigating the journey was dependent upon several social structural and psychological processes interacting with each other, determining whether said conversations led to a more positive or negative experience for the participants, as well as for those they interacted with. Through the analytic process it became evident that many of these dimensions did not sit within participants’ loci of control.

> *‘…I think it’s slightly different for every person you speak to, so you have to gauge your audience…’ (Participant 9b)*
>
> *‘…I don’t think, like I’ve said a few times, you can’t prepare, because every situation is different…’ (Participant 3c)*

From the data it became evident that participants’ social structural processes included the walking of two paths simultaneously - the path of the dying and the path of the grieving. The path of the grieving required continued attention to effectively use varied modes of communication. This path was not timebound, unlike the path of the dying. Participants disclosed conversations occurring ante, intra and post-mortem with the grieving (and subsequently bereaved) and balancing the two paths required continual internal shifts in their attention.

> *'…they [the family] take over the role of the patient if you want…' (Participant 8b)*

> *'…it was then about really supporting the wife because it's quite a difficult conversation…' (Participant 7b)*

From the analysis undertaken, walking with the dying, and with the grieving, was neither a simple nor linear process for the participants. Traversing the ever-changing paths called upon different resources at multiple points in the journeys. Said resources were neither infinite nor always readily available, yet the participants' disclosed calling on internal reserves of understanding and experience from previous situations to successfully interact and support patients and their loved ones.

4.5.1. Walking the path with the dying

The first category constructed from the data, when considering the concept of Navigating the Journey was *Walking the path with the dying*. Analysis evidenced that the frequency of communicating directly with patients was irregular, and for some of the participants this hardly ever occurred.

> *'…it wasn't so often you'd speak to the patient as well…' (Participant 10b)*

> *'…now having direct conversations with patients is not as frequent, as you are having with the families…' (Participant 7b)*

However, irrespective of the frequency of direct communication, the same participant explored how attempts were made to support patients who remained on the ward for a longer period, with the inherent difficulties associated with discussing mortality acknowledged.

> *'…because he'd been with us for quite a long time, they felt they could have those conversations with us, about how they were feeling, and around, you know, death and dying, which is always really difficult to talk about…' (Participant 7b)*

When considering what it meant to start walking with the dying for the participants, three key subcategories were constructed from the data, as follows.

4.5.1.1. Managing the journey

Managing the Journey emerged from the data as the first subcategory when communicating with patients at, or near, the end-of-life. Two dimensions were co-constructed as ways in which participants' perceptions and understandings of how to best interact with patients and ultimately manage this specific journey were determined. These were identified as '*doing the nursing bits'* and '*dealing with different death'*.

4.5.1.1.1. Doing the nursing bits

For some of the participants, '*doing the nursing bits'* provided a sense of normalcy and a framework within which to act. This social structural process offered safeguards to instigate interactions with patients, and a sense of deconstructing the dying process into waypoints which could be reached.

> *'…then the nurses come in between, you know …...They will let us know, ok, we think that patient is, like, suitable for this end of life, and then then comes the nursing bits, you know…' (Participant 1a)*

Subsequent comparison of cases highlighted how '*doing the nursing bits*' involved communicating practical aspects of the dying process. Participants shared how these practicalities could be explained with confidence as this aspect of care was well-known. This enabled participants to speak from a position of confidence, and subsequently allowed opportunities to offer reassurance to patients. The purpose of these interactions was to provide a sense of comfort and focus on the physical aspects of care delivery.

> *'…we had conversations around, erm, anticipatory medications as well, so when the time came, erm, there was medications that were in place and managed symptoms and things like that...' (Participant 7b)*

> *'…so we spoke…..directly spoke to him to reassure him that we have a supply of medications that will help treat any of the symptoms that he feels, and should he be agitated we can give him something for that……he then mentioned that he was frightened, so we were able to say 'we've got things for that, absolutely no problem, we'll give you what you need…' (Participant 6b)*

Despite some of the participants having had significant exposure to managing end-of-life care, they disclosed that '*doing the nursing bits'* could be insufficient in achieving a positive outcome, due to the unpredictable nature of external forces impacting the desired end goals for patients. Such goals could include the availability of care home placements, or for care to be at home as a desired place of death. This, in turn, would subsequently lead to feelings of sadness and disappointment that the conversations of reassurance had not translated into what was wished for by the dying.

> *'...they end up being here then like a couple of weeks waiting for a place to go, and unfortunately we didn't get her home, and she died here……you kind of feel a bit sad…...we'd had the conversation with her, she'd wanted to go into a nursing home, and obviously that didn't happen…' (Participant 7b)*

However, when reviewing *'doing the nursing bits'*, one specific component *('doing the paperwork'*) was not consistently viewed as a positive way to engage with patients. Whilst for one participant it was felt that the use of paperwork supported managing the journey for their patients…

> *'…we've got the end-of-life care plan and that actually encourages discussions and the recording of discussions... (Participant 10b)*

…. for another participant *'doing the paperwork'* was perceived as a task that prevented opportunities for more meaningful conversation to be had, and that the paperwork moved nursing staff away from interaction with patients and/or families.

> *'…the newly qualified nurses in place, the task orientation, and over focus on paperwork …... the healthcare system has become too protocolised…' (Participant 4b)*

4.5.1.1.2. Dealing with different deaths

The second dimension of managing the path with the dying was abstracted from participants' experiences as dealing with different deaths.

The impact of sudden versus expected death, or young versus old, affected participants as part of their emotional and psychological response to the incidences of dying. Feelings of apprehension, difficulty, and awareness of self within the process of dying shifted participants from the sense of normalcy felt when dealing with their own constructions of a ‘normal’ death. This then led them to more keenly acknowledge their own grief, as the similarities broke through the professional role.

> *‘…and that’s harder the younger they are, so your teens and your twenties are very difficult, erm, because they also tend to be the traumatic deaths to a certain extent…’ (Participant 5b)*

> *‘...as I say I felt a little out of my depth, it was more because of the acuteness of the situation, and the, err, the fact we were dealing with somebody much younger…’ (Participant 11d)*

Moreover, in situations where participants identified with the dying person’s life, analysis showed that this had the potential to more starkly overwhelm their normative protective processes, which could lead to a blurring of professional roles and personal experience.

> *‘...so, like a young man came, and he’s like [got] young kids, because I’m also a Mum, so I just thought, you know, like, we start co-relating things a bit, you know. I started thinking in that way, and yeah, that was like a hard part for me...’ (Participant 1a)*

What is evidenced from the interpretation of the data is the impact that unique types of death had on participants– none were the same, and therefore, interactions with patients varied according to the type, sequence, action, and context of the death happening before them. In each instance, internal resources for delivering the desired goals were tested as participants engaged with patients and their families in sometimes emotionally laden and unexpected circumstances, which could lead to a shift in their grieving process, not only for the individual but also for the wider team.

> *‘…we had a patient who unfortunately…...had been waiting to go to the Neuro-rehab[imitation] hospital, erm, and died in the ambulance on the way there….so we’ve got a very distraught ward team, [thinking] did they miss something?...’ (Participant 5b)*

4.5.1.2. Advocating for the patient

The second subcategory evidenced how participants would begin advocating for the patient. This interaction was undertaken in different ways and ensured that the patient’s needs and wants were recognised. Advocating for the patient through conversation was acknowledged as being a complex process, requiring a sense of confidence to negotiate with other parties (whether they were families or other healthcare professionals), underpinned by a clarity of purpose to meet the patient’s needs.

> *‘…I think you get to a point where you, you feel that you’re doing the best for the patient in just getting them into their preferred place of care, and letting them live their last days, weeks, in a place that they’re familiar with…’ (Participant 7b)*
>
> *‘…if we can get that right and we make sure that we’re keeping our patients pain-free, agitation-free, comfortable, you have a good outcome...’ (Participant 9b)*

The sense of responsibility to ensure the dying person’s voice and desires were heard were apparent, particularly in situations when the physical voice was no longer present, and the desires of others was at risk of overtaking the wants of the patient:

> *‘…sometimes it’s [palliation] actually about the spiritual and psychological and emotional side of it, and he needed me to carry on for his own reasons. So, I felt like I’d be doing him an injustice if I didn’t carry on [undertake dressing changes], even if it wasn’t helping him…’ (Participant 3c)*

> *'...no matter what we said, they [the family] were not ready to accept, so I mean I need to look after the family, but I have to advocate for the patient...' (Participant 9b)*

Despite most participants clearly demonstrating a clarity of purpose, the data evidenced that the level of advocacy undertaken by the participants was dependent upon professional experience and situated knowledge. For those participants who identified as being less experienced, '*doing the nursing bits'* became the dominant social structural process employed when walking the path with the dying, as it advocating actions being required. A key influence on this behaviour was a strong belief in the limitation of participants' own authority to act.

4.5.1.3. Supporting a 'good' death

The final subcategory constructed from the data when walking the path with the dying was supporting a 'good death'. Ensuring that the physical, psychological, and spiritual needs of the patient were met was a constant unconscious driver, as in many cases the participants didn't recognise this as being the purpose of their actions until this was explored with the researcher.

> *'…yeah, it was actually, was quite, it was dealt with, it was quite nice. It's a weird way to say, you know the words 'nice death', but in a way for her I think it was dealt with and managed as nice as it could have been…' (Participant 3c)*

As well as reacting to situations the data showed how participants needed to anticipate subtle changes and be pro-active in their communication to support a 'good' death.

> ‘...*with my experience in that particular situation, it’s more often addressing what really the patient asks for and then, of course anticipating the needs…….so that they’re able to go like, erm, peacefully or calmly...’(Participant 2a)*

> *‘…she just wanted to be assured that she wouldn’t be in any pain, she was very happy that she’d lived her life, thank you very much….. she was very pragmatic, and I still to this day swear that she chose the day she died…’ (Participant 5b).*

In summary, when walking the path with the dying, distinct social structural processes were used by participants to walk the path with the dying successfully which, in turn, helped their own grieving, through a sense of purpose and clarity. Participants would call on previous experiences and knowledge of physical care delivery at the end-of-life, as a comfort to communicate with confidence about things know. However, there remained an awareness of the potential uncertainty of different kinds of death, and how this could impact participants’ own internal resources, and grief response.

Secondly, advocating for patients was clearly articulated, as participants focussed on the importance of meeting patients’ wishes wherever possible, although this was more commonly seen from those with a greater level of experience and seniority. Finally, all participants wished to ensure a ‘good’ death was achieved to gain a sense of satisfaction that they had discharged their duty of care, which enabled them to sense-make as part of their own grieving process.

When undertaking a Grounded Theory study the constant comparative process not only focusses on cases and incidents from the empirical data but seeks to aid understanding of how the emergent theory and its categories are engaged with the literature (Urquhart, 2013). It is vital that the ongoing work of weaving literature throughout the findings and theoretical developments evidences both the convergence and divergence of findings with other researchers (Charmaz, 2014). Throughout this chapter the wider literature is shared from supporting literature searches using variations of terminologies found within the categories and subcategories, to best place the findings and developing theory.

A ‘good death’ is recognised to not only benefit the patients and families, but also nurses (Costello, 2006). However, Costello (2006) found that a ‘good death’ related to the degree of control that the nurses had and an associated patient passivity, which was not found in this study. Whilst the participants in this study recognised that interactions were not as frequent as those with families, where possible they would engage with patients, dependent upon their cognition, ability and/or desire to communicate.

In keeping with this study, Casey et al (2011) noted that the development of a relationship with the patient was a key determinant in supporting patients to die well (‘a good death’); likewise, the infrequency through which death and dying was discussed with patients was also identified. However, Casey et al (2011) found that participants would actively use techniques to block discussions with patients, which was not found in this study for any of the participants interviewed.

Tornøe et al (2015) concur in their findings that nurses’ emotional resources can be challenged when dealing with the death of younger patients, or for those patients who have similar characteristics to themselves, such as similar ages, familial situations, or personal relationships. This finding has also been noted by Doka (2014). Finally, Cipolletta & Oprandi (2014) share that participants’ determinations of a ‘good death’ are being able to meet the needs of patients in terms of privacy and being pain-free, akin to this study. However, it is noted that a clear descriptor of what constitutes a ‘good death’ could not be articulated by their participants. From the analysis of the data in this study, it is evidenced that participants were consistent in their understanding of a ‘good death’, which culminated in meeting the physical, emotional, and psychological needs of the patient, whilst striving to achieve the patients’ wishes of their preferred place of death.

The following section will consider the dimensions and their inter-relationships when walking the path with the grieving, which forms the other key interactive process when Navigating the Journey.

4.5.2. Walking the path with the grieving – ‘*Then is the time we talk with the families*’

The path of the grieving is one which participants shared as being more complex to negotiate. The data evidenced a complementary yet more focussed set of internal resources required to those used when walking the path with the dying. These resources and strategies were deployed by participants to support and constructively interact with families throughout their journey and allow them to maintain an internalised psychological state of grieving quietly. Many of these personal and professional supportive interactions, termed ‘*microprocesses*’ within this study, are subtle and small shifts in approach, attention, demeanour and thought process, often which are unconscious and responsive to the social structures that the participants enter as the interactions between all the parties develop over time.

Such basic social structural processes include a subconscious use of a combination of interventions such as explaining, listening, and empathising, leading to a deeper sense of contextual understanding thereby engaging participants to interact at a more meaningful level. Such interventions were evidenced as being employed at different rates and levels of intensity, in response to familial action and reaction. Underpinning these structural and psychological processes with families was the responsibility of balancing their attention between both paths. Two key subcategories were identified; Smoothing the way and Walking in others' shoes.

4.5.2.1. Smoothing the way

The first subcategory constructed as part of walking the path with the bereaved was Smoothing the way. This was a deliberate strategy employed by all participants to situate families within the environment of an acute ward setting, explaining both practical and perceived emerging emotional issues that may surface for them.

This purposeful interaction with families often followed the 'breaking bad news' conversation, undertaken either by medical teams or by the participants themselves. Within this subcategory specific structural processes emerged, coded as signposting, managing family expectations, and caring for the family.

> *'…we have a lot of erm families who, erm, we assist with the doctors when they bring them into the office, or by the bedside or wherever the conversation is had…..we help out, erm, with the discussion….Because although end of life is end of life for the patient medically, you can explain in five minutes what's happening there. The rest is a large what happens next, that's what families often need to know, medically they see that things aren't, aren't, going the right way, but then it's what happens next,*

> *they stay here, where do they go, what do they do, what does it cost, who does it, do we have to still do it? That sort of thing, it's a big minefield…' (Participant 8b)*

4.5.2.1.1. Signposting

The first property of smoothing the way, Signposting, was evidenced to be one of the early social structural processes that occurred with families when participants recognised that end-of-life was planned, or indeed imminent. From the data, it is proposed that the action of signposting was akin to '*doing the nursing bits'* when walking with the dying.

However, distinct microprocesses emerged within each contact with families. The way in which signposting microprocesses were engaged depended on the way families engaged with the offer to discuss the envisaged journey, with many of them being deployed unconsciously. Signposting microprocesses were found to be both explanatory and supportive, providing options for families to aid either immediate or longer-term decision-making. Whilst leading these interactions participants began underlying, unconscious and complementary explorative microprocesses with families.

Outlining what could, or could not be done, was discussed with the grieving as the move from curative to palliative care was enacted by the treating teams. The purpose of this was to identify 'where' the families were on the journey.

> *'…like there's a leaflet about care in the last days, and what symptoms you might expect, and usually I give that and then discuss briefly, 'these are the things you might see', and try and involve them as well…' (Participant 10b)*

> *'…the best way I can…by showing them that I'm there…….so yeah, offering them let's say if they want to stay overnight, because I think that helps, offering them a side room, or offering them a drink…' (Participant 2a)*

Signposting occurred on multiple occasions, with the participants intuiting when further work was required with families to ensure clarity about the direction of care. The data highlighted an unconscious and highly nuanced sensitivity to the complexity of family understanding, with internal checks being made by the participants to identify when a conscious reckoning of the situation was being reached. As these microprocesses were evidenced as moving from an unconscious to a more conscious state, the result was a pro-active conversation with family members to externally validate their position on the path.

> *'…going back and having that conversation to say, 'something's still wrong, talk to me' and building up that relationship so they talk to you and if you say you're going to go back and talk to them you go back…' (Participant 5b)*
>
> *'...really just giving them the time that they need to process it, erm…..you've had a conversation with them one day and they have to go away and …...then revisit and have another conversation about it, like the following day…' (Participant 7b)*
>
> *'…you know like in the corridor, or in the bedside when they stop you to find out how the relative is…...you're almost trying to prepare that person so sort of, like, I suppose at that point while they're still being treated, it's kind of hope for the best and prepare for the worst...' (Participant 9b)*

Whilst signposting, participants were also engaged in a complementary social psychological process when communicating with families – Managing expectations

4.5.2.1.2. Managing Expectations

Managing expectations was abstracted as a social structural process interwoven with signposting, thereby enabling families to continue their own journey along the path. The management of expectation was seen as having a greater draw upon the internal resources of the participants when families' expectations were not realised or met.

> *'…with end of life care you've got one opportunity to get it right, just one, and if you don't the impact that has on their loved ones… and it's awful, awful…' (Participant 9b)*

> *'…families know that their loved one is not going to get better, or they've come in and they look really unwell and they might say to you, you know, things like, 'I know they're not going to come out of hospital, I know they're not going to make it', and it's about how you respond to those kind of conversations…... that's a really awkward thing to answer…..you do get put in situations where people ask you difficult questions about end of life…' (Participant 7b)*

The wide gamut of expectation from families was recognised by participants, ranging from more practical desires (such as being nursed in a side room) to those which were more emotive and fundamental, particularly regarding prognosis and diagnosis. The data evidenced that further microprocesses were being deployed, including solution-finding, and suggesting alternatives to manage expectations, with an underpinning desire to reduce familial distress. A genuine wish to resolve perceived emerging tensions became evident through the analysis, strengthening the proposed interdependence between these two dimensions of Signposting the Way.

> *'…so, I very much try and tell them all these things and hope that they're going to come back to me if there's something they're not happy with...' (Participant 6b)*

To manage expectations for families, the development of multiple time-bound interactions emerged as a key strategy to ameliorate perceived future high-charged and emotive interactions. Ultimately this unconscious protective process was devised to prevent a further drain on participants' energies and resources.

> *'…I think most of the steps I do is because I'm trying to prevent something from happening that I know has happened before…...it's just little bits building up…' (Participant 6b)*
>
> *'…I think it's those little conversations that you have, not necessarily bringing into an office and having a sit-down meeting, but just those general conversations, so she would just ask us things while we were looking after him in the bay...' (Participant 7b)*
>
> *'…and maybe spend a lot more time trying to make, you know, kind of reassure them…' (Participant 10b)*
>
> *'...you're giving them every opportunity to be supported, and I think if they understand the process, sometimes…...I mean that helps as well…' (Participant 9b)*

Throughout the process of managing the expectations of the families, the final dimension of smoothing the way emerged as an underlying internal need for the participants – Caring for the family.

4.5.2.1.3. Caring for the family

Caring for the family was conceptualised as the property of the subcategory Smoothing the Way. A tangible sense of caring for the family was seen consistently in the data and across all participants**.** Whilst it may be considered that the function of 'caring' is inherent within the practice of nursing, specific social psychological processes were engaged by the participants when communicating about end-of-life care. These were predicated on a desire to make the journey as easy as possible for the families, no matter the length of time it took.

> *'…because erm, we're there not only to look after the patient but also, erm, to look after the family…' (Participant 2a)*
>
> *'…we can make it easy for everyone, for the family as well…' (Participant 1a)*

The data showed how participants were cognisant of the impending loss of a loved one and the subsequent impact this would have on family members. This led them to instinctively and unconsciously moderate their interactions, attempting to strike a balance between being neither overly intrusive nor perceived as 'absent'. Additionally, the data evidenced a more nuanced microprocess of softer inquiring skills, attempting to understand familial emotion so participants could respond appropriately and meet families' needs more keenly. Whilst not shared by all, some participants described a staged process of involvement, without assuming the need for an immediate 'rescuing' response to high levels of emotion. Cautious and incremental interactions were undertaken to gauge when and where to deepen communication.

> *'…if the relative is extremely upset, for example, then just because they're upset, then you don't go in to the full, I don't know, full details…' (Participant 10b)*
>
> *'…it takes me two minutes to put my head in their room every day…...'I'm here if you need a chat. My door's always open', because then they feel that they can [engage]…' (Participant 9b)*

Further analysis evidenced how participants acknowledged and supported familial grief. Participants engaged in both the social psychological and structural processes of observing and managing grief, in readiness to prepare to provide more intense support for those families closer to the end of their journey in the hospital. Despite many patients dying in hospital, the abnormality of the grieving process for families was recognised.

> *'…but it's a horrible grieving process. It's not like a normal grieving process, this wait is horrid….. we're living it with them if you want, so their distress and their fear, they come out screaming in the middle of the night, 'aaah, he's not breathing!!'…' (Participant 8b)*

> *'…we'd looked after this man for three months so you can't be a nurse for somebody for three months and not have, you know, a personal attachment in some way, as so many of the team did, but it's just about giving them [the family], I think, giving them the time because the grieving process has already started…' (Participant 9b)*

The social structural process of communicating with families did not always end at the point of the patient dying. Where unanswered questions remained, the data evidenced communication continuing. Participants continued to manage and support familial grief, as part of the caring process. Whilst acknowledged as a nursing responsibility, it was identified as a pull on participants' limited resources and energy.

If the perceived successful conclusion of the journey had not been achieved, feelings of frustration were evidenced in the data. Moreover, due to the volume of activity occurring in the ward environments, these feeling intensified as the energy required to recall and remember events detracted participants from managing the 'here and now'.

> *'…I don't want to be at the receiving end of a difficult face to face meeting with families who are bereft, or six/seven hours writing a letter of apology takes you the whole day…' (Participant 6b)*

> *'…I'm in two minds as to whether I can actually phone her and explain…...I've ordered the notes up so I can just refresh my memory…...or write, so I'm just trying to see at the moment what fits best…' (Participant 8b)*

Underpinning the process of caring for the family was a desire to provide the best possible experience, with the data evidencing participants' wishes to facilitate a meaningful experience for families, whilst being cognisant of the limited time and resource afforded them to be able to do so. The prioritisation of available energy and attention emerged from the data, as the participants acknowledged that reaching the end of the path successfully with the grieving and newly bereaved was of paramount importance, and the associated responsibility that came with getting it right.

> *'….even though you know you've got a thousand and one other things…...you've got to give that good experience for that person…... it's the only time they're going to be told…' (Participant 10b)*

> *'…if you get it wrong with the family that's the memory they have, erm, and it doesn't matter how well the rest of it goes, when that patient dies the memory they have is that you did it badly…' (Participant 5b)*

> *'…I think if you can just offer a good experience to families of patients who are end of life…. they leave feeling that although it might not have been the situation [they wanted to be in] …... they'd hoped that the care was really good…' (Participant 7b)*

4.5.2.2. Walking in other's shoes

Walking in others' shoes was conceptualised as the second subcategory of walking the path with the grieving. This subcategory was intricately intertwined with Smoothing the Way to develop meaningful conversations with families. Analytically, Smoothing the Way is posited to represent the externalisation of intelligence gathered by the participants, whilst Walking in others' shoes is the internalised social psychological process through which the participants were better able to situate themselves when entering conversations. The combination of internalised and externalised microprocesses which are evidenced within these subcategories is proposed to be core to the achievement of supporting families. However, the success or failure of these basic social psychological and structural processes, are predicated on the availability of resources which may be required at any point.

The data evidenced clear microprocesses from the experiences of the participants that provide a deeper understanding of the nuances involved when such interactions occurred. This is due to the unique nature of family groups and the individuals who are members of the groups. For some of the participants, priorities focussed on understanding the root of family emotion, whilst for others situating self within the experience of the families resulted in a more truthful understanding, thereby aiding communication opportunities. A key unconscious microprocess for each participant was the way in which they would protect themselves emotionally, whilst balancing the desire to expose themselves more personally so that deeper interactions could happen.

> *'…I still know how it feels to feel that loss and feel that hurt, it hurts, it physically hurts, and I think I'm, yeah, as I've got older, I've got and had other experiences, I think I'm able to provide that shoulder and that arm around…' (Participant 3c)*
>
> *'…showing compassion and empathy for the people that you're having the conversation with, you know, we've all been there, we've all lost people that we love...' (Participant 7b)*

The two key dimensions of this subcategory were determined as Situating Self and Understanding the context.

4.5.2.2.1. Situating self

Within this dimension of walking in others' shoes, participants were engaging in a reflective psychological process, defined as situating self. This reflection was undertaken during the conversations with families, and in the spaces between. This unconscious process was used by participants as part of preparatory work to better gauge how they could positively impact the journey for the grieving through communication, listening, and acting on what was heard. By doing so participants could better understand how, when, and where communication would have the greatest effect in improving the experience for the grieving.

> *'…as a nurse, for me, the best way I can show them, by showing them that I'm there, that I'm listening and I'm really able to understand and feel for them…' (Participant 2a)*
>
> *'…I don't know how you feel, so I'm not presuming that, I wouldn't do that, because everyone is different…...it's not, not the same, and everybody is different how they deal with it….I do try and put myself in their shoes…' (Participant 8b)*

Participants also expressed the importance of being able to display empathy whilst communicating with patients.

> *'…you want to show empathy, obviously, don't you?...' (Participant 10b)*
>
> *'…so, it's just being sympathetic, empathetic to that person, listening to what they're saying, giving them time to talk…' (Participant 8b)*
>
> *'…I think I have the conversation in a way that I would like someone to have that with me, or my loved one…...so I feel like I'm good at showing empathy to people, erm….I*

> *feel like you learn to obviously detach yourself from situations as well, but not, not show that you're detached at the time…' (Participant 6b)*

When participants dealt with situations where families were dissatisfied with outcomes, or the way in which end-of-life communication or care was handled, the data showed how situating self was a vital process, helping participants consider the situation objectively and move away from a naturally defensive position.

> *'…all they can see is their memory of their agitated Mum, that's all they see, and they're still so upset by it, which I understand, completely….I cried when I came out of the meeting because I just thought nobody should see that, there's no reason for it…' (Participant 9b)*

Exploring this incident further, it became clearer how this participant situated self to affect a deeper understanding of the importance of meaningful conversations and interactions with the grieving. Following a difficult conversation with the family the participant was deeply affected. Whilst they recognised the strain on their personal resources, such a reflection evidenced the way in which their use of microprocesses had changed and had moved from an unconscious to a more conscious state.

> *'…I'm a lot calmer, I'm probably a bit more self-aware of how sometimes I can come across if I'm busy. Sometimes I'm much more self-aware…... always trying really hard to make sure that I make the time that these people need from me, and I think it's just about self-awareness...' (Participant 9b)*

An additional facet of situating self was constructed from the data, which was the use of personal experience when holding conversations. Situating self in this way allowed participants to form a deeper attachment to families, thereby aiding future interactions.

> *'…showing compassion and empathy for the people that you're having the conversation with, you know, we've all been there, we've all lost people that we love, so it's just understanding that these conversations are really difficult, but we do have to have them…' (Participant 7b)*

> *'…I suppose I've grown up experiencing a lot of death and traumatic experience, family type experiences…...so death isn't something I'm frightened of…...so I'm quite comfortable talking about it, erm, I'm quite comfortable discussing it with patients and families…' (Participant 5b).*

When situating self some participants moved beyond an internalised psychological process of reflection, or being the receiver of emotion and experience, to consciously sharing end-of-life situations. This externalisation of experience with families enabled them to engage more closely with families and move forward on the journey together.

> *'…so, my conversation of a half an hour, and we were both tearing up in the corridor, literally discussing my father, not that that's, you know, we were just talking anyway…' (Participant 8b)*

> *'...if you've experienced people that have died before, I suppose you're bringing all that sort of, you can't help but bring that with you to those conversations…' (Participant 6b)*

4.5.2.2.2. Understanding the context

The second dimension of Walking in others' shoes was the participants' understanding of the context within which the grieving situated themselves.

Understanding the context of families was evidenced as being a key supportive and interactive microprocess. By doing so participants were able to offer information that could positively impact their journey, whilst also increasing participants' knowledge of the experience to date for the grieving. This acquisition of contextual information over time formed an important part of the unconscious preparatory microprocess, so that any predicted challenges could be averted, where possible.

> *'…I think you know as much possible information as you can about the situation, possibly not just about the condition, but actually about the family dynamics……understanding who's with them, what support they've got…' (Participant 3c)*

As part of understanding the context, the importance of understanding family dynamics, including any complexities within relationships was key. However, this could leave the participants feeling concerned that they would not achieve a successful outcome if they were involved in managing multiple conversations and having to repeat information multiple times.

> *'…sometimes there are families who don't get along……so of course immediately you need to know who is the next of kin……but you can't deprive the others as well of not coming in to see the patient…' (Participant 2a)*

> *'…sometimes siblings don't agree with the plan, erm, between each other, err, we definitely have families that are, I don't know whether the word unrealistic is the right word, but…' (Participant 6b)*

Challenges were seen when participants attempted to gain a deeper understanding of the context of the families they communicated with. From the analysis it was shown how understanding the context of family dynamics was seen as a more conscious social structural process to attempt to help re-orient the family whilst they were on the journey, when they did not wish to engage with the participants directly.

> *'…some of it's around family dynamics where the people don't agree on the plan….sometimes siblings don't agree with the plan, erm, between each other…'(Participant 5b)*

> *'…we get a lot of families, 'oh yes, but we don't talk to him', or 'we don't talk to them', and you think 'accchhh' [sic]……...so as I say going forward, we need a plan…' (Participant 8b)*

It was evidenced further that by understanding the context the last participant was able to explore ways in which they could attempt to steer the family towards finding a cohesive way to move forward.

> *'…you don't know how somebody feels, or how somebody is coping, what their life is at home…just hear what they have to say and make sure they understand the process as best you can…' (Participant 8b)*

In summary, the data showed how participants were oscillating between multiple microprocesses which were either unconsciously or consciously used; internally driven actions deepened understanding about a patient's family, and then externalising said understanding enabled the participants to support those who were grieving. This was seen to be achieved by empathising with others' experience. Often the participants would undertake these processes naturally and instinctively with the underlying driver being to minimise the risk of families having a poor experience.

Peterson et al (2010a) evidence in their study that the communication issues which arise for nurses when working with families were more focussed on how families were coping rather than the process of information-giving about patients' clinical conditions and prognoses. In line with this study, however, family dynamics were also identified as something nurses became aware of. The findings in Peterson et al's (2010b) study noted the challenges that stemmed from the differences identified between family wishes and those of the patients. Such a finding was not evidenced in this study; in contrast, families were described as having a comparable sense of advocacy to the participants.

Boroujeni et al (2009) noted in their grounded theory study on the experience of Iranian nurses that the central concept was on nurses ‘finding a balance’. As has been highlighted in this phase of the analysis, ‘finding a balance’ for the participants to journey both paths with the dying and the grieving provides an insight into the complexities nurses face on a daily basis. Moreover, Boroujeni et al (2009) describe multiple ways in which the nurses attempted to ‘find a balance’, when moving into a palliative phase (balanced against restoration), between the provision of information and the giving of hope to families and between a position of intimacy and one of professional distance. The participants in this study are likewise seen to attempt to find a balance in their positioning of intimacy and professional distance; however, this was predicated on the individual circumstances and personal context of the participants, showing a greater or lesser sense of personal comfort in disclosing personal information with families.

Finally, McCallin (2011) in her grounded theory study of nursing practice in end-of-life in New Zealand, identified that ‘moderated guiding’ was the way in which nurses managed patients’ and families’ expectations during end-of-life. Both controlling and non-controlling aspects were identified, which align to the analysis undertaken within this study. Through processual interactions with patients and families, it was evidenced that nurses are unconsciously and consciously interacting with those immediately involved in the episode of care. McCallin (2011) notes three sub-processes within her study – 'Checking out', 'Involving' and 'Supporting'. Similarities with this study are evidenced in the microprocesses used when 'walking beside' the patients and families, supporting choices, providing information, and gaining a deeper understanding of the context of what patients and families knew, understood, and needed. In harmony with McCallin's (2011) findings, the participants in this study are also seen as balancing a position of becoming more involved with the familial situation, whilst holding a degree of distance to minimise the risk of blurring boundaries. However, it is argued that this thesis shows a greater degree of clarity on the conscious and unconscious microprocesses used by nurses as part of their ongoing communicative preparatory work, and post conversation planning and management.

Within the next section of the chapter, the key challenges for participants will be explored, which will enable the reader to comprehend more keenly how the sufficiency, or lack, of resources impacts how well participants are able to commit to navigating the journey of communication in end-of-life situations.

4.6. Battling Time – '*Challenge is the time; the biggest challenge is the time*'.

All participants in the study disclosed that there was an unending struggle with time. Within the category Battling Time, three key subcategories emerged from the data. These represent the internalised social structural processes participants entered with time, which could negatively impact on their ability to have multiple meaningful conversations and prevent them successfully navigating the journey with the dying and/or the grieving. These interactions with time are recognised as the interchangeable and competing subcategories of noting, wanting, and finding time whilst participants attempted to support the best possible outcomes for the dying, the grieving and themselves.

4.6.1. Noting time

The subcategory of Noting time was a key basic social psychological process which emerged from nearly all participant interviews. Noting time was multifactorial, in that it not only related to the limited time the dying and the grieving had, but also referenced the time needed more generally when working in an acute hospital ward to effect meaningful communication. Noting what time was needed focussed on how participants could successfully manage all aspects of nursing care for every patient within their sphere of responsibility.

> *'…so there are nine patients that I had to look after, so you know it's a matter of working your way around those nine patients, erm, of course got to spend time with each and every one of them…' (Participant 2a)*
>
> *'…as a nurse you're concerned about the other patients who are, you know, another five or eleven patients, who I'm doing something for them as I'm dealing with this relative, this family, you know, so you've got those time constraints always in the back of your mind…' (Participant 11d)*

Within this subcategory two dimensions emerged which showed how participants would determine the potential challenges they could face to provide the time needed to communicate effectively with either dying patients or their families.

4.6.1.1. Accepting the busyness

Accepting the busyness was the first dimension identified as a constant. Working in the acute setting for the participants was seen in the data as being 'busy', and participants accepted this as a norm, utilising the tasks associated with ward activities as a method of quantification.

> *'…I can't remember the specific but it's usually very busy…' (Participant 10b)*
>
> *'…it was busy, but it was an afternoon, erm, not too busy though……but I'm overseeing the discharges, the double up, the IVs, this, that and the other...' (Participant 8b)*

For some of the participants who were not working in direct patient care roles or operationally leading the shift, they recognised that the levels of busyness were different for members of their team. Through this acceptance of busyness in self and others, they were able to better facilitate time for conversations with patients and families, when required, and where possible.

> *'…I think because they're busy, they've got eight or nine other patients to see, and although, 'yeah your Mum's really poorly', you know, 'but he's bleeding out there, erm I've got a catheter change there, I've still got to do the IVs on that patient there.' Not that they'd say that, but that's going through their mind…..they're not quite on the same wavelength as perhaps the senior staff…' (Participant 8b)*

As can be evidenced from the participant's account above the internalised recognition of accepting the busyness is also identified as a social structural process by which participants recognised the competing priorities placed upon them.

4.6.1.2. Assessing the caseload

A passive acceptance of being busy was not the only dimension of how participants noted time. An unconscious planning microprocess was determined, evidencing by participants assessing the caseload for themselves personally, or in totality in the ward environment. This was a naturalistic process shown as part of the ongoing preparatory work done by participants to provide an ongoing information stream that allowed them to act on what could be done to best support the dying and the grieving.

Participants' accounts evidenced that through the assessment of activity the challenge of being able to have supportive conversations was balanced against the needs of other patients, leading to responsive and dynamic decision-making microprocesses being enacted to meet the needs of all in their care.

> *'…medicine was like they were very poorly patients, surgical is like a patient going to theatre, coming back to theatre, post op care and all those things, so the main thing is the time. Because when someone is on end of life it's not just end of life, there are a lot of things to be done for the patient, the family…communication wise, a lot of things,,.' (Participant 1a)*
>
> *'…the pressures on the wards, so it's competing priorities, erm, and obviously if someone's really, really sick or there's no beds and they want discharges, they're all competing priorities…it gets the better of a lot of people, I think…' (Participant 10b)*

A deeper exploration with this participant elicited the impact of competing priorities on staff, and how being able to assess the caseload in the ward environment was not always recognised or managed successfully, which could lead to a failure in accurately noting the time required to support patients and families at the end of life.

> *‘…if you’re on the ward and you’ve got a hundred things going on and you’re short staffed and you’re stressed about something, and this, that and the other, I think that can get lost…..when you have a person at end of life, they do take up more of your time, and they should...’ (Participant 10b)*

For others the practicalities of managing multiple patients at the end-of-life in an acute care setting was an area of concern. The ongoing assessments of how to provide equity of time and attention to the caseload of end-of-life patients and families versus the acutely unwell patients who required active treatment became clearer from participants’ accounts. For one, it was recognised that the requirement to preserve life could be at the detriment of time and privacy for those at the end of life.

> *‘…sometimes we can have, we can have a good half a dozen patients who are on the end of life pathway, or perhaps have two or three in the side rooms who are dying…but obviously up on these wards we’ve got the diarrhoea and the sickness…..they go over the end of life…..which is really sad…’ (Participant 8b)*

4.6.2. Wanting time

Whilst Noting Time was a way to understand the dynamic situation participants found themselves and others in, Wanting Time was the second subcategory constructed from the data, which best explained participants’ recognition that to successfully walk the paths with the dying and the grieving, time was needed for them to engage in this process constructively and meaningfully.

> *‘…you don’t want to be rushed for this person, you want to actually give the right information, in a style and a manner that will actually help…’ (Participant 11d)*

> *‘…time, time, honestly time. Because in my ideal world…..I would like to say that I could get out on the ward and just walk round and talk to people. I can’t. I have not got the time, and that is what I would like to be able to do, as the ward manager, go*

> *round…..it would be so much nicer to just get out there and talk and have time to be with the patients and spend time with patients…' (Participant 8b)*

Irrespective of role or responsibility, participants wanting time is constructed from the data as the need to have protected time for meaningful conversations or opportunistic touch points with patients and families, thereby providing a sense of contact. In addition, wanting time is also described below as the need by participants to have an opportunity to reflect on journeys taken, as part of the post communicative work needed to process incidents and then reset internal resources for the next encounter.

> *'…you don't often get time to sit down as a team, erm, and discuss difficult situations that have happened, which is something that I think would be quite beneficial, 'cause a lot of people, it's upsetting when you care for dying patients...' (Participant 7b)*

> *'…there is places to go, but the thing is, err, same thing, lack of time…' (Participant 1a)*

The data have evidenced that wanting time is a key factor which impacts on participants' satisfaction about how they discharge their duties to the grieving and the dying. The final subcategory of battling time emerged as Finding Time, and the strategies employed to do so.

4.6.3. Finding time

The importance of Finding Time for dying patients and those who were grieving for them was clearly identified. For those wanting time, an internalised social psychological process to find and give of time to others gave participants a sense of satisfaction, as this was perceived as being the right thing to do. Despite the subsequent issues and work this would generate for participants, finding time was evidenced as being the goal. As noted above, participants wanted to ensure patients and families were communicated with and afforded whatever time was needed to meet their needs.

> *‘…it’s not something that you can rush, you don’t want to rush a conversation like that. So, we do always try and, you know, you put that face on, don’t you, that you’re not busy, even though you know you’ve got a thousand and one other things, because you’ve got to give that good experience for that person, because it’s the only time they’re going to be told’ (Participant 10b)*

> *‘…I think one of the most important things when you’re having those conversation is that the patient or the family must have all the time in the world and never feel like you’re trying to get out...’ (Participant 5b)*

The importance of ensuring patients and families felt listened to was apparent from the data, enabling participants to develop a relationship that was based on a sense of trust and openness, no matter the content of the discussion.

> *‘…it does give me the opportunity to be able to take families and spend that time with them…..you’re giving them the time to express and getting to the core of, you know, what their concerns are, what bit they don’t understand, you know…’ (Participant 9b)*

> *‘…yeah, it’s when things come out, you’ve just got to listen, it’s having the time to listen, I think, and well just hear what they have to say and make sure they understand the process as best you can…’ (Participant 8b)*

For the participants to do this, deprioritising was a key conscious social structural process undertaken to provide the standard of care desired. This decision-making process gave participants permission to find the space and time required to focus their attention on patients and families. The responsibility of not showing there being any collateral stressors which could burden others was an underpinning principle. This sense of permission allowed participants to find time confidently and seek the support of others to do so.

> *'…I don't want to be in a conversation about end of life and then have to run off, you know, err, in that case you know I try and draw somebody else to have my bleep and be able to do my job whilst I have those conversations…' (Participant 11d)*

> *'…your colleagues come and help you with some of your workload, so you can give that time…' (Participant 9b)*

From this section of the analytic process, it is posited that there are clear social structural and psychological processes in play for participants who are constantly battling time. The success or failure in finding time impacts the participants' sense of satisfaction and professional standing. Whether it is time for families to be with their loved ones at the end of life, or time for the participants and their colleagues to reflect on journeys taken, this struggle continues without end.

> *'…I think just taking, realising it doesn't matter how busy you are, just to take that time and it's worth it for everyone involved…..don't get clouded by everything else on the ward…' (Participant 10b)*

When considering the findings of this section of analysis against the extant research there are similarities to other studies; however, an exploration into the specific aspects of how nurses and other healthcare professionals manage the battle with time through distinct social psychological and structural processes was not found explicitly.

Warnock et al (2010) note that a lack of time is a key challenge for nurses when they are involved in breaking bad news to families. However, the challenges were more acutely related to a lack of time to explain and provide bad news over the telephone. Issues in relation to the ward environment were also highlighted as being an issue in not being able to communicate effectively with families; however, this was not reported strongly in this study – only one participant mentioned a lack of a suitable environment to hold conversations.

In their subsequent research, Wornock et al (2017) again cite issues for nurses having inadequate time; however, these were noted within the context of not being able to manage events, in addition to having insufficient staff. In contrast to this study, issues pertaining to the prioritisation of time for end-of-life patients and families against those who required curative treatments was not seen; however, it is recognised that the methodologies of both studies may have precluded this being explored in greater detail, as both of Warnock et al's studies were questionnaires with free-text sections.

Aligned with Warnock et al's findings, Caswell et al (2015) described in their study that a lack of contact may have impacted on the opportunities for nurses to develop a relationship based upon a clear understanding between family members and staff. However, in contrast to the findings in this study the observations of practice within the study shared a lack of importance identified by nurses for clear and effective communication as necessary to support family members having a deeper level of understanding. It is interesting to note that within Caswell et al's (2105) study, which sought to seek both the experience of family carers and staff when communicating about end-of-life in the acute setting, it was the family carers who noted the 'busyness' of staff, rather than the staff themselves.

Further exploring the concept of ‘busyness’, Dosser and Kennedy (2012) noted in their study of carers’ and health professionals’ view of providing support at the end of life, that the ‘busyness’ of the ward was not only seen as a barrier to difficult conversations, but also as a strategy for avoidance by staff. The nature of avoidance of communication was not noted within this study with any of the participants; however, it is recognised that this may be due to the increased attention that has been paid to supporting a ‘good death’ over the past decade and the requirement to evidence compassionate and meaningful conversation with patients and families in line with NICE guidance and CQC regulatory standards.

More recently, in an Australian study conducted by Kerr et al (2020) it was identified in a wider study, which considered the challenges that nurses face when communicating with patients with life-limiting illnesses, that the requirement to undertake more technical tasks, (akin to ‘doing the nursing bits’ as reported earlier in this study), as well as multiple interruptions, negatively impacted nurses’ abilities to engage in conversation. This was identified as a lack of time. Interestingly, similarities are also found for the participants in this study; however, the strategies employed by the nurses to find time and to have the confidence to deprioritise other tasks was not found in Kerr et al’s (2020) findings. The sense of being time-poor resonates with the participants in this study. However, in contrast to this study there is no evidence to support that the nurses involved in Kerr et al’s (2020) study would move outside of a more task-orientated form of care to facilitate meaningful communication. This may be due to the nature of the system within which the nurses were working, although this cannot be confirmed definitively.

As interestingly, although again caveated as a study which occurred within a different healthcare system (Canada), Kryworuchko et al (2016) noted that the impact of not having time to move communication forward with families who may not agree with treatment plans coalesced with nurses' lack of experience and skill. However, it is interesting to note that within the system observed end-of-life care was not given parity with life-sustaining treatment. In contrast with this study, where there is a strong sense from all participants of the desire to create and find time to engage, Kryworuchko et al (2016) concluded that time was not considered to be a priority to proactively engage with patients and families who were at or near the end-of-life, with death being considered 'a failure'. Therefore, it could be surmised that due to this paradigm of thought the opportunity to engage in a meaningful, supportive, and purposeful conversation with the dying and their families would be lost.

The analysis of the data has highlighted that participants in this study are undertaking multiple, complex interactions with the dying and the grieving. Resources are internally sourced, as evidenced through participants' abilities and desire to determine the context, complexity and dynamics that exist within the familial or relational group. Whilst doing so participants specifically situate themselves in these interactions and conversations, thereby attempting to positively affect experience through communication and develop meaningful yet timebound relationships that are supportive in nature. These microprocesses are both unconscious and conscious in nature, and their state is predicated upon the experience and knowledge of the participants.

In addition, the external resources available to the participants is not a constant and can impact on their ability to manage the expectations of families through conversation, whether that is in relation to the actual process of dying and acceptance of death, to more practical needs and wants. The recognition that the opportunity to support and care for families in the right way is not something that can be repeated (one chance to get it right) is itself a stressor.

The ability of participants to be able to meet the needs of the dying is a key determinant in their belief of whether a ‘good death’ is achieved, or not. However, within the context of this study, speaking with the dying patient and understanding their wants is of vital importance, although in some situations it is recognised this is not possible due to patients’ inability to physically communicate. At this stage, the process of advocating for patients is undertaken as part of nursing dialogue with families and other healthcare professionals.

The participants in this study make instinctual and ever-changing decisions through a series of social structural and psychological processes relating to the prioritisation of time, attention, and effort, to meet not only the needs of the grieving but all other patients and relations in their care. These external factors jostle against internalised desires to successfully support the dying and the grieving at such a critical time of life and death.

This research study offers that the intricacies of multiple microprocesses being performed by nurses who are working in acute ward settings has not been clearly explained previously and adds to the contribution of knowledge. The following section of findings will now consider the impact that engaging in such processes has on them in greater detail and introduces the continuum on which the nurses find themselves travelling.

4.7. Becoming Lost – ‘*that’s the sad part, that we should consistently be getting it right’*

4.7.1. Feeling emotionally drained

As has been referenced earlier, the participants in this study are navigating multiple journeys, with differing start and end points. For some of the participants there are multiple patients and families who are at different points on their paths and walking beside all can lead to a sense of feeling emotionally drained. This was the first subcategory of ‘becoming lost’ constructed from the data.

> *‘…erm, well it’s exhausting. I think these things are, you know……and like I say experiences you think go well, and actually don’t, erm, sometimes when you get bereavement feedback, and you think, ‘no’…’ (Participant 10b)*
>
> *‘…and it will upset you, because we are all human beings, so when someone’s having an attack on you…..it becomes really hard then because, you know, it emotionally hurts you…’ (Participant 9b)*

For one participant the emotional burden of causing distress to families was something that they battled with, and the impact that it had on them earlier in their career caused them to feel emotionally drained by not being able to separate self (as noted earlier) from the situation they found themselves in.

> *'…yeah, I remember it being a bit too frequent at one point, and part of the reason I left was because I was so young and wasn't able to separate myself from, erm, what was going on…' (Participant 3c)*

When exploring this concept with them further, despite having moved into a different specialty, the impact of those earlier experiences still affected their ability to enter conversations with the dying or families:

> *'…so I think that still now, a little bit older now, I still struggle to have conversations like that I know that are going to cause or upset someone…' (Participant 3c)*

4.7.2. Feeling a failure

As has been mentioned earlier, achieving a 'good death' is something that was a key driver for staff when walking the path with the grieving. However, when it was perceived that they had failed to achieve a 'good death' the data evidenced how this subcategory of becoming lost was a key emotional stressor and something which impacted upon them personally and professionally. This led to a sense of feeling a failure. A key aspect of this subcategory was participants' grieving for poor experiences.

> *'…so, I won't forget that, I won't forget the daughter that came here that I had to sit with and meet and was furious…' (Participant 6b)*
>
> *'…so all they can see is their memory of their agitated Mum, that's all they see, and they're still so upset by it, which I understand, completely...' (Participant 9b)*

The sense of feeling a failure was not only in relation to those interactions which the participant above was personally involved with, but the sense of responsibility and associated failure was keenly felt when working in a position of authority and responsibility. Other participants also referenced the requirement to manage situations when the actions of others impacted on the grieving process and how this further compounded the sense of failure.

> *'…I just thought nobody should see that, there's no reason for it, because as soon as she told him, the other sister came in at 5 o'clock in the morning and told this nurse that actually she was going to be a formal complaint in with his name on it, he went and got some [pain relief] from another ward. So there was no need for it, there was no need for that patient to…and I can't bear the thought of a patient suffering on my ward...' (Participant 9b)*

> *'…sometimes because, and sometimes I feel really angry if I see this letter of complaint. Especially when I, err, if things don't go well you can't help but feel it's a reflection of something you haven't done right as the [ward] sister...' (Participant 6b)*

4.7.3. Being thrown in the deep end

Participants keenly sensed the impact that not achieving a 'good death' had on the grieving, which subsequently impacted their own grief, leading to feelings of embarrassment, panic, shock, and trauma. Some participants were unable to share these experiences of perceived failure when they occurred and would internalise them, subsequently leading to the third subcategory of becoming lost – being thrown in the deep end.

> *'…how can I explain that I was so much mentally stressed on that shift…..[I] have to reach the expectation…..so that moment sometimes when I have bad days, I don't want even to come back to my shift...' (Participant 1a)*

> *'…God, it's really hard to explain, as I say, just being thrown in the deep end sort of…' (Participant 7b)*

> *'…should I tell her? Was I not to tell her? I wasn't quite sure and whether I should keep telling her…' (Participant 3c)*

The data evidenced participants entering a state of being thrown in the deep end as a social psychological problem of having insufficient internal resources to manage a challenging situation, which subsequently caused them to question their actions and interactions. The then led to a developing sense of feeling unprepared and conflicted in knowing what the right thing was to say or do, with an accompanying sense of being along, and not being supported.

4.7.4. Feeling the pressure

As these internalised psychological processes continued, a construction of the heightened and overwhelming sensitivity of feeling the pressure became clear. The demand to manage conversations and deliver care within the context of a time-pressurised environment was shown to be an increasing stressor, with the realisation that having one chance to get the communication right was an additional layer of pressure keenly felt.

> *'…so as a nurse I had to facilitate it [the conversation] because, of course, who else will do it?....or sometimes when I am being asked 'oh can you speak to this family' when, you know, um I wasn't the one looking after that patient but because I was the ward sister…' (Participant 2a)*

> *‘…I am very aware there’s only one opportunity to get end of life care right. There’s no rerun so if we, if we don’t get it right and we haven’t on all occasions there’s nothing you can do, you know…you can’t do that again...’ (Participant 6b)*

> *‘…it is difficult, especially if we’re short staffed and we have more than our usual quota of patients. Erm, it is hard to make sure that you’re giving those people the attention and the support that they need, whilst looking after all your other patients…’ (Participant 7b)*

> *‘…we are running around like headless chickens...’ (Participant 8b)*

As the participants continued to feel the pressure of time, competing priorities, whilst attempting to meet the needs of the dying and the grieving, yet not feeling able to do so, from the data the sense of frustration developed**.** These frustrations were both externally and internally focussed. External frustrations focussed on ‘others’, whether they were ‘other’ nurses not reaching an expected standard, medical staff not communicating well, or a sense of wanting ‘others’ to also feel a sense of responsibility in providing a good experience. I

> *‘...that’s with nurses and with doctors, and you see some people rush [the conversation] and you know that’s really, has a bad, a bad outcome, because then the relatives or the patient are anxious…’ (Participant 10b)*

> *‘...sometimes it’s just too much, you know, they can’t just be passing everything on to me, when they could have done it themselves. Because sometimes what happens, there’s a difficult patient or a difficult relative, and they pass it on to you, when actually they could have probably walked the extra mile and tried to sort it out themselves, so yeah...’ (Participant 2a)*

> *‘…I don’t know if it’s, quite often you end up sort of interjecting a little bit [with doctors], and making sure that the message is really getting through…..It just makes me feel a little, it probably makes me feel a little frustrated, because I can see on the family’s faces they are so, they’re confused at that point...’ (Participant 9b)*

In addition, data have shown how the impact of having to manage post communicative work when a desired outcome has not been achieved for the family is clearly identified amongst participants. The energy and ongoing interactions required to continue to support the bereaved through the raising of concerns was recognised and shared as a key frustration, and also a sense of grief that things had not gone well.

> *'…writing a letter of apology takes you the whole day, and while you're writing it you're feeling sorry and angry...' (Participant 6b)*

4.7.5. Becoming Lost (Suffering Silently)

Whilst these external frustrations at others were being experienced by the participants, internalised frustrations became clear. These inwardly focussed frustrations ultimately coalesced into a sense of wishing to be better. These sensations and emotions were further compounded by a sense of not feeling supported, despite wishing for resources to be made available to them. The sense of personal and professional ownership identified within participants' accounts became more crystallised through the analytic process, and an overwhelming sense of suffering silently emerged.

> *'…quite a few times we have given IV fluids on a patient who is end of life….it's like we are in the middle…..then comes a doctor who comes and prescribes a bag of fluid. So we are telling family we can't do it because this is the…..we are not supposed to do it because that is what end of life is. Because obviously that person is dying, erm, he is not going to drink much…..and IV fluid is going to just prolong the things, painful, it will be more painful for the patient, yeah. So it becomes like us being like, err, like a football…' (Participant 1a)*

As can be seen from this one account above, feelings of blame for potentially prolonging a patient's death are evident, through their deferral to other clinicians' decision-making, with a palpable sense of suffering by the participant. Despite a sense of knowing what the right thing was to do, the passivity of 'being a football' effectively precluded them from being able to advocate effectively, or to navigate the journey for the family successfully. This was also identified by other participants who had more experience in nursing.

> *'…it can be obviously difficult because the doctors are more qualified medically than, a lot more qualified medically than nurses…' (Participant 7b)*

For other participants the inability to be able to predict an outcome for families was a particular source of worry, as this could often lead to difficult and challenging conversations. For some participants undertaking more challenging conversations was burdensome and impactful for them, leading them to a sense of becoming lost and associated sense of suffering.

> *'…the inability of being to be able to see when people are going to die. I think that's the only thing. I wish we could, wish we could know. That's the question, 'how long?', that's the classic. I'd like to be able to give people a bit more of a time frame…' (Participant 8b)*

> *'…I don't like sitting in front of a family that we haven't delivered good care to. I'm embarrassed…I feel that sort of epic fail thing when people are really upset if we haven't done something...' (Participant 6b)*

Participants recognised that the support offered to them in times of managing complex conversations and not achieving a desired outcome was not always recognised, let alone offered, which further compounded the feelings of loneliness. The sense of becoming lost was more keenly felt when available resources were perceived as not being there.

> *'…I think that there is a lack of support…..I think when you come in, come to be a nurse, I think you're possibly expected that this is just part of the job, and actually I don't really know whether that's how it should be perceived, that it's just part of the job…' (Participant 3c)*
>
> *'…we don't have, we don't have any sort of, I don't know what you'd call it, reflective feedback session, after someone dies, no...' (Participant 6b)*
>
> *'…there's nothing formal in place staff can access to gain immediate support and guidance after a distressing event, either within or outside the context of end of life…' (Participant 4b)*
>
> *'…if that initial experience [end of life conversation] is bad we lose nurses quite commonly, erm because they haven't felt supported, you know, during that phase...' (Participant 11d)*

As seen above, for nurses to become lost was multifactorial and led to participants moving along a continuum towards the social psychological problem of suffering silently. The sense of responsibility, which could not be shared, and being unable to achieve the best possible outcome for patients and families is heavily borne. Suffering silently is also compounded by participants' attempts to find solutions to minimise the frustrations with systems, processes and individuals not aligning to the same sense of direction and purpose.

In contrast to the findings above, the following section of analysis outlines how participants were positively impacted by the successful management of complex communication and ability to lead the way for the dying and the grieving with a greater sense of confidence and purpose.

4.8. Leading the Way – ‘*Because sometimes you don’t even have to do anything, other than show you care.*’

For the participants in this study, when the social structural processes were in place to access sufficient resources, the analysis of the data the category of leading the way for the dying and the grieving through meaningful and supportive communication was evidenced. Through the social structural processes required when leading the way positive feelings and beliefs were experienced, which included the sense of becoming and being confident, experienced, and satisfied. However, the data also showed preparatory conscious and unconscious microprocesses being undertaken which underpinned the possibility of these feelings to develop. The microprocesses included the acts of preparing self, preparing the team, and ensuring sufficient protections were in place to minimise harm to self and subsequent negative feelings.

4.8.1. Being confident

Being confident was the first subcategory of leading the way constructed from the data. This confidence was shown through participants’ active engagement in supportive yet sometimes challenging conversations with patients or families, directed by a purpose to provide information, advocacy, and support for those travelling along their respective paths. Concerns or issues were addressed with sensitivity and understanding.

> *'…I'm more confident now than I was four years ago, and I feel like I would be able to sit down and have a conversation, you know, those difficult conversations with family, so yeah…' (Participant 7b)*

> *'…I feel more confident, I know what I'm talking about…..it's just knowing what you're talking about, and understanding what you're talking about, and it's as I say, trying to talk to the people, talk to the families, as if they were my family…' (Participant 8b)*

4.8.2. Being experienced

Alongside being confident participants had a clear sense of being experienced. Whilst this may appear to be an obvious partnering subcategory, it is recognised that a misplaced sense of confidence without the associated experience can lead to issues in the management of complex situations. The participants in this study noted how their experiences, and being able to learn from them, moved them from a position of feeling experienced to knowing and being experienced, which subsequently enhanced their understanding their own confidence.

> *'…because of the, having the background of having worked in stroke then for about twelve years or so, and had conversations….around supportive care and end of life…..alongside consultants…. it was a conversation I could have…' (Participant 11d)*

> *'…I think it's about, it's the phrases that you use and the way that you talk to people, and the way that you listen to people, and I think that's all gained through experience…' (Participant 7b)*

For two of the participants the sense of being experienced moved them to a heightened sense of awareness of potential situations that would require earlier interventions for patients or families, as evidenced below:

> *‘…I do use intuition. You know, there have been times in my career where I’ve noticed patients who have started to become disinterested, aren’t speaking as much, and I’ve just known that things are getting worse. So, I’ve started those conversations with families that things may be starting to decline…’ (Participant 4b)*

> *‘…I think sometimes you have a, and I don’t know where it comes from necessarily, but sometimes you have that innate sixth sense, erm, to be able to manage those situations…’ (Participant 5b)*

When this was explored with the participant further it was noted that the level of experience gained over the years provided a sense of confidence in understanding the subtle changes in patients that may indicate a potential end of life scenario – stemming from a position of being confident through being assured by their own experience.

> *‘…I think there is a huge part, I have on more than one occasion gone to the doctor ‘you need to make sure her pain’s ok, because she’s going to die today’, there is something, and they’ll say ‘no, she isn’t’ and there’ll be something about her, if you pick up a look, a colour, a what…’ (Participant 5b)*

4.8.3. Guiding

The combination of being confident and experienced supported the participants to embody the process and role of guiding. This subcategory included values and behaviours focussed on a relentless sense of honesty in communication, a passion for delivering high quality end-of-life care, whilst being present with the patient and their family.

The combination of these social structural and psychological processes provided the participants with the sense of having a holistic approach in their interactions. The strength of these values and behaviours created an identity of becoming and being the guide, enabling them to lead the way confidently.

> *'…the lady was thankful to me for being honest at the time…' (Participant 11d)*
>
> *'…so first listen and depending on what, you know, they tell you, then you respond as honestly as you can…' (Participant 2a)*
>
> *'…start sensitively and see how you go, so I suppose that would be one of the main things, it's sensitivity…' (Participant 6b)*
>
> *'…I feel like, I do feel quite passionate about end of life care, erm, and I think that I would…..I'd really make an effort to promote, promote good end of life care, so I think that's how it's shaped me…' (Participant 10b)*
>
> *'...actually, it just comes back down to your basic, compassionate, human, it's not even a nursing skill, it's a human interaction isn't it?...' (Participant 9b)*

From the analysis of the data practical microprocesses were identified that participants went through as they entered conversations with the dying and the grieving, and for them to lead the way confidently. The two key microprocesses or tasks which emerged were identified as Preparing Self and Protecting Self.

4.8.3.1. Preparing self

Participants began the process of preparing self to become mentally flexible to accept any reactions from either the dying or the grieving. This allowed them to be nimbler and subsequently more accommodating in their responses to emotions and sometimes very acute grief.

> *‘…also expect, expect different reactions, so they’re never the same. Erm, and kind of be prepared for all, all reactions…’ (Participant 10b)*

> *‘…be prepared for the unexpected, don’t expect the response, don’t expect the response you expect…..don’t expect them to burst into tears and cry, because actually that might not be the case. Don’t expect them to be angry because that might not also be the case. So, deal with what comes at you, erm, rather than go in with, erm, any preconceived expectations...’ (Participant 5b)*

For other participants when preparing self, the focus was more on whether a plan for the conversation was required, or whether there should be a greater internal focus to prepare for what may come. What is evidenced from the data is that these individualised microprocesses were borne from previous experience, whether positive or negative. For some participants the preparation focussed more on content, whilst for others it focussed more on knowing who would be involved in the conversation.

> *‘…I think it’s that preparing. I don’t think you can prepare the conversation you can only prepare yourself for the conversation...’ (Participant 3c)*

> *‘…I think having your conversation planned, as to what you want to say and how you need to say it is probably really important, because you need to feel confident…..believe in what you’re saying…’ (Participant 9b)*

> *‘…just go in prepared, because they’re obviously going to ask you questions that you won’t anticipate, but just going in prepared, knowing what your options are...’ (Participant 7b)*

> *'…it's getting to know that person before you, if you can, before those, you end up having those conversations…' (Participant 11d)*

4.8.3.2. Protecting self

The second microprocess enacted by the participants was coded as protecting self, as an internalised action taken post conversation to segregate the intensity and periods of communication whilst also managing the 'busyness' and competing priorities within the acute ward environment. Protecting self included being able to empathise and situate self during the conversation, then move away from the situation to be functional as a nurse with responsibilities for several patients, a ward team, or a series of ward areas.

> *'…but then I have to just walk away for a few minutes and have to compose myself, I can't do this, I can't do this at all, you know, I can't be weepy. Because at that point we are the, we are the one who are going to support them, so we can't be the weak links, you know…' (Participant 1a)*

> *'…I feel like you learn to obviously detach yourself from situations as well, but not, not show that you're detached at the time, but you can't take all of your experiences home with you…' (Participant 10b)*

> *'…I think as well the next day you come in there's a whole new day of new challenges…' (Participant 6b)*

> *'…you can be the sounding board, and you can listen, and you can be, but if you took every person's thought and feeling, and actually took it in, you wouldn't be able to function as a human, so it is about allowing them to have that to do it, but not taking it personally, so having a professional…barrier's the wrong word but a professional shield that people can't see because you're still that loving, caring person, but equally you still need to be able to function and go on to the next thing…' (Participant 9b)*

As the data have shown, participants were protecting self to function professionally and personally, and combining this microprocess with preparing self, it allowed them to continue leading the way effectively, and with compassion and humility. This forms a further understanding of the post conversation work that is required by all participants in order to move forward and compartmentalise where possible. The intensity of the interaction with the dying and the grieving is recognised as a key challenge; however, it is proposed that the post conversation work of then protecting self to enable care to be provided to others is not something noted elsewhere.

4.8.4. Feeling Satisfied

The successful application of these microprocesses by participants, alongside the recognition of developing confidence and experience, culminated in the final subcategory becoming clear, that of feeling satisfied. The sense of satisfaction was rooted in knowing that others had been supported at such a critical time in their journey.

> *‘…if we’ve got it right on the ward and the patient’s happy, and they’ve died with dignity, and the family are happy, I get great comfort from knowing we’ve got things right. I’m very proud of the ward...’ (Participant 6b)*
>
> *‘…I think she felt more comfortable around, with us, as well, which was nice, it’s always nice when they feel that they can build relationships with us, because we’re doing, we’re looking after someone really important to them…’ (Participant 7b)*
>
> *‘…so for me I think giving end of life care and supporting families is a privilege, it really is…’ (Participant 9b)*

4.8.5. Leading the Way (Reconstructing Meaning)

From the analysis of the data, the impact of internalised microprocesses being engaged with fully and by using the available social structural processes in place to support participants communicate effectively, it is evidenced how they moved along the continuum towards a reconstruction of meaning from the journeys taken with the dying and the grieving. Reconstructing meaning as a positive social psychological process required participants to begin reflecting on journeys taken as a method of exploration and learning. Further detail of reflecting on journeys taken is shared in the next section of this chapter.

Extant research supports the findings identified within this section of analysis. Hopkinson et al (2003) note in their study that the impact of caring for the dying changed and was unique to everyone. Whilst this study did not focus on communication alone, it did recognise the balance between 'tensions' and 'anti-tensions', which align to the categories identified in this study as 'becoming lost' and 'leading the way' respectively. Tensions aligned to feelings of guilt, frustration, and anger, with an example given of having to choose what time would be given to other patients or the one that was dying. This reflected the intensity of how the nurses felt in their study, similarly to the feelings shared in this study.

In Hopkinson et al's (2005) subsequent study, which considered how nurses coped with caring for dying people, a model of how anti-tensions formed a 'translucent web' to support nurses through the experience of caring for a dying person was theorised. It is interesting to note the reference to translucence, as in this study the unconscious and conscious states of internalised microprocesses has been evidenced as a way in which participants have used psychological and structural strategies to prepare and protect themselves both prior to, and following, conversations.

Similarly, Thompson et al (2006), in their grounded theory study exploring nurses' perceptions about the quality end-of-life care on an acute medical ward, identified the challenges of attempting to deliver high-quality care whilst being required to manage multiple competing priorities. In contrast to Hopkinson et al's (2005) study, more practical aspects of being able to 'create a haven for safe passage' were identified as the key social processes being enacted by study participants. Within this context it was identified that changing the rules and focussing on families being cognisant of a patient's prognosis were the key determinants of 'being there' for patients and families, and an enabler to good communication, which was similarly found in this study. In contrast to this study, 'getting what's needed' was also a primary requirement so that care could be provided to the standard expected – however, it is recognised that this study has focussed on communication, whereas Hopkinson et al's (2005) study encompassed all aspects of care delivery at the end-of-life.

Within this study, whilst some of the participants entered a state of 'becoming lost' when they were not fully advocating for the patient, the philosophy of palliative care was not seen to be a key barrier to high quality care delivery as noted by Thompson et al (2006). However, it is recognised that the context of Thompson et al's (2006) study was set in Canada, which as noted earlier in this chapter, evidences a culture in which palliation is not consistently considered to have as great an importance as curative approaches to care.

Set in a different cultural context (Hong Kong), Mak et al (2013) noted the dissatisfaction of nurses not being able to be more closely involved with dying patients and their families, due to inflexible hospital policies. This led them to be more distant in the act of caring. Whilst this finding is not reflected in this study, similarities do exist in how participants gained a sense of satisfaction when they were able to undertake high quality care for the dying and their families, and the opportunity to enhance learning for other colleagues (Mak et al, 2013).

In summary, this section of analysis evidences the different impacts on nurses when they have end-of-life conversations. These impacts can be either negative (becoming lost) or positive (leading the way). The determination of the impact is dependent upon multiple factors, which are either generated by the participants themselves, through embedded feelings and thoughts which stem from previous experience, or the perceived availability of required resources in the 'here and now'. The combination of past, present, and future coalesce in these time-limited conversations and interactions, with the underlying recognition that there is only one opportunity to enter this space.

The following section of analysis provides a deeper exploration into the opportunities participants have to reflect on their experiences of communication with patients or families at, or near, the end-of-life. Reflecting on journeys taken is the key category co-constructed from the data that offered participants a window through which they could recognise the conditions which affected them in their practise. This process impacted their own sense of success, or failure, in navigating the journey with patients and those close to them – allowing them an opportunity to move along the continuum of quiet grief from suffering silently towards reconstructing meaning. However, it is important to note that this was not always achieved.

4.9. Reflecting on journey taken

Reflecting on journeys taken is a key social psychological process either undertaken alone or with others. Whilst not identified by participants as 'clinical supervision', experience was shared when and how they would reflect on interactions in that moment or take an opportunity to share experience with team members. This professional and personal journey was initially identified from the data as the process through which individuals recognised themselves as becoming personally reflective.

4.9.1. Becoming personally reflective

For some of the participants, and as evidenced in the data, the opportunity to reflect on their own practice was valued, to learn from experiences and to gain a sense of where there were opportunities for change. For one participant it was recognised that it was important to consider how to reflect and adapt to different circumstances.

> *'…because we tend to do these things in quite isolated conversations with just the relative or with the patient and the only feedback we might get is from them….our communication style, we can adjust can't we?...' (Participant 11d)*

For another participant the opportunity to reflect on situations that hadn't gone as well allowed them to consider whether, at times, others should be involved in leading communication with patients or families.

> *'…I suppose that would be one of the main things, it's sensitivity. Emotional intelligence to know whether you should be carrying on or is that person really not engaging, and even am I the right person to have that conversation?...' (Participant 6b)*

From the data a subcategory of reflecting on journeys taken was co-constructed from participants' accounts, which focussed on how the participants developed a deeper sense of their own emotions, and the potential impact these could have when entering conversations with the dying or the grieving.

4.9.2. Being aware of own emotions

Participants' self-awareness was heightened when reflecting on previous experiences, often with associated feelings of sadness of how their own emotions and frustrations could be received or witnessed by family members. For others it was the sense of attachment and grief which was linked to the patients who were cared for by the team for longer periods of time.

> *'…I always, I always feel really sad because I get quite emotional and I get quite, erm, attached to our patients…' (Participant 7b)*

> *'…I just walked away once and I was just crying in the loo, because I couldn't see that, but then later on, you know, I have to just come out of that toilet…' (Participant 1a)*

For most of the participants, it was recognised that the opportunity to speak with others was a huge benefit to address grief and suffering, and something which allowed the participants to decompress and continue with their professional roles.

> *‘…I’m definitely a ‘problem shared problem halved’ kind of person, so after that just letting it off, having a chat with someone and then realising ‘ok so that went alright’ and then you can move on to the next. Because when you do work on the ward it is too busy spend the rest of the day feeling sad about the situation in the morning, so you’ve got to find a way of being able to put that there, and then revisiting it at another time…’ (Participant 3c)*

> *‘…I would go to say the other Band 6’s or some of the Band 5’s that I’d known well, and sometimes you just, erm, like reflect don’t you, or just have a little informal chat, to kind of, I don’t know, debrief I suppose…’ (Participant 10b)*

> *‘…so it’s things like when we sit in the staff room, you might over, when you’re having your cup of tea or your lunch, you might, you will talk about things sometime…’ (Participants 7b)*

From the data, whilst there was no indication of a formalised process where or when this occurred, the more informal processes of talking things through was conceptualised from the data as ‘debriefing with others’.

4.9.3. Debriefing with others

As part of the analytic process, participants’ accounts highlighted a desire to seek ways in which their practice could improve and change. For those in roles of responsibility the importance of influencing others through learning and sharing incidences and experiences was recognised. Multiple ways of undertaking these interactions with the teams or with peers emerged from the data and an appreciation of how others would reflect on situations in their own way was key.

> *‘…getting each other’s perspective is often quite good to share perspectives rather than just get caught up in your own thoughts and feelings...’ (Participants 11d)*

> *‘…actually the staff deal with it differently and its allowing those staff to deal with it in a way that’s right for them, and not expecting everybody to deal with it in the same way...’ (Participant 5b)*

For the last participant, the process of debriefing with others also opened an opportunity to reassure staff who may be harbouring a sense of feeling a failure or pressurised. This was achieved by providing reassurance and offering ways in which they could minimise self-blame and doubt, thereby easing suffering.

> *‘…it’s actually making sure that you feed back to them from mortality reviews. It’s making sure that they know that they didn’t do anything wrong…..but it’s letting them know that you’re there for them and that actually whatever they need isn’t too stupid…’ (Participant 5b)*

> *‘…to reassure someone and do that reflection with them, to realise that they’ve done a good job and what could they do even better next time, or what, you know, I feel like I’ve probably influenced a few people in that way…’ (Participant 10b)*

However, for other participants the focus was on ensuring that where learning had been identified a core responsibility was to share both positive feedback and poor experience and to work with the team to improve, through debrief and open communication, whether formally or informally.

> *‘…I would definitely speak to my junior ward sisters about things that we haven’t done so well, and can we please work better at that…..I very much try and share the good things though as well…..I always try and leave the team on an upbeat feedback…’ (Participant 6b)*

In summary, this section of analysis provides an insight into how participants in this study undertake the social psychological process of reflecting on journeys taken, as a way to learn more about their own reactions and emotions and enhancing their own self-awareness. In addition, for some of the participants this became a more social structural process of debriefing with others to provide an opportunity for shared learning, and to minimise potential social psychological problems which may be developing for colleagues when concerns were perceived to have been raised.

4.10. Conclusion

This chapter has presented the analysis of the findings of participants' experiences of navigating the journey at the end of life through communication. Two distinct ways in which participants communicate have been co-constructed from the data, which are walking the path with the dying and walking the path with the grieving.

The impact of engaging in these dialogic processes, which are emotionally laden and complex, leaves participants in a state of grief; however, this is a state that is shielded from those that are cared for – identified as grieving quietly. The conditions which affect participants ability to traverse a continuum towards either the social psychological process of reconstructing meaning, or the social psychological problem of suffering silently are predicated on participants' access to sufficient internal and external resources to provide the level of care and support needed.

The most important of these resources has been identified as time, with participants sharing how they use both conscious and unconscious microprocesses to mitigate ongoing and diverse risks to delivering the best care possible for the dying and the grieving.

5. CHAPTER 5 - DISCUSSION

5.1. Introduction

In this chapter the substantive theory of Navigating the Journey (Grieving Quietly), developed as a co-constructed interpretation of how nurses manage the impact of undertaking end-of-life conversations in the acute general (non-specialist) inpatient ward setting, is considered against extant theories and academic literature. As with all proposed grounded theory studies, its place must be found within such contexts (Charmaz, 2014).

Part of the process of developing the theory as part of GTM, specifically adopting a constructivist approach (CGT), supports the integration of relevant findings from the extant literature, which are aligned to the subject area into the research findings, to illustrate how the proposed theory is relevant in today’s healthcare setting. The impact of Covid19 and the volume and complexity of end-of-life situations that have been encountered by NHS staff over the past two years, is unprecedented and cannot be underestimated. Now more than ever, it is beholden upon employers, policy makers and educators to give credence to the impact that managing multiple complex conversations with the dying and the grieving can have on our healthcare workers, and particularly nurses.

However, to progress the relevance of the substantive theory itself it is important that other theories and models are presented so that the research findings and theoretical position can be situated more clearly. The following section details both similarities and divergences between the proposed substantive theory of Navigating the Journey (Grieving Quietly) and other chosen relevant theories, identifying where new knowledge is proposed as being found. A further comprehensive literature search was conducted when the developed theory was co-constructed during the constant comparative analytic process, yet no substantive theories specifically related to the impact of end-of-life conversations on nurses working in adult general wards were found. However, theories were identified which reflected important properties and dimensions in keeping with elements of the developed substantive theory. The following theories and models were recognised as partly aligning to the newly co-created substantive theory, best supported many of the findings, and are:

- Humanising Nursing Communication Theory (Duldt-Battey, 2004)
- A Model of Health Professionals' Grieving Process (Papadatou, 2000)
- Dual Process model of coping with bereavement (Stroebe & Schut, 1999, 2010), involving the concept of Disenfranchised Grief (Doka, 1989)
- Theory of Human Caring (Watson, 1988, 1997, 2005)

In addition, one paper identified as part of the comprehensive literature review proposed a theory to support nurses, relating to coping with end-of-life care within the acute general setting (Hopkinson et al, 2005) 'The Theory of the translucent web'. Therefore, this chapter will synthesise the findings of these models and theories with the proposed substantive theory so that its value and contribution to knowledge and the existing body of research is justified. A synthesis of the extant literature will also be compared against the proposed substantive theory so that new knowledge identified in this area is offered.

5.2. Comparison of Navigating the Journey (Grieving Quietly) with other models and theories

A systematic literature review, which was presented in Chapter 2, highlighting both the convergence of findings and gaps in knowledge, was repeated following the development of the substantive theory during the analytic process. Only one proposed theory was closely aligned to the topic studied (Hopkinson et al, 2005), although it is recognised that this theory focusses on all aspects of caring for the dying in acute hospital wards rather than communication alone.

Following the conclusion of this literature review, a comprehensive literature was undertaken which focussed on communication theories, nursing theories and grief theories. A subsequent review was undertaken as part of the constant comparative approach, against the findings of the proposed substantive theory, and the synthesis of the findings are presented below.

5.2.1. Comparison of the substantive theory of Navigating the Journey (Grieving Quietly) with Hopkinson et al's (2005) theory of 'The translucent web of support'

Hopkinson et al (2005) offer a theory of a 'translucent web of support' to understand how nurses cope when working with the dying in acute hospital wards. The theory focusses on how nurses enter relationships with the dying and those close to them in order gain a shared understanding of experience. It is noted in their study that techniques used by nurses include preparation for information giving and receiving, thereby taking action to shape outcomes that minimise distress to self.

Furthermore, it is reported that learning from experience and controlling the level of involvement is key to further minimise distress that could impact on patient care. The concept of ‘anti-tensions’ (Hopkinson et al, 2005) is proposed as a series of directional, situational, dynamic, and translucent actions that nurses take for them to cope with caring for the dying. As such, the theory developed is predicated by the Cognitive-Motivational-Relational Theory of emotion (Lazarus, 1991), which was identified as the transactional theory being refined (Lazarus, 1966). It is noted within the ‘translucent web’ theory that actions are only partially identified as being in a nurse’s awareness, and that they are used in a particular way with each situation with the dying person.

Within the context of this study’s substantive findings, participants were also engaged in a series of actions which were situational, dynamic, and for many, unconscious – akin to ‘translucent’. Indeed, it was noted that it was not until the participants had engaged in the interview process did they note the strategies being used to engage in communication with the dying and the grieving.

Hopkinson et al (2005) note in their theory that participants often imagine themselves or a member of their family in a patient’s position (identified as measuring – one of the actions within the translucent web). For many of the participants in this current study the analytic process identified similar actions being taken, theoretically categorised as Walking in others’ shoes and Situating self. By using these strategies participants were better able to plan the support for the grieving whilst minimising the potential impact on their own grieving process. In alignment with the concept of ‘controlling involvement’ in Hopkinson et al’s (2005) theory, participants in this study were found to be engaged in microprocesses categorised as preparing self and protecting self.

The difference found in this study was that the interdependence between preparation and protection was key. Participants could only fully function in their nursing role if they undertook adequate preparation, minimising negative outcomes with the grieving, and allowing them to use associated protective microprocesses as part of their post conversational work to orient themselves back into the wider context of the ward environment. This sense of being able to balance the intensity of communication whilst caring for others who were recovering from their illness was not fully represented in both studies, and it is proposed that this has been more clearly defined within this thesis. It is also argued that within the context of adult acute general wards, the level of emotional labour and resilience required to successfully achieve such a state has not been considered elsewhere and is a new phenomenon to consider.

5.2.2. Comparison of the substantive theory of Navigating the Journey (Grieving Quietly) with Humanising Nursing Communication Theory (Duldt-Battey, 2004)

Following the initial development of a Humanistic Nursing Communication Theory (Duldt & Giffin, 1985), a position paper was produced which refined the theory with a clearer focus on humanism, nursing, communication, and holistic care (Duldt-Battey, 2004). Hubble et al (2008) note that the Humanising Nursing Communication Theory espouses the importance of interpersonal relationships between nurses and others so that inappropriate outcomes caused by ineffective communication are minimised. Duldt-Battey (2004) postulates that the theory provides '*a benchmark of holistic and humanising theoretical orientation for interpersonal communication between nurses, clients and others which is appropriate in all areas of nursing practice*' (p6). Furthermore, she is clear in confirming that the philosophical underpinnings of this theory moved away from the early humanist and existential philosophies of Sartre and Kierkegaard. Hence the change from Humanistic to Humanising Nursing Communication Theory.

Within the theory it is noted that communication can either lead to a dehumanising outcome, or one that ensures the humanising components of the nurse are shared within the relationship with patients and those close to them. By becoming more aware of the potential for interpersonal influences and communication skills, these can be used in a deliberate fashion to deliver positive results (Duldt-Battey, 2004).

Within the theory, definitions are provided for nursing, with three elements being enshrined as the core concepts: communicating, caring, and coaching. Within the concept of communication ten characteristics are proposed for interpersonal communication, which recognise the dynamic processes undertaken, and the requirement of continual adaptation and adjustments. It is shared that caring evidences a genuine concern about an individual's well-being, and that the provision of nursing care is generated from genuine feelings of concern and responsibility. Finally, the coaching element of nursing is identified as the planning undertaken to support and encourage others to meet identified goals (related to health) (p13).

Duldt-Battey (2004) espouses that interpersonal communication is an existential process that involves the exchange of meanings, and that said meanings include facts and feelings, and occurs through a dialogic process. Within this process there are two dimensions: the first is the attitude by which communication occurs is on a continuum and moves between humanising communication (involving an awareness of the unique characteristics of being human) and dehumanising communication, which ignores these. The second dimension is the pattern of interaction.

It is posited that through interpersonal communication being identified and understood as a process, the humanising aspects of communication will be realised. This position is underpinned by Berlo (1960) when it is stated:

> *'If we accept the concept of process, we view events and relationships as dynamic, ongoing, ever-changing, continuous. When we label something as a process, we also mean that it does not have a beginning, an end, a fixed sequence of events. It is not static, at rest. It is moving. The ingredients within a process interact; each affect all of the others.'*

Within the Humanising Nursing Communication Theory, the 'I-Thou' relationship is defined as being experienced during interpersonal communication through the process of meeting, confronting, and encountering with a genuine commitment to the awareness of the 'other' (Buber, 1970). This is differentiated from the 'I-it' relationship, which evidences a calculated response focussed on strategy, being deceitful and defensive in nature. In support of the Humanising Nursing Communication Theory, Shaver (2002) evidences how patients may suffer a psychospiritual crisis and, as such, the Humanising Nursing Communication Theory proposes that the nurse is best able to support others out of such crises towards wholeness (Duldt-Battey, 2004).

In this study similar aspects of practice to those defined within the Humanising Nursing Communication Theory have been evidenced and extended further. Participants shared multiple examples of how they entered a level of interpersonal communication that was humanising in nature, and went beyond condition, prognosis, and treatment planning. Due to the context within which the participants were situated (end-of-life), the existential nature of 'being human' is proposed as being more likely to be shared, and is indeed evidenced in the findings of the research. This is seen through examples of how communication with the dying and the grieving caused participants to reflect on their own mortality and that of those close to them.

The subcategory of Smoothing the way aligns closely with the 'I-Thou' relationship. The commitment made by the participants to truly understand and, at times, confront the painful experiences of the dying and the grieving, was regularly shown in the data. Specifically, when considering how participants were walking the path with the dying, the potential for psychospiritual crises to occur was illuminated. However, the new knowledge identified within this study was the use of unconscious and conscious social psychological and structural microprocesses to mitigate crises for the grieving or the dying; however, this was at times to their own detriment. When the participants were lost and moved along the continuum of grief towards the social psychological problem of suffering silently, they themselves had started entering a psychospiritual crisis, which had potential lingering effects.

Duldt-Battey's (2004) theoretical findings, specifically relating to humanising communication align with this study's findings. From the data it is shown how participants engaged in a dynamic process requiring continual adjustment and adaptation, using multiple strategies to support a positive outcome, some of which were known to the participants and other were more naturalistic and instinctual. Such processes could only occur as participants became fully aware of the ‘other’ people engaged in the conversations, with much of the detail focussed on meanings, facts, and feelings. Some feelings were acutely felt and elevated by patients and families, which led to participants having to process and manage these in situ, and for others this continued post event. However, by opening themselves to such feelings, it is proposed that the participants were more closely engaged in an ‘I-Thou’ relationship. Moreover, actions being taken by participants were evidenced as humanising in nature as they acknowledged the unique characteristics of ‘being human’ when engaged with the dying and the grieving

The concept of interpersonal communication being a process rather than a ‘thing’ (Berlo, 1960) is particularly relevant to this thesis. As evidenced by the substantive theory proposed in this thesis the act of end-of-life communication is processual as both structural and psychological series of states and interactions, without defined endpoints, are described – the transience of beginning and end is suggested as not being found elsewhere. Participants articulated how they continued to engage in the process of interpersonal communication past the death of the patient – referenced and acknowledged as post-mortem communicative work, requiring comparable levels of resource and energy to engage in. This new knowledge has evidenced how nurses lead others through grief, bereavement and, in some cases, psychospiritual crisis, towards wholeness for longer periods of time than previously considered or evidenced in the literature. Furthermore, it is proposed that such findings have not been described in research undertaken within the context of an acute non-specialist adult ward setting.

5.2.3. Comparison of the substantive theory of Navigating the Journey (Grieving Quietly) with a proposed model of Health Professionals' Grieving Process (Papadatou, 2000)

Papadatou (2000) presents a theory of professional grief based on her work as a clinical psychologist in Greece within paediatric services (Papadatou 1991, 1997), and proposes professional grief as unique, in that it cannot be understood within the context of pre-existing theories of grief. This is due to such theories focussing on the death of a loved one and the associated effect of the internal and external world of those bereaved (Papadatou, 2000). Through transcultural studies in Greece and Hong Kong, and across healthcare settings (Papadatou et al, 2001), a model for understanding how professionals grieve has been developed to support education strategies, and future research.

Firstly, Papadatou (2000) identifies the six major categories in which professionals may exhibit loss. These include: the loss of a close relationship with a specific patient with whom there has been a significant journey; loss due to identifying with the pain of family members; loss of unmet expectations and professional self-image; loss related to the professional's system of beliefs; a trigger of unresolved losses or those which are to come; and the mortality of the professional themselves. The complexity of loss for professionals is further supported by Barnard (1995), when it is shared that entering the intimate space when undertaking palliative care episodes has the potentiality to lead to the ‘undoing’ of the professional themselves.

This position is further supported by Kaplan (2000) when they share their model of caregiver grief, and that the acknowledgement of pain and grief is critical to prevent the risk of ‘burnout’ and the subsequent impact of professionals no longer being able work in the same environment. The concept of ‘burnout’ is explored further by Sabo (2006) in their study which considers compassion fatigue, caused by the combination of burnout and secondary traumatisation that ongoing contact with suffering brings to healthcare professionals. Similarly, within this thesis, the category of suffering silently is presented as a theoretical category encompassing the overwhelming sense of secondary traumatisation of the participants caused by having insufficient resources in place to meet the needs of the grieving and the dying, with associated feelings of failure and guilt.

Papadatou (2000) recognises that the way in which professionals grieve is unique and individual, and that factors which influence this are dependent upon the professionals’ own lifestyle and how that interacts with the workstyle of the unit itself, with spoken and unspoken rules on what is permissible to manage grief therein. It is further postulated that two distinct processes occur, which initially either focus on the loss itself, or avoid/repress grief reactions by moving away from the loss to conserve energy to meet work challenges. This is focussing on the practical tasks, or in some cases dehumanising the patients under care.

When walking the path with the dying, participants engaged in ‘doing the nursing bits’ is perceived as a way in which to communicate with confidence on the practical aspects of care (which are offered as being protective). Similarly, the process of signposting when walking the path with the grieving to situate the family within the healthcare environment was also identified a key social structural process, although this was more dynamic and dependent upon families’ engagement. Interestingly, the process of smoothing the way is constructed from the data as being more exploratory in nature, thereby engaging with the grieving in their planned future loss, whilst preparing themselves for the loss at the same time. It is argued that this has not been evidenced in the literature previously when considering end-life-life conversations being led by adult nurses.

The oscillation between repressing and then experiencing grief allows professionals to create meaning and then transcend the death experience (Papadatou, 2000). The oscillation of processes for the participants in this study allowed them to focus on the loss itself through the lens of the grieving, whilst protecting self from the direct loss with the dying. However, this could only be achieved if the participants had sufficient internal resources to be able to do this – it was not always achieved.

It is noted that the concept of making meaning within Papadatou’s (2000) model in part originates from the work of Nadeau (1998), who describes it as:

> *The social act whereby an actor interprets the stimuli in a setting and represents the situation to himself or herself in symbolic terms.*

For the participants in this study, reconstructing meaning was evidenced as the social psychological process located at one end of a continuum which, if reached, formed part of the reparative process through which the participants learnt from experiences. By doing so, this process enabled them to move beyond the specific event itself and gain a deeper understanding of how to translate the actual events into more symbolic meaning, that would underpin future strategies and microprocesses – many of which would not be consciously employed. It is argued that this finding contributes to new knowledge within the context of end-of-life conversations and the impact on nurses working in adult acute general wards.

Furthermore, it is noted within Papadatou's (2000) theory that the process of making meaning is not only individualistic but also a social event, through involvement with the team. Whilst the premise of a 'death ritual' is not evidenced explicitly within this thesis, it is intimated by the confirmation of the passage of the dying through the unit when debriefing with others. The social bonds that existed for the participants in this study were nearly universally recognised as the social context of the ward team itself, with bonds deepening through the social structural processes of taking time for each other, creating spaces to talk and opening conversations to reflect and learn.

However, when internal resources are overwhelmed, Papadatou (2000) propose a sense of 'stuckness' can occur, which can destabilise the professional. Similarly, within this study the theoretical category of Becoming Lost and the subsequent social psychological problem of Suffering Silently was constructed from participants' experience when there was a perceived lack of internal or external resource available. The similar sense of isolation in not being able to move forward and process events occurred when the final outcomes were not congruent with participants' expectations of achieving a 'good death'.

The data from this study have shown that when walking the path with the dying and walking the path with the grieving, an oscillation of protective measures and focussing on the potential future loss (Papadatou, 2000), through the lens the grieving, occurs. Furthermore, the concepts of reconstructing meaning and suffering silently, as found in this study, align with the premises of making-meaning and 'stuckness' in Papadatou's (2000) model. However, understanding the interdependencies which play across the cyclical feelings of blame, frustration and self-doubt resulting in the social psychological problem of suffering silently, is proposed as being a concept not considered in depth in this theory, and offers new insights into the experiences of those suffering from professional grief.

5.2.4. Comparison of the substantive theory of Navigating the Journey (Grieving Quietly) with the Dual Process model of coping with bereavement (Stroebe & Schut, 1999, 2010)

Influenced by the development of Cognitive Stress Theory (Lazarus & Fokman, 1984) the Dual Process model of coping with bereavement was developed to integrate existing grief theories, whilst introducing a new concept of oscillation between different forms of coping behaviours, those which were loss focussed and those which had a greater restoration-orientation (Buglass, 2010). The purpose of this theory is to describe how people come to terms with the loss of someone close to them. The theory identifies both positive and negative meanings which can be undertaken by an individual as part of their everyday life experience (Stroebe & Schut, 2010).

Aligned to Cognitive Stress Theory it is noted that the oscillation between confrontation versus avoidance of stressors is a key determinant within the theory, and that the movement between positive and negative appraisal and re-appraisal of the loss forms an integral part of the coping process during grief (Stroebe & Schut, 2010).

The dynamic process of oscillation is offered to provide a framework to understand more complicated forms of grief. Such forms of complicated grief have also been identified as 'disenfranchised grief' (Doka 1989, 2002). For those who are not allowed to express their grief, whilst their feelings may be intense, impacts on the ease of access to the resources required for resolving them. It is subsequently proposed that healthcare professionals may experience disenfranchised grief as it would not be considered acceptable to express their emotions in front of the grieving or their colleagues. The lack of acknowledgement of their own loss may subsequently lead to a sense of their own grief becoming complicated and long-standing (Wilson & Kirshbaum, 2011).

Therefore, within Stroebe & Schut's theory (1999, 2010) it is recognised that the oscillation between a focus on the death itself (loss-orientation) and the associated realisation of being unable able to change the outcome, versus the restoration-orientation which focusses on secondary sources of, and coping with, stress must be acknowledged. The substantial changes that occur as a secondary consequence of a death should not be ignored such as impact on finances, employment, and family life. In addition, the central premise of the theory is that the relationship between oscillating and mental and physical health outcomes is clear. Oscillation must occur for people to adjust to their new reality (Stroebe & Schut, 1999), and that it is the movement between confronting the loss and avoiding it that will be of best benefit.

Within the context of this study elements of oscillation are aligned. As with Stroebe & Schut's (1999) and Papadatou's (2000) theories, the participants in this study exhibited activities which oscillated between a focus on the death, albeit through the lens of the grieving, versus strategies to distance themselves from entering a loss-orientation too frequently. The concern for doing so would be that participants would begin feeling emotionally drained, as part of the process of becoming lost.

Furthermore, for the participants who had continued involvement with the newly bereaved, particularly when the perceived standards of care did not achieve a 'good death', staff oscillated towards a restoration-orientation state. However, this was due to secondary stressors, which included the management of complaints and concerns being raised – within the context of being in a professional role, the demands placed on nurses to manage poor experience intra and post-mortem, and the subsequent impact on not having time was shown to be a clear stressor. Subsequently, the data showed how participants would start feeling a failure as part of their ongoing grieving process.

Such feelings were evidenced as leading to a state of disenfranchised grief, not only for the death of the patient, but also for any failures in the management of end-of-life conversations in that instance – the participants experienced situational grief. Indeed, throughout all interactions with the dying and the grieving the constant of grieving quietly is shared across all research sites and for all the participants who contributed to this thesis. Feelings of loss, sadness and emotion are heavily regulated, aligned with the concept of disenfranchised grief (Doka, 1989, 2002). The analysis of the data examined how participants were acutely aware of what was considered acceptable grieving within the context of ‘being a nurse’.

Stroebe & Schut’s (1999, 2001) dual process model of coping with bereavement aligns with this study through an exploration of reactions to loss and bereavement, similar to those experienced by relatives; although it is proposed that it is not the same due to the social structures and norms within which healthcare professionals work. The main processes proposed in Stroebe & Schut’s (1999, 2001) theory are reflected in this study as the process of oscillating between loss and restoration-orientated activities occurs, moving individuals forward in their own grieving process; however, dependent upon the resources available the risk of moving along a continuum of grief to the social psychological problem of suffering silently is not evidenced – again, this is proposed as being unique due to the multiple interactions that nurses have with numerous patients and families. Moreover, the concept of grieving quietly is proposed as the neutral state on the continuum throughout the process of Navigating the journey, as a recognition of complying with social norms and accepted behaviours when working as a nurse with the dying and the grieving. Whilst aligned with the concept of disenfranchised grief, the findings of this study have evidenced how the use of social psychological and structural microprocesses aid nurses along the continuum with the goal of being able to start reconstructing meaning. It is proposed that this has not been evidenced within this model or the extant literature.

The findings of this study more clearly articulate how the depth of exposure with the dying and the grieving may lead to the emotional burden becoming overwhelming, with an associated overfocus on a grieving process which encompasses not only the death but the management of end-of-life care and their conversations, without recourse to turn away. This in turn then leads to the social psychological problem of suffering silently, compounding the process of disenfranchisement, which occurs silently as it is not deemed socially acceptable to share the emotional impact more widely (Doka, 1989). This is offered as new knowledge that has not been explicitly described within the context of adult acute non-specialist wards.

5.2.5. Comparison of the substantive theory of Navigating the Journey (Grieving Quietly) with the Theory of Human Caring (Watson, 1988, 1997, 2005)

The Theory of Human Caring (Watson, 1988, 1997, 2005) provides nurses working in any setting with a framework to enhance professional understanding about the human experience, incorporating aspects of health, illness, quality of life and death. Watson (2006) explores the three main concepts within her theory, which include the ten clinical caritas processes, the transpersonal caring relationship and the caring moment or occasion actualised through a caring consciousness. Further work was undertaken to determine the model of the attending caring nurse within the United States, which proposes to move the ‘being of nursing’ beyond the prescription of nursing practice previously identified (Watson & Foster, 2013).

Originally identified as the ten carative factors as the ‘core of nursing’ (Watson, 1988), the clinical caritas processes evolved to incorporate a spiritual dimension that involves caring beyond the biological domain, underpinned by a clear moral foundation aligned to the centrality of human caring (Watson, 2005). However, caution is given that to use this theory there are ‘*critical, reflective practices that must be continuously questioned and critiqued in order to remain dynamic, flexible, and endlessly self-revising and emergent*’ (Watson, 1997).

To develop a transpersonal caring relationship, the moral commitment and intentionality, combined with the caritas consciousness, allows the nurse to co-create their own meaning for existence, healing, and living and dying (Watson, 2005). It is offered that this focus ensures that the subjective-spiritual significance of the person [patient] will be maintained despite threat or despair, thereby honouring the ‘I-Thou’ relationship, aligning with Dult-Battey’s (2004) Humanising Nursing Communication Theory.

Watson (2002) proposes that nurses must fully embrace their own mortality to cultivate a transpersonal caring relationship with patients and those close them. By doing so the intention which informs the choices and actions allows nurses to become sensitised to what is most meaningful within the work environment. Within this context caring is identified as ensuring a ‘pain free death’, one that is dignified, predicated by an underpinning belief of the spiritual change beyond death (Watson, 2002).

Moreover, it is recognised within this theory that the combination of the uniqueness of the nurse and the 'other' in a human-to-human transaction can create a caring moment, which can be felt by all those involved in the occasion (Watson, 2005).

Participants who participated in this thesis have shared experiences which evidence caring occasions with both the dying and the grieving. From the analysis of their experiences, it is shown how during these caring moments many participants transcended the biological and physical conditions to engage with the dying and the grieving at a more meaningful level, through multiple processes explained within the theoretical categories of walking the path with the dying and walking the path with the grieving. The complexities of these processes are more clearly defined within the analytical dimensions identified as understanding the context, situating self and through the situated internalised process of reconstructing meaning, often realised by reflecting on journeys taken. Whilst the latter process was not always achieved, the intentionality of participants is clearly evidenced from the data.

When walking the path with the dying, participants focussed on supporting a 'good death', which closely aligns to Watson's (2002) consideration of the importance of providing a 'pain free death', and one that was dignified. This was achieved by participants advocating for the patient, with a clarity of purpose underpinning their consideration of the 'other'.

Whilst not explicitly commenting on those close to patients, it is proposed by the researcher that Watson's (2005) tenth caritas '*soul care for self and the one being cared for*' should extend to the grieving. Within the findings of this study, it is evidenced that through the processes of smoothing the way, incorporating nurses' focus on caring for the family, and by walking in other's shoes, participants continued to provide 'soul care' for the grieving. Therefore, it is argued that there is an alignment between the caring caritas processes and the substantive theory presented, and that the substantive theory presented in this thesis moves the Theory of Human Caring forward to incorporate families and those close to patients as part of the wider construct of 'soul care' for others.

Through an evaluation of Watson's (1988, 1997) Theory of Human Caring, the social psychological and structural processes identified above evidence that several of the 'clinical caritas processes' developed by Watson (2005) are found within this study as participants care for the physical, emotional, and spiritual needs of the dying and the grieving. These processes are illustrated throughout the substantive theory of Navigating the Journey (Grieving Quietly) and it is offered that a unique approach to the concept of transpersonal care within the context of end-of-life conversations being managed by nurses has been shared.

5.3. Summary

In summary, this section proposes that upon reviewing and synthesising the key findings from the theories identified above the co-created substantive theory of Navigating the journey (Grieving quietly) contributes to the knowledge and theoretical understanding of how nurses undertake meaningful interpersonal communication to support the dying and the grieving. Navigating the Journey (Grieving Quietly) brings together the key concepts found in the theories identified that enable others to better understand the depth and complexity of the interactions which occur at multiple points when nurses communicate with the dying and the grieving at the end-of-life.

Moreover, the theoretical categories of the co-created substantive theory of Navigating the Journey (Grieving Quietly) are presented as a new contribution to the theoretical understanding of how nurses are impacted when working with patients and those close to them at the end-of-life. It is proposed that the totality of this theory expands the current knowledge available concerning how nurses working in acute adult general (non-specialist) wards grieve following the death of a patient. Moreover, it is posited that within this specific context the impact of being so closely involved in end-of-life conversations, whilst understanding the variety of constraints that are faced by nurses, and explained through the social psychological process of reconstructing meaning or the social psychological problem of suffering silently, has not yet been identified within the current literature.

The following section of this chapter will now explore how the main theoretical categories of the substantive theory of Navigating the Journey (Grieving Quietly) is situated within the context of existing literature.

5.4. Situating the substantive theory and findings within the context of the existing literature

Navigating the Journey (Grieving quietly) provides a conceptual framework and theory to more clearly understand how nurses are impacted by undertaking end-of-life conversations with the dying and the grieving. The findings of this study have highlighted key concepts which allow for a more nuanced and contextualised understanding of how the requirements for internal and external resources can lead nurses to enter either a social psychological process of reconstructing meaning or the social psychological problem of suffering silently.

Within the next section of this chapter, the key theoretical categories which have been co-constructed from the data, using the constant comparative method within a CGT approach, are presented against the synthesis of wider literature.

5.4.1. Navigating the Journey

5.4.1.1. Walking the path with the dying

Walking the path with the dying was the first theoretical category to be co-constructed from the data, which helped to explain how the participants were traversing one of two paths. From the data it became clear that there were three key social processes at play, identified as the dimensions of walking the path with the dying. The first of these was managing the journey, which involved the externalised process of ‘doing the nursing bits’ to situate themselves within the context of the nursing role at, or near, the end of life. The second process, with a greater internalised focus, was described from the data as dealing with different deaths. This was recognised as a more humanistic situation of self, through the identification of human, and sometimes similar, characteristics with the dying that moved the participants beyond mechanistic and task-orientated processes.

Aligned to the experiences of some of the participants in this study, the aspects of nursing practice in ‘doing the nursing bits’ was also identified by Dosser & Kennedy (2012), who noted the importance for nurses of meeting the physical care needs of the patients rather being more focussed on communication. However, for other participants within this study the focus on communication was clear and shared across the research settings.

When managing the journey an alignment to the experiences of nurses interviewed by Kryworuchko et al (2016) were found, where nurses were required to prepare the way for patients, prior to medically led conversations, which focussed more on clinical prognoses. The participants within this thesis were similarly involved in informal conversations that could stray into the realms of prognosis and diagnosis, which were managed carefully, as the authority to act through conversation was not always clear. However, participants shared how they would manage such situations with care and seek support as part of their management processes.

Furthermore, the internalised process of dealing with different deaths is also described by Tornøe et al (2015) and Doka (2014). It is recognised that the impact of working with patients who have similar characteristics to themselves can lead to significant challenges being placed upon nurses’ own internal emotional resources. Where the resources are insufficient such interactions resulted in a failure of the protective mechanisms constructed by nurses to safeguard them from emotional harm. Within the context of this thesis through the analytic process, such challenges are evidenced as having the potential to tip the balance for participants from entering the social psychological process of reconstructing meaning towards the social psychological problem of suffering silently.

The second dimension of walking the path with the dying co-constructed from the data was advocating for the patient. Within the context of an acute ward setting participants shared how they would ensure that the needs and wants of the patients themselves were recognised and supported, seeking clarity for those who may not be able to communicate for themselves. The sense of responsibility to hear the voice of the dying was clear to participants; however, the ability to engage in advocacy behaviours was predicated upon participants' perception of their ability to act with authority.

The concept of lacking confidence is identified as a key constraint on nurses' abilities to advocate for patients, within the context of providing end-of-life care. Caswell et al (2015) noted that for some nurses the lack of confidence in being able to act prevented an opportunity to advocate fully. The inability of nurses to advocate due to the fear of inflaming an emotionally charged situation also impacts on the process of advocacy (Warnock et al, 2017). This aligns with the deep sense of responsibility to the grieving, as well as the dying, the participants shared as part of this study, and the impact this had their capacity in fully advocating for the patient.

The final dimension identified as part of the theoretical category of walking the path with the dying was supporting a 'good death'. A consistent drive was evidenced by all participants to meet the wishes of the dying, which underpinned the concept of a 'good death'. When this was achieved feelings of satisfaction were described by participants as they perceived their delivery of the desired standard of care. By doing so this supported them in being able to begin reconstructing meaning. The concept of a ‘good death’ is recognised to benefit nurses (Costello, 2006), and that this can often be achieved with the development of a relationship with the patient (Casey et al, 2011), leading to a death which is pain-free and private (Cipolletta & Oprandi. 2014). The findings in this thesis have identified how communication barriers can prevent nurses always achieving a ‘good death’ for their patients, which must influence future training programmes for education providers, and policy developments for organisations, to better support healthcare professionals supporting patients at, or very close to, the end-of-life.

5.4.1.2. Walking the path with the grieving

The theoretical category of walking the path with the grieving was the second to be co-constructed from the data. This category offers a theoretical construct to explain the greater level of complexity and the associated skills needed to engage with multiple individuals who are at different stages of their journey through grief. The requirement for the participants to manage how, and when, to engage in conversation, balancing family dynamics and expectations against the needs of the patients themselves was a common experience identified from the data. Often these interactions would occur after the formalised ‘breaking bad news‘ conversation, which had been undertaken by medical professionals or the participants themselves. Such conversations could either lead to a seamless transition of ongoing communication or a journey that was more disjointed, which then required greater ongoing effort to repair.

As explored previously, the first dimension of walking the path with the grieving was identified as smoothing the way. Within this dimension there were clear actions and interactions in play. The first was described as signposting the journey for the families by the participants, providing information that was explanatory about the next stages of the process, and offering supportive solutions through collective decision-making, and acting in an advisory role. The intuitive nature of signposting was recognised as a tool by participants when managing expectations. The breadth and variety of expectations across and within familial groups was seen as a particularly fluid situation for the participants, often balancing more practical requests against highly emotional needs and desires.

Furthermore, the desire to minimise tensions within the family group was clearly conceptualised from the data by the participants actively caring for the family. The emotional tightrope walked was pronounced, evidenced by participants moderating their interactions with the grieving so as not to be perceived as either overbearing or absent. Strategies enacted when caring for the family included devising a staged process of involvement, moderating an innate need to ‘rescue’ during periods of high emotion. Interestingly, such strategies were recognised as having been developed through experience rather than formalised training. The need for nurses to identify how families cope with the dying’s prognosis have been highlighted elsewhere (Peterson et al, 2010a, 2010b), with the difficulties of managing family dynamics clearly articulated as a key area of focus, and sometimes, concern. Furthermore, balancing the needs of both the dying and the grieving is recognised as a challenge for nurses (Boroujeni et al, 2009), highlighting the complexities of working in such an emotionally laden environment.

The second dimension of the category walking the path with the grieving more keenly explored how participants would begin walking in others' shoes, enacting internalised processes to engage in more meaningful conversations with the grieving. Through the process of situating self within the dialogic process, participants could identify in 'real-time' what was important for the grieving, so they could better support them in their journey. By situating self, participants would undertake an objective assessment to determine when and how to communicate sensitively. In tandem participants were also mindful not to adopt a more defensive position when familial grief emotions were heightened, thereby avoiding conflict.

In harmony with this process, when nurses committed to understanding the context for the grieving, it allowed them to predict potential challenges to plans of care, through the acquisition of sensitive and personal information about family dynamics. This enabled participants to re-orient the family to progress along the path collectively. It is recognised that the management of expectations for families can be challenging during the end of life (McCallin, 2011). Through the conscious and unconscious microprocesses of nurses balancing the needs of families against other priorities, it is vital that any process affords a degree of protection to minimise the blurring of boundaries, and the psychological and emotional consequences that may result if this happens (Boroujeni et al, 2009). As can be seen from this thesis, the balance between intimacy and professional distance is challenging, and requires significant emotional and mental effort and control, and it is offered that this is not acknowledged or understood in previous studies; therefore, it is proposed that this study will go some way to correct this gap in knowledge.

5.4.2. Battling Time

The unending struggle with time cannot be underestimated. The third theoretical category of battling time was a constant for all. Time was needed in a variety of ways for the participants involved in this study, whether to have conversations with the dying or the grieving, to process the events which had occurred, to plan for events which were to come, or to meet with others to learn and share together.

Through the cyclical process of noting time and recognising 'busy' as a constant state, wanting time, when the requirements of others appeared to overwhelm the needs of one patient or family, and finding time, when decisions were made to offer what was needed, the consequences of any actions taken were keenly felt. If focussing on end-of-life conversations was given the time that was required participants knew that other aspects of care delivery would suffer, leading to feeling of guilt and remorse. However, the overriding requirement to afford the grieving the time needed to make sense, to seek clarification, and understand what was happening was key to lead the journey to a meaningful conclusion.

The impact of time, or the lack thereof, on developing meaningful relationships during end-of-life care is a common theme (Warnock et al, 2010; Warnock et al, 2017; Caswell et al, 2015; Kerr et al, 2020). Within these studies the lack of time was identified as being specific to either managing conversations over the telephone, the balance between technical tasks and focussing on communication, or the lack of staffing available to release staff to talk. However, it is interesting to note that within the geographical and environmental context of this thesis, compared to the studies reviewed, the participants in this study would consciously sacrifice other aspects of work to find time to speak with the grieving, and acknowledge the implications of this.

Further research is required to determine whether this is specific only to the research sites used as part of this study, recognising most participants worked in medical/care of the elderly environments, or whether this finding is transferable. Should this be the case then hospital leaders should recognise this and ensure that nurses are afforded the level of support required to commit the time required to support the grieving as it is clear there is only one chance to get it right. When this does not go well it is offered that the impact on nurses is multifactorial and complex, requiring significant effort and time for recovery to occur. Without the needed support in place when nurses begin battling time again, time will win.

5.4.3. Becoming Lost (Suffering silently)

The fourth theoretical category developed from the data highlighted the impact on the participants when end-of-life conversation led to an outcome that was challenging. There was a clear sense by participants that a failure in care had occurred, which resulted in distress for the grieving and left participants feeling emotionally drained. In extremis the burden of causing distress to others was evidenced as resulting in nurses leaving their specialty to avoid similar situations in the future. In tandem with causing distress, when participants had not achieved a ’good death’ and had not met the needs and wishes of the dying, this was identified as an emotional stressor.

Such stressors were shown as having a profound impact on participants personally and professionally, leading to an overwhelming sense of feeling a failure. This was particularly prevalent when a death was unexpected, sudden or the attempts to fulfil wishes were not achieved. This was even more pronounced when participants identified themselves as being in positions of authority and responsibility. The acuity of feelings of shock and embarrassment could not always be shared with others, and through the internalisation of the negative experience participants expressed a sense of being thrown in the deep end, and an acute sense of feeling the pressure to manage multiple conversations against a backdrop of time-pressure and competing demands.

The culmination of these events led participants to becoming lost with the associated social psychological problem of suffering silently. The impact of having insufficient internal and/or external resources to hand created an overwhelming sense of grief for the dying, the grieving, and for the perceived failures in navigating the journey successfully. Underlying this grief were associated feelings of frustration with processes, systems and individuals who were not felt to be a supportive member of the team or did not have the same sense of purpose to achieve a ‘good’ death. Such feelings are recognised as tensions for nurses when they engage in end-of-life care practices (Hopkinson et al, 2003), with frustrations being exhibited as anger in some situations. To avoid such situations in the future nurses have been identified as actively disengaging in communication, by avoiding eye contact, and thereby creating a barrier against entering conversation (Caswell et al, 2015)

Making such choices between the living and the dying is something that is noted as being an ongoing challenge, given the time pressures for nurses (Hopkinson et al, 2005; Thompson et al, 2006), and the success or failures of strategies employed can have a significant impact on those providing care at, or near, the end-of-life. It is proposed that the findings of this study go some way to show the potential impact that unrecognised and unsupported feelings of grief, frustration and anger can have on nurses.

Moreover, it is offered that the findings of this study offer new insights to support organisations and nursing leaders in planning readily available and accessible resources to support nurses to reflect safely on incidences of care. By doing so it is proposed that nurses will be better prepared to provide the level of care to the dying and the grieving they wish to achieve.

5.4.4. Leading the Way (Reconstructing Meaning)

The fifth and final theoretical category developed from the data was identified as Leading the Way, which best constructed the process that participants undertook in ensuring that the dying and the grieving were supported, resulting in varied positive feeling and associated beliefs on their own professional practice. Furthermore, the way in which participants unconsciously followed a series of microprocesses to prepare and protect self were identified as part of the analytic process.

The first dimension of this category was a sense of being confident in engaging with the patients or families and feeling able to manage the difficulties and challenges that such conversations could expose. Alongside the sense of confidence in managing such situations the second dimension – the belief of being experienced was constructed from the data. The combination of confidence and experience enabled them to progress from a sense of feeling experienced to knowing their experience and thereby enhancing their confidence in managing the journeys required, recognised as the process of guiding.

The guiding interaction was underpinned by a relentless focus on honesty, delivery of high-quality care and being present with the dying and the grieving. The practical application of guiding, as found in other studies, included the provision of information was meaningful and understood (Caswell et al, 2015), thereby supporting the development of relationships which were based on trust (Rejnö et al, 2017). However, the microprocesses of preparing self and protecting self were not clearly evidenced in the literature reviewed, with a greater focus on preparing the way for patients and families identified (Kryworuchko et al, 2016). Specifically, within this thesis, participants recognised the preparation of self as being key, in addition to the actual content of what was to be said, and that having a strong belief in what was being said was of paramount importance. Interestingly, whilst noted that the sense of protection may reference the importance to limit the amount of contact with families to protect self (Hopkinson et al, 2005), for the participants in this study protecting self more clearly focussed on how they would segregate the intensity of the conversations held whilst also managing the competing priorities of the ward and its other patients.

The combination of successfully utilising the external and internal resources available to participants, which met the demands of navigating the journey, left participants in this study feeling satisfied. The analysis of data conceptualised how this final dimension of the category was key to support participants to enter the social psychological process of reconstructing meaning. The positive outcomes which are identified by nurses both professionally and personally, which focus on how they have been able to help patients and relatives prepare for the future to come is something that brings a sense of satisfaction (Warnock et al, 2010).

The findings of this study are offered to support organisations, educators, and policy makers to understand the complexities of preparation, management, liaison, communication, and self-protection that are experienced and managed by nurses, on multiple occasions, during every shift. It is proposed that such knowledge and understanding will support those in leadership roles to make changes to the current support offered through education, supervision, debrief, practical support and resource availability to maximise the opportunities for nurses to continue leading such processes successfully and feel satisfied when doing so.

5.5. Summation of the substantive theory

This chapter has provided a discussion regarding the co-created substantive theory of Navigating the Journey (Grieving Quietly). Following the schematic presentation and overview of the theory, a synthesis of existing theories identified has been presented, which reflected various important components of the substantive theory alongside those theories and models already known.

Firstly, a comparison was made against Hopkinson et al’s (2005) theory of ‘A translucent web’ of coping, as this was the only existing piece of literature identified as part of the comprehensive literature review. A theoretical view on nursing work at the end-of-life in the acute ward setting has been offered, with similarities identified to this thesis, evidencing how nurses use strategies that are situational, dynamic, and for many, also translucent. Said strategies are used so that the participants can more keenly understand the experience of the dying and the grieving, whilst also being able to moderate involvement to protect self.

Dult-Battey's (2004) theory of Humanising Nursing Communication provided a deeper consideration of how nursing communication can have a positive impact through the development of interpersonal relationships between nurses to maximise outcomes and recognised the uniqueness of the 'other' in the communication process. Similarities were found in this study as the data have articulated how participants use strategies to gain a deeper understanding of the meanings that the dying and the grieving are making, to provide a more individualised level of support.

Papadatou's (2000) model of professional grief provided a further context by evidencing how such grief was individualised and unique, with consideration given to the unspoken rules of 'permissible' grief within the work setting, and the processes undertaken to either focus on the loss itself, or to manage grief reactions to be able to continue to care for others. Further alignments with this theory were highlighted through the analytical concept of grieving quietly.

Whilst not related to healthcare professionals, Stroebe & Schut's (1999) dual model process of coping with bereavement also evidenced coping behaviours through the oscillation between loss focussed behaviours and restoration-orientation behaviours. Noting this model's consideration of complicated grief, the concept of 'disenfranchised grief' (Doka, 1989) was also reviewed. Such concepts were also noted within those key processes identified by participants in this study as they were Navigating the Journey and Grieving Quietly.

Finally, the theory of Human Caring (Watson, 1988, 1997, 2005) was identified as a relevant nursing theory that encompassed many of the caring processes being undertaken by the participants in this study. Due to the context within which this study was taken (end-of-life), many of the caring caritas presented within the Human Caring Theory were recognised as being aligned to the processes undertaken by the participants in this study. From the data, and subsequent analysis, it is argued that when Navigating the journey participants are engaged in a process of sensitisation that allows them to know what is most important for the dying and the grieving, and that grieving quietly is a state in which the participants are aware of their own mortality and a humble recognition of the spiritual dimension of the caring process at the end-of-life.

To place the theory within the wider literature reviewed, a deeper exploration into the five key theoretical categories has been offered, alongside a secondary discussion utilising extant empirical research. The alignment of key dimensions and aspects of each theoretical category have been offered with proposals regarding the findings of this thesis that will potentially impact future decision-making. Detailed recommendations will be offered in the next chapter.

Within this chapter, through the discussion and comparison of existing theories and models, and through an exploration of the key theoretical categories, an alignment of said theories and findings has been shown with the substantive theory of Navigating the Journey (Grieving Quietly), with new areas of knowledge identified through contextual understanding, an identification of social psychological and structural processes, or the use of unconscious and conscious microprocesses by nurses to manage multiple complex conversations with the dying and the grieving.

It is proposed that this theory is unique due to the depth of the interpretation of challenges that are experienced by nurses working in acute adult general (non-specialist) wards. Furthermore, this theory uniquely offers a theory to explain how nurses move across a continuum of grief, from a neutral state of grieving quietly towards the social psychological problem of suffering silently or the social psychological process of reconstructing meaning.

Such end points are offered as being predicated by the availability and accessibility of both internal and external resources for nurses. This substantive theory highlights both the rewards and challenges of being involved in managing end-of-life conversations with the dying and the grieving. Therefore, it is proposed that this study offers a more comprehensive analysis and helps to address the paucity of information known about this subject currently available in the literature.

The following section of this chapter will now consider the strengths and limitations of the study.

5.6. Quality of the Thesis

5.6.1. Credibility

As a hybrid researcher with significant experience of clinically managing end-of-life conversations and having responsibility for the delivery of end-of-life programmes in the acute setting, the researcher had great familiarity with the topic prior, during and following the completion of the thesis. Whilst the total number of participants was adequate (n=11) due to the confirmation of theoretical saturation with reviewers as justified earlier, the breadth of experience was evidenced through a multi-site approach for participants. This therefore enabled the researcher to evidence sufficient breadth and depth to support the constant comparison of the data and it is proposed that this study meets the requirements of a Constructivist Grounded Theory approach.

5.6.2. Originality

The uniqueness of this study, which has been supported through a rigorous literature review and analysis of extant theories within the previous chapter, is based upon the small amount of original research that has focussed solely on the aspect of communication by nurses in the acute adult general (non-specialist) ward environment. As has been shown throughout the findings and discussion chapters, the categories and their associated dimensions provide a greater depth of insight into the actions and interactions that occur with both the dying and the grieving.

The co-construction of categories provides new insights into how nurses manage the challenges of entering said conversations within the context of a time-bound and operationally challenging environment. The significance of this research theoretically evidences the potential damaging social psychological problem that can occur for nurses when internal and external resources do not meet the demands placed upon them. It is proposed that this study provides an original view on this topic.

5.6.3. Auditability

Utilising the CGT method has supported the clarity of process that has allowed for an exploration of the experience of nurses involved in managing end-of-life conversations. The rigorous approach of the methods involved, including the constant comparative approach, through the cycles of data collection, analysis, and coding within and across incidences supports that the theoretical categories of this thesis are grounded in the data, thereby providing a deep and accurate analysis of the topic under study.

The focus of this study is evidenced as being the co-construction of theory and the analytic process has focussed on actions and processes for the participants, evidencing variation where found, and the substantive theory offers an insight into the specific processes which occur for nurses working within the context of an acute adult general (non-specialist) ward with patients and families at the end-of-life.

5.6.4. Transferability

As will be noted below, there are limitations to the study, which include the homogeneity of geography and the specialties within which participants worked (medicine/care of the elderly). However, it is proposed that the substantive theory can be applied and compared with data in other similar settings, and that this theory can also provide a base from which future research can be undertaken. Such impacts may well occur for nurses working in different geographical locations, and within different specialties of nursing, such as surgery. To answer the question of transferability the categories and theory were tested with the researcher's clinical colleagues to determine if they made sense and were relevant to today's healthcare setting. This was confirmed.

5.6.5. Usefulness

The substantive of theory of navigating the journey (grieving quietly) opens the window to more keenly understand the impact that engaging in end-of-life conversations can either positively or negatively have on nurses working in acute adult general (non-specialist) wards. The theory offers that the lack of internal and external resources available to nurses to engage in this action and interaction with the dying and the grieving is inconsistent and, at times, insufficient. The complexity of the resources required relates to both external and practical resources, managing the multiple priorities of working in such an environment, the time needed to meaningfully engage in multiple conversations fully, and the internal resources required to prepare, protect, process, and reflect on the outcomes of said interactions.

The theory further offers that the cyclical nature of these conversations, and the impacts they have is continuous, with the time-bound and often chaotic environments within which nurses work as one of the key external challenges faced when attempting to meet the needs of the dying and the grieving. The theory is proposed to provide clinicians, professional leaders, educators, and policy makers an opportunity to more fully understand the complexities of practice and the impact on staff, so that changes can be made to support nurses in the delivery of the standards of care they so desperately wish to achieve.

5.7. Limitations of the research

The key limitations to the study have been identified and will be discussed in the section below, which include participant sample, data collection, and methodology.

5.7.1. Limitations related to the sampling of participants

The sample recruited to this study was limited to one geographical area in the East of England; therefore, the transferability of these findings may not be appropriate to other healthcare organisations in other geographical regions. However, it is proposed that this theory could be compared with similar data across other similar settings to determine if this is the case.

Secondly, the sample recruited resulted in eleven participants being interviewed. It could be argued that a greater number of participants was required to fully explore the topic under study. However, from the analysis of the participant data it was noticed that there were variations in experience, role, sub-specialty, and protected characteristics. Variations were identified across incidences and shared as part of the research findings. Furthermore, it was identified as part of the constant comparative method that upon conclusion of the eleventh participant interview and the associate analysis, no new insights or dimensions were identified and with the support of the review by the researcher's supervisor it is argued that theoretical saturation had been achieved.

Finally, it is argued that the paucity of literature within the context of the acute adult general (non-specialist) ward was identified which allowed new knowledge to be identified, and sufficient information was gathered to answer the research question and objectives.

5.7.2. Limitations of the researcher

As has been discussed in the methodology chapter, the hybrid researcher position is one that can be fraught with challenges. One of the key challenges is ensuring that the professional position of the researcher does not impede upon the sharing of open experiences, and a recognition of the potential power imbalances that occur during the interview process. As discussed in Chapter Three, the researcher undertook a reflexive interview to understand implied and unconscious biases, which led to the development of a model that could be used as a basis from which to reflect and understand what was being heard and perceived during the analytic process.

The reflexive stance undertaken through regular supervision sessions, the use of a journal and memoing throughout the research journey ensured that the maximum number of mitigations were in place to minimise the risk of bias influencing the construction of the grounded theory.

5.7.3. Limitations of the methodology

As has been previously explored many will consider the use of qualitative research as being a limitation to identifying the generalisability of the findings of this study. However, as has been consistent throughout this thesis, no claims to being able to do so have been proposed. The purpose of CGT is to ensure that any analytic processes undertaken are co-constructed between the researcher and the researched within the context of the time, place, and situation within which the study has occurred (Charmaz, 2014). The proposed substantive theory is offered as a way in which others can explore what has been offered in clinical practice.

It is proposed that the findings of this study can also influence future decision-making so that the resources required to support nurses when they are navigating the journey of end-of-life conversations in acute adult general (non-specialist) wards are freely available. It is considered that by doing so nurses will more readily enter the social psychological process of reconstructing meaning and avoid the social psychological problem of suffering silently, thereby improving staff experience, a sense of satisfaction and ultimately improving the standards of communication and care for the dying and the grieving.

5.8. Conclusion

This chapter has offered the proposed substantive grounded theory of Navigating the Journey (Grieving Quietly) within the context of relevant known theories related to nursing practice, familial and professional grief, and end-of-life care. The five main theoretical categories have been further explored, against the extant research identified from the comprehensive literature review. From the discussion it is proposed that this substantive theory offers a unique insight into the impact that managing end-of-life conversations within the context of acute adult general (non-specialist) wards has on nurses in today's healthcare environment.

The substantive theory has also exposed the micro-processes that nurses undertake to begin walking the path with the dying and walking the path with the grieving. Moreover, the impact of walking these paths on nurses is highlighted and evidences the internal and external resources required at different times to reach a meaningful conclusion. Within the context of known research and the recognised theories reviewed, the new knowledge developed by this thesis is now proposed.

The purpose of this constructivist grounded theory study was to offer a useful and new insight into clinical practice that was helpful and transferable to other healthcare settings. The dimensions of quality and rigour have been explored in relation to a grounded theory study (Charmaz, 2014), with the limitations of the study being presented for consideration. In the following and final chapter of the thesis, the categories and associated dimensions which have been presented as part of the research process will provide the rationale for the recommendations for future practice considerations, organisational decision-making, educational programme development, research proposals and policy formation.

6. CHAPTER 6 – CONCLUSION AND IMPLICATIONS FOR PRACTICE

6.1. Introduction

This thesis concludes with a summary of the findings of the study and a clear outline of the contribution to knowledge that has been made regarding end-of-life conversation being managed by nurses in acute adult general (non-specialist) wards. Following this, recommendations for clinical practice, future research, organisational decision/policymaking, and education programme implementation are shared.

At the beginning of this process the research questions posed were:

‘What is the impact of managing end-of-life conversations on nurse working in acute adult general (non-specialist) wards?’

What are the actions and interactions that nurses engage in when managing end-of-life conversations?

To answer these questions several research objectives were identified, and agreed as follows:

1. To explore and describe the social processes, interactions, and experiences of engaging in end-of-life conversations with patients and those close to them, and how these impact on nurses working in adult acute general wards.

2. To identify the factors that facilitate or inhibit such experiences by nurses being positively or negatively perceived.
3. To develop a co-created substantive theory that supports healthcare professionals and organisational leaders gain a deeper understanding of the complexities of communicating with patients and their families at the end of life, and what resources are needed to do so successfully.
4. To understand the place of the substantive theory within the context of other relevant theoretical literature
5. To outline recommendations that focus on the need for easy access to resources for nurses that will support managing such conversations in a way that provides the best possible outcome for all those involved. Such resources should support individual staff beyond pre-known and commissioned education and training.

6.2. Findings and contribution to knowledge

The aims of the study were met through the exploration of participants' experiences and the co-construction of a substantive theory, using the constructivist grounded theory method. Eleven participants were interviewed to understand their experiences of managing end-of-life conversations in acute adult general (non-specialist) wards. A rigorous approach to method was applied, through the transcription, coding, and constant comparative analysis of data utilising QDAS (NVivo) software.

This study is significant as a theory of Navigating the journey (grieving) has been co-constructed using a constructivist grounded theory methodology. The theory has offered new points of reference and insights into nurses engaging in end-of-life conversations when working in acute non-specialist adult wards in hospitals in England. The new knowledge is proposed as a level of understanding of the conscious and unconscious microprocesses that nurses deploy as part of their management of end-of-life conversations with the dying and the grieving, before, during and following death. Furthermore, the concept of post communicative work undertaken by nurses is proposed as not having been considered both following individual conversations and following the death of the patient and the departure of the bereaved families. Some of the processes proposed within this study are structural whilst others are psychological; however, it is offered that these are both interwoven and interdependent.

The findings of this study also offer the concept of a continuum of professional grief. A neutral, socially accepted, and normative state of grieving quietly is shared, which meets the requirements of professional distance and socially constructed boundaries within a hospital ward setting. During the interactions with patients and families, and influenced by the availability and accessibility of resources, nurses traverse the continuum of professional grief, whether positively or negatively affected. Through their interactions with patients and families, deploying psychological and structural microprocesses to prepare, engage and protect self, they either are progressively negatively impacted and head towards the social psychological problem of suffering silently, or are positively enriched as they travel towards the social psychological process of reconstructing meaning.

It is offered that these concepts, whilst aligned with certain aspects and components of other theories (Duldt-Battey, 2004; Papadatou, 2000; Stroebe & Schut, 1999, 2010; Watson, 1988, 1997, 2005; Hopkinson et al, 2005), Navigating the journey (grieving quietly) is the first study which has developed a substantive grounded theory that offers these concepts together to aid a clearer understanding of this social reality.

The following section of this chapter will now consider the implications and recommendations for clinical practice, future research, organisational policymaking, educational programme development, and healthcare policy.

6.3. Recommendations from the substantive theory

6.3.1. Recommendations for clinical practice

This study identified areas of practice that highlighted nurses fully engaging in conversations with the dying and the grieving which supported the best possible outcomes. This was observed across the research settings. However, it was clear from the findings that in many cases there was insufficient preparation across the multidisciplinary team to fully engage with nurses earlier in the process, or offering clarity as to who held responsibility to manage communication. In addition, a clear escalation pathway was not always in place that was easily accessible for nurses to trigger. Therefore, the clinical recommendation from this study are as follows:

- Early identification of the dying patient should be escalated to ward leaders at the earliest opportunity to scope the capacity and capability of members of the

MDT to act as primary liaison with the patient and/or the family, with a recognised skill set in managing end-of-life communication. Challenges to sourcing this should be escalated through the Trust's staffing and site management protocols and processes, to seek alternate sources of support where required. It is proposed that the implementation of this recommendation should be led by the Trust's lead End of Life Care nurse or team, supported by senior nursing staff with responsibilities for nursing workforce and operational flow. This should be trialled in specific sub-specialties within medicine, which invariably have a higher rate of death. PDSA cycle approaches to quality improvement have already been used to support rapid allocations of staffing resource during Covid-19 and therefore this approach is recommended to be followed, as a recognised methodology for implementation of improvements within the NHS.

- Clear and consistent referral pathways through to the Specialist Palliative Care Team should be developed if not already in place, or strengthened, with existing pathways reviewed considering the findings of this study. Nurses should be able to access sources of immediate specialist support when faced with difficult and challenging situations relating to end-of-life conversations in a timely way.

6.3.2. Recommendations for organisational decision-makers

The findings from this research have evidenced the need for time to be able to process, reflect and learn from experiences of managing end-of-life conversations with the dying and the grieving – identified as reflecting on journeys taken. Multiple concerns were raised by participants on their inability to secure time to reflect either individually, or with others, in a meaningful way that supported their practice in the future, and their levels of confidence in navigating future journeys. Based on the findings the recommendations for organisational decision-makers are as follows:

- Where already in place staff should be supported to seek opportunities to share experience more widely, such as through Schwarz Rounds (Maben et al, 2021) and by engaging in debrief sessions and post-incident support (Burman, 2018). The important of creating a psychologically safe space to reconnect with professional values and promote compassionate care delivery cannot be dismissed. However, it is noted that the critical mass of debriefers is required to offer this consistently, and this should be considered as part of any planning phase. Furthermore, it should be recognised that Schwarz rounds are not for everyone and should part of a multi-solution well-being programme in order to meet the needs of the majority of staff (Taylor et al, 2018).
- The role of the Professional Nurse Advocate (NHS England and NHS Improvement, 2020) should be fully implemented in all clinical areas, ensuring time to fulfil the role, so that a further psychologically safe environment can be developed for nurses to reflect on clinical issues pertaining to clinical situations, which may be professionally challenging.
- Organisations must now fully consider the ambitions for palliative and end of life care (National Palliative and End of Life Care Partnership, 2021). Specifically, it is recommended that organisations now focus on Ambition Five: *All staff are prepared to care*. Such actions must step from an executive governance level ensuring that environments *‘in which all staff can provide the best of their professionalism and humanity’* (p32) are developed and sustained.

6.3.3. Recommendations for education programmes

Consistently evidenced in this study was the view that current education programmes on communication were insufficient or inappropriate to the needs of the ward environment, and it has been evidenced that participants were using unconscious and ultimately with variable success microprocesses to minimise distress and anxiety in patients and their families. Concerns were raised that ‘managing difficult conversations’ as part of mandatory/essential training were too generic and did not allow an opportunity to gain the skills needed were shared. Therefore, the recommendations from the findings of this theory relating to educational programmes are as follows:

- Education programmes related to end-of-life communication should be co-designed, commissioned, and operationally delivered as a stand-alone programme for all qualified nurses working in hospitals, and considered as a mandatory component of role-based training. Such programmes need to be evidence-based, such as the national SAGE & THYME^{TM} programme of communications skills (Connolly et al, 2009), which allows participants to explore perceptions and understand the transferability of these skills when engaging in conflict, specifically within the context of grief (Shannon et al, 2011).
- Additional training should be made available to all other members of the ancillary staff working in the ward environment, such as in-house end-of-life care training, conflict resolution and communication training, affording them the

opportunity to better understand death and dying, fostering a culture of openness and acceptance, and allowing them to form part of the holistic care approach for the grieving and bereaved.

6.3.4. Recommendations for further research

The recommendations for further research, extrapolated from the findings of this theory are as follows:

- Further research is required to understand whether the findings of this study are transferable to other specialties, such as surgical ward environments. The findings of this study may be related solely to a medical specialty environment, due to the professional background of the majority of research participants.
- The findings of this study should be tested in specialist areas of nursing practice, including palliative and oncology care. Whilst new dimensions and properties may well be realised and understood, it is believed that this will evidence some transferability of the findings.
- Further research should also be considered that focusses on different cultural impacts on end-of-life conversations. The majority of participants in this study were white British, and it is proposed that cultural diversity has not been explored due to the homogeneity of participants.
- Further research should now focus on the impact that Covid-19 has had on ward environments, due to the significant increase in death and dying which has occurred in acute adult general (non-specialist) ward environments over the past two years. The impact on nurses has not yet been fully understood,

and it is recognised that patients now attend hospitals with increased morbidity and mortality, which in turn will result in a continued increase in patient death.

6.4. Concluding statement

Dame Cicely Saunders radically improved clinical practice for people at the end of life and paved the way for a more holistic model of person-centred care. Cicely's legacy is still evident in hospital wards, and can best be summarised by one of her most famous quotes (Costello, 2018), and quoted by Robert Twycross in his tribute to Dame Cicely during her memorial service on 8th March 2006:

*"You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die." (*pg 452)

Whilst this sentiment could be clearly seen when interviewing each participant in this study, the findings would suggest that there is still some way to go recognise their needs to achieve this ambition. By failing to do something about the challenges identified in this study, it could be argued that the healthcare system does not believe that nurses truly matter. It is hoped that the findings of this study will help start making the changes necessary at an organisational and system level, to support our nurses to be the best they can be. By doing so, we will enable them to deliver the standard of care they wish for every patient, and every family, at each opportunity.

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7. REFERENCE LIST

Allen D (2004) Ethnomethodological insights into insider-outsider relationships in nursing ethnographies of healthcare settings, *Nursing Inquiry*, 11, pp14 – 24

Annells M (1996) Grounded theory method: Philosophical perspectives, paradigms of inquiry, and postmodernism, *Qualitative Health Research*, 6, pp379 – 393

Annells M (1997a) Grounded theory method, part 1: within the five moments of qualitative research, *Nursing Inquiry*, 4, pp120 – 129

Annells M (1997b) Grounded theory method, part 2: options for users of the method, *Nursing Inquiry*, 4, pp176 – 180

Arber A (2006) Reflexivity: A challenge for the researcher as practitioner? *Journal of Research in Nursing*, 11, 2, pp147 – 157

Atkinson P & Silverman D (1997) Kundera's immortality: The interview society and the invention of the self, *Qualitative Inquiry*, 3, 3, pp304 - 325

Aveyard H & Sharp P (2013) *A beginner's guide to evidence-based practice in health and social care (2nd edition)*, London: Open University Press

Aveyard H, Payne S, & Preston N (2016). *A Postgraduate's Guide to Doing a Literature Review in Health and Social Care (2nd edition),* Berkshire, Open University Press.

Bakewell F, Pauls MA & Migneault D (2020) Ethical considerations of the duty to care and physician safety in the COVID-19 pandemic, *Canadian Journal of Emergency Medicine,* 22**,** pp407 - 410

Barnard D (1995) The promise of intimacy and the fear of our own undoing, *Journal of Palliative Care,* 11**,** pp22 - 26.

Beck CT (1993) Qualitative research: the evaluation of its credibility, fittingness, and auditability, *Western Journal of Nursing Research*, 15, 2, pp263 - 266

Berger R (2015) Now I see it, now I don't: researcher's position and reflexivity in qualitative research, *Qualitative Research*, 15, 2, pp219 - 234

Berlo D (1960) *The Process of Communication*, New York: Holt Rinehart

Birks M & Mills J (2015) *Grounded theory: A practical guide*, London: Sage

Bishop EC & Shephard ML (2011) Ethical reflections: examining reflexivity through the narrative paradigm, *Qualitative Health Research*, 21, pp 1283 – 1294

Blaikie P (2000) Development, post-, anti-, and populist: a critical review. *Environment and Planning A,* 32**,** pp1033-1050.

Blumer H (1969) *Symbolic Interactionism (Volume 50),* Englewood Cliffs, New Jersey: Prenctice-Hall

Bondi L (2003) Empathy and identification: conceptual resources for feminist fieldwork, *ACME: An International Journal for Critical Geographies*, 2, 1, pp64 - 76

Bone AE, Finucane AM, Leniz J, Higginson IJ & Sleeman KE (2020) Changing patterns of mortality during the COVID-19 pandemic: population-based modelling to understand palliative care implications, *Palliative medicine,* 34**,** pp1193 - 1201

Bonner A & Tolhurst G (2002) Insider-outsider perspectives on participant observation, *Nurse Researcher*, 9, pp 7 - 19

Bourdieu P & Wacquant LJ (1992) *An invitation to reflexive sociology*, Chicago: University of Chicago Press

Boroujeni AZ, Mohammadi R, Oskouie SFH & Sandberg J (2009) Iranian nurses' preparation for loss: Finding a balance in end-of-life care, *Journal of clinical nursing,* 18**,** pp2329 - 2336.

Breckenridge J (2009) Demystifying theoretical sampling in Grounded Theory, Grounded Theory Review: An international journal, 8, 2, pp114 – 125

Bridges D (2001) The ethics of outsider research, *Journal of Philosophy of Education*, 35, 3, pp371 - 386

Brinkmann S & Kvale S (2015). *Interviews: Learning the craft of qualitative research interviewing*, Thousand Oaks, California: Sage

Brunero SJ & Jeon YH (2015) The journey of positioning self as both mental health nurse and qualitative researcher: a critical reflection, *Journal of Psychiatric and Mental Health Nursing*, 22, pp543 - 548

Brunero S & Lamont S (2012) The process, logistics and challenges of implementing clinical supervision in a generalist tertiary referral hospital, *Scandinavian Journal of Caring Sciences*, 26, 1, pp186 - 193

Bryant A (2009) Grounded Theory and Pragmatism: The Curious Case of Anselm Strauss, Forum Qualitative Sozialforschung / Forum: Qualitative Social Research, 10, 3, accessed at http://www.qualitative-research.net/index.php/fqs/article/view/1358 - 11 November 2017

Bryant A & Charmaz K (2007) Grounded theory in historical perspective: An epistemological account (pp31-57), in Bryant A & Charmaz K (eds.) *Handbook of grounded theory*, Thousand Oaks, California: Sage, pp31 - 57

Bryman A (2016) *Social research methods (5th edition)*, Oxford University Press, Oxford

Buber M (1970) *I And Thou (Kaufmann W, Trans.),* New York: Charles Scribner's Sons

Buglass E (2010) Grief and bereavement theories, *Nursing standard (Royal College of Nursing (Great Britain)),* 24, pp44 - 47

Burgess L, Irvine F & Wallymahmed A (2010) Personality, stress and coping in intensive care nurses: a descriptive exploratory study, *Nursing in critical care,* 15**,** pp129 - 140

Burls, A (2009). *What is critical appraisal?, accessed at* *https://citeseerx.ist.psu.edu/viewdoc/download?doi=10.1.1.734.5910&rep=rep1&type=pdf* on 23rd November 2020

Burman A (2018) Debrief and post-incident support: views of staff, patients and carers, *Nursing Times,* 114, 9, pp 63 - 66

Care Quality Commission (2016) *A different ending: Addressing inequalities in end-of-life care - overview report,* London: Care Quality Commission.

Casey D, Murphy K, Ni Leime A, Larkin P, Payne S, Froggatt KA & O'Shea E (2011) Dying well: factors that influence the provision of good end-of-life care for older people in acute and long-stay care settings in Ireland, *Journal Of Clinical Nursing,* 20**,** pp 1824 - 1833

Caswell G, Pollock K, Harwood R & Porock D (2015) Communication between family carers and health professionals about end-of-life care for older people in the acute hospital setting: a qualitative study, *BMC palliative care,* 14**,** pp 1 - 14

Cevik B & Kav S (2013) Attitudes and experiences of nurses toward death and caring for dying patients in Turkey, *Cancer nursing,* 36**,** pp E58 - E65

Charmaz K (1980) *The social reality of death*, Massachusetts: Addison-Wesley

Charmaz K (1990) ‘Discovering’ chronic illness: using grounded theory, *Social Science & Medicine*, 30, 11, pp1161 - 1172

Charmaz K (2000) Constructivist and objectivist grounded theory, in Denzin NK & Lincoln YS (eds.) *Handbook of qualitative research (2nd edition)*, Thousand Oaks, California: Sage, pp509 - 535

Charmaz K (2008a) Constructionism and the grounded theory method, in Holstein JA & Gubrium JF (eds.) *Handbook of constructionist research,* New York: Guilford Publications, pp 397 - 412.

Charmaz K (2008b) Grounded Theory as an Emergent Method (Chapter 7) in, Hesser-Biber SN & Leavy P (eds) *Handbook of Emergent Methods*, New York: The Guildford Press, pp155 - 172

Charmaz, K (2009) Shifting the grounds: Constructivist Grounded Theory Methods, in Mose JM, Stern PN, Corbin J, Bowers B, Charmaz K & Clarke AE *Developing grounded theory: The second generation***,** New York: Routledge, pp 127 - 154.

Charmaz K (2014) *Constructing grounded theory (2nd ed)*, Thousand Oaks, California: Sage

Charmaz K (2017) Special invited paper: Continuities, Contradictions, and Critical inquiry in Grounded Theory, *International Journal of Qualitative Methods*, 16, pp1 – 8

Chesney M (2001) Dilemmas of self in the method, *Qualitative Health Research*, 11, pp127 - 135

Chiovitti RF & Piran N (2003) Rigour and grounded theory research, *Journal of Advanced Nursing,* 44**,** pp427 - 435.

Cipolletta S & Oprandi N (2014) What is a Good Death? Health Care Professionals' Narrations on End-of-Life Care, *Death Studies,* 38**,** pp20-27

Clarke, AE, Friese C & Washburn RS (2017) *Situational analysis: Grounded theory after the interpretive turn (2nd edition)*, Thousand Oaks, California: Sage

Cooke A, Smith D & Booth A (2012) Beyond PICO: The SPIDER Tool for Qualitative Evidence Synthesis, *Qualitative Health Research,* 22**,** pp1435 - 1443.

Colbourne L & Sque M (2004) Split personalities: Role conflict between the nurse and the nurse researcher, *Nursing Times Research*, 9, 4, pp297 - 304

Connolly M, Perryman J, McKenna Y, Orford J, Thomson L, Shuttleworth J, Cocksedge S (2009) SAGE & THYME^{TM}: A model for training health and social care professionals in patient-focussed support, *Patient Education and Counseling, 79, pp98 - 93*

Cooney A (2011) Rigour and grounded theory, *Nurse Researcher*, 18, 4, pp17 - 22

Corbin J & Strauss A (2015) *Basics of qualitative research: Techniques and procedures for developing grounded theory (4th ed)*, Thousand Oaks, California: Sage

Costello, J (2006) Dying well: nurses' experiences of 'good and bad' deaths in hospital, *Journal of Advanced Nursing,* 54**,** pp594 - 601.

Costello J (2018) The provision of effective palliative care for adults (Chapter 15, pp 434 – 458) in, Burns D (ed) *Foundations of Adult Nursing,* London: Sage

Creswell JW (2014) *Qualitative, quantitative and mixed methods approaches*, Thousand Oaks, California: Sage

Currin-Mcculloch J, Chapman B, Carson C, Fundalinski K, Hays M, Budai P & Kaushik S (2021) Hearts above water: Palliative care during a pandemic, *Social Work in Health Care,* 60**,** pp93-105.

Cutliffe JR (2000) Methodological issues in grounded theory, *Journal of Advanced Nursing*, 31, 6, pp1476 – 1484

DeLyser D (2001) "Do you really live here?" Thoughts on insider research, *Geographical Review*, 91, 1-2, pp441 - 453

Denzin (2001) The reflexive interview and a performative social science, *Qualitative Research*, 1, 1, pp23 - 46

Department of Health (2008) *End of Life Care Strategy*, London: DH Publications

Department of. Health (2009). End of Life Care Strategy: Quality markers and measures for end-of-life care, London: HMSO

Department of Health (2017). One Year On: *The Government Response to the Review of Choice in End-of-Life Care,* London, HMSO

Dixon-Woods M, Shaw RL, Agarwal S & Smith JA (2004) The problem of appraising qualitative research, *BMJ Quality & Safety,* 13**,** pp223 - 225

Dixon-Woods M, Agarwal S, Jones D, Young B & Sutton A (2005) Synthesising qualitative and quantitative evidence: A review of possible methods, *Journal of Health Services Research & Policy,* 10**,** pp45 - 53

Dixon-Woods, M & Shaw, R (2007) Appraising qualitative research for inclusion in systematic reviews: a quantitative and qualitative comparison of three methods, *Journal of Health Services Research & Policy,* 12**,** pp42 - 47

Doka KJ (1989) *Disenfranchised Grief: Recognizing Hidden Sorrow,* Lexington, Massachusetts: Lexington Books.

Doka, KJ (2002) *Disenfranchised Grief: new directions, challenges, and strategies for practice*, Champaign, Ill: Research Press

Doka, KJ (2014) Caring for the carer: The lessons of research, *Progress in Palliative Care,* 22**,** pp150-154.

Dosser I & Kennedy C (2012) Family carers' experiences of support at the end of life: carers' and health professionals' views, *International Journal of Palliative Nursing,* 18**,** pp491-497

Doubal F, Cowey E, Bailey F, Murray SA, Borthwick S, Somerville M, Lerpiniere C, Reid L, Boyd K, Hynd G & Mead GE (2018) The key challenges of discussing end-of-life stroke care with patients and families: a mixed-methods electronic survey of hospital and community healthcare professionals, *Journal of the Royal College of Physicians of Edinburgh*, 48, pp217 - 224

Downar J, Seccareccia D & Associated Medical Services Inc. Educational Fellows in Care at the End of Life (2020) Palliating a pandemic: "all patients must be cared for", *Journal of Pain and Symptom Management,* 39**,** pp291-295

Downing S, Polzer K & Levan K (2013) Space, time, and reflexive interviewing: implications for qualitative research with active, incarcerated, and former criminal offenders, *International Journal of Qualitative Methods*, 12, 1, pp478 - 497

Drew N (1989) The interviewer's experience as data in phenomenological research, *Western Journal of Nursing Research*, 11, pp 431 - 439

Duldt BW & Giffin K (1985) *Theoretical Perspectives for Nursing*, Boston: Little, Brown & Company

Duldt-Battey BW (2004) Humanism, nursing, communication and holistic care: A position paper – accessed at http://www.bwbatteyconsult.com/position_paper.pdf - 09 September 2020

Dunne C (2011) The place of the literature review in grounded theory research, *International Journal of Social Research Methodology,* 14**,** pp111-124.

Feder S, Smith D, Griffin H, Shreve ST, Kinder D, Kutney-Lee A & Ersek M (2021) "Why Couldn't I Go in To See Him?" Bereaved Families' Perceptions of End-of-Life Communication During COVID-19, *Journal of the American Geriatrics Society,* 69**,** pp587-592

Fernandez R, Lord H, Halcomb E, Moxham L, Middleton R, Alananzeh I & Ellwood L (2020) Implications for COVID-19: a systematic review of nurses' experiences of working in acute care hospital settings during a respiratory pandemic, *International Journal of Nursing Studies,* 111**,** pp1036 – 1037

Field D & Copp G (1999) Communication and awareness about dying in the 1990s, *Palliative Medicine,* 13**,** pp459 - 468.

Finlay L (2002) Negotiating the swamp: the opportunity and challenge of reflexivity in research practice, *Qualitative Research*, 22, pp 209 – 230

Fineout-Overholt E & Johnston L (2005) Teaching EBP: Asking searchable, answerable clinical questions, *Worldviews on Evidence-Based Nursing,* 2**,** pp157 -160

Frank G (1997) Is there life after categories? Reflexivity in qualitative research, *Occupational Therapy Journal of Research*, 17, pp 84 - 98

Gesi C, Carmassi C, Cerveri G, Carpita B, Cremone IM & Dell'osso L (2020) Complicated grief: what to expect after the coronavirus pandemic, *Frontiers in psychiatry,* 11**,** p489

Glaser B (1978) *Theoretical Sensitivity*, Mill Valley, California: Sociology Press

Glaser B (1992) *Emergence v Forcing Basics of Grounded Theory Analysis*, Mill Valley, California: Sociology Press

Glaser B (1998) *Doing Grounded Theory: Issues and Discussions,* Mill Valley, California: Sociology Press

Glaser (2012) Constructivist Grounded Theory?, *The Grounded Theory Review*, 11, 1, pp28 - 38

Glaser B & Strauss A (1967) *The Discovery of Grounded Theory,* New York: Aldine Publishing Company

Greenberg N, Docherty M, Gnanapragasam S & Wessely S (2020) Managing Mental Health Challenges Faced By Healthcare Workers During Covid-19 Pandemic, *British Medical Journal,* 368:m1211

Greene MJ (2014) On the inside looking in: Methodological insights and challenges in conducting qualitative insider research, *The qualitative report*, 19, 29, pp1 - 13

Grix J (2010) *Research Skills: The Foundations of Research,* Basingstoke, Palgrave MacMillan.

Hall WA & Callery P (2001) Pearls, Pith, and Provocation: Enhancing the rigor of grounded theory: Incorporating Reflexivity and Relationality, *Qualitative Health Research*, 11, 2, pp257 - 272

Hayfield N & Huxley C (2015) Insider and outsider perspectives: Reflections on researcher identities in research with lesbian and bisexual women, *Qualitative Research in Psychology*, 12, 2, pp91 - 106

Healthcare Quality Improvement Partnership (2016) *End of Life Care Audit - Dying in hospital report for England* – accessed at https://www.hqip.org.uk/resource/end-life-care-audit-dying-hospital-executive-summary-2016/ - 17 April 2020

Health Research Authority (2017) *UK Policy Framework for Health and Social Care Research* – accessed at https://www.hra.nhs.uk/planning-and-improving-research/policies-standards-legislation/uk-policy-framework-health-social-care-research/ - 16 June 2018

Heath H & Cowley S (2004) Developing a grounded theory approach: a comparison of Glaser and Strauss, International Journal of Nursing Studies, 41, pp 141 – 150

Henwood K & Pidgeon N (2003) Grounded theory in psychological research in Camic PM, Rhodes JE & Yardley L (eds) *Qualitative research in psychology: Expanding perspectives in methodology and design*, Washington: American Psychological Association

Holloway S & Wheeler I (2002) *Qualitative research for nurses (2nd edition)*, London: Blackwell Science

Hopkinson JB, Hallett CE & Luker KA (2003) Caring for dying people in hospital, *Journal of Advanced Nursing,* 44**,** pp525 – 533

Hopkinson JB, Hallett CE & Luker KA (2005) Everyday death: how do nurses cope with caring for dying people in hospital? *International Journal of Nursing Studies,* 42**,** pp125 – 133

Hubble R, Trowbridge K, Hubbard C, Ahsens L & Ward-Smith P (2008) Effectively using communication to enhance the provision of pediatric palliative care in an acute care setting, *Journal of Multidisciplinary Healthcare,* 1**,** p45

Jack BA, Gambles M, Murphy D & Ellershaw JE (2003) Nurses' perceptions of the Liverpool Care Pathway for the dying patient in the acute hospital setting, *International Journal of Palliative Nursing,* 9**,** pp375 - 381.

Jackson K & Bazeley P (2019) *Qualitative data analysis with NVivo*, London: Sage

Jameton A (1984) *Nursing practice: The ethical issues*, Englwood Cliffs, New Jersey: Prentice-Hall

Joanna Briggs Institute (2014) *Reviewers' Manual,* Australia, Joanna Briggs Institute – accessed at https://jbi.global/scoping-review-network/resources - 4 March 2020

Kacen L & Chaitin J (2006) The times are a changing: understanding qualitative research in ambiguous, conflictual and changing contexts, *Qualitative Report*, 11, pp 209 – 228

Kaplan LJ (2000) Toward a Model of Caregiver Grief: Nurses' Experiences of Treating Dying Children, *OMEGA - Journal of Death and Dying,* 41**,** pp187 – 206

Kearney MH (2001) Enduring love: A grounded formal theory of women's experience of domestic violence, *Research in Nursing & Health,* 24**,** pp270 – 282

Kerr D, Milnes S, Ammentorp J, McKie C, Dunning T, Ostaszkiewicz J, Wolderslund M & Martin P (2020) Challenges for nurses when communicating with people who have life-limiting illness and their families: A focus group study, *Journal of Clinical Nursing,* 29**,** pp 416-428

Kryworuchko J, Strachan P, Nouvet E, Downar J & You J (2016) Factors influencing communication and decision-making about life-sustaining technology during serious illness: a qualitative study. *BMJ open,* 6:e010451 – accessed at https://bmjopen.bmj.com/content/6/5/e010451 - 20 September 2020

Lazarus, RS (1966) *Psychological stress and the coping process*, New York: McGraw-Hill

Lazarus RS & Folkman S (1984) *Stress, appraisal, and coping*, New York: Springer Publishing Company

Lazarus RS (1991) *Emotion and adaptation*, Oxford: Oxford University Press

Leadership Alliance for the Care Of Dying People (2014) *Once chance to get it right: Improving people's experience of care in the last few days and hours of life* – accessed at https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf - 17 April 2020

Lear H, Eboh WO, Diack L (2018) A nurse researcher's guide to reflexive interviewing, *Nurse Researcher*, 25, 4, pp35 – 42

Lee RM (1993) *Doing research on sensitive topics*, London: Sage

Lincoln YS & Guba EG (1985) *Naturalistic Inquiry*, Thousand Oaks, California: Sage

Lumen Learning (no date) *The Symbolic Interactionist Perspective* accessed at https://courses.lumenlearning.com/boundless-sociology/chapter/theoretical-persctives-in-sociology/ - 12 November 2017

Maben J, Taylor C, Reynolds E, McCarthy I & Leamy M (2021) Realist evaluation of Schwartz rounds® for enhancing the delivery of compassionate healthcare: understanding how they work, for whom, and in what contexts, *BMC Health Services Research,* 21, 709 accessed at https://doi.org/10.1186/s12913-021-06483-4 - 6 May 2022

Mak YW, Lim Chiang VC & Chui WT (2013) Experiences and perceptions of nurses caring for dying patients and families in the acute medical admission setting, *International Journal of Palliative Nursing,* 19**,** pp423 – 431

Mayland CR, Harding AJ, Preston N & Payne S (2020) Supporting adults bereaved through COVID-19: a rapid review of the impact of previous pandemics on grief and bereavement. *Journal of Pain and Symptom Management,* 60**,** pp e33 - e39

Mayland CR, Hughes R, Lane S, McGlinchey T, Donnellan W, Bennett K, Hanna J, Rapa E, Dalton L & Mason SR (2021). Are public health measures and individualised care compatible in the face of a pandemic? A national observational study of bereaved relatives' experiences during the COVID-19 pandemic, *Palliative Medicine***,** 35, 8, pp1480 – 1491

McCallin, AM (2011) Moderated guiding: A grounded theory of nursing practice in end-of-life care, *Journal of Clinical Nursing,* 20**,** pp2325 -2333

McCann T & Clark E (2003a) Grounded theory in nursing research: Part 1 – Methodology; *Nurse Researcher*, 11, 2, pp 7 – 18

McCann T & Clark E (2003b) Grounded theory in nursing research: Part 2 – Critique; *Nurse Researcher*, 11, 2, pp 19 – 28

McCourt R, Power J. & Glackin M (2013) General nurses' experiences of end-of-life care in the acute hospital setting: a literature review, *International Journal of Palliative Nursing,* 19**,** pp510 – 516

McDermid (no date) *Pragmatism – Internet Encyclopaedia of Philosophy* accessed at http://www/iep/utm/edu/pragmati - 12 November 2017

McGhee G, Marland GR & Atkinson J (2007) Grounded theory research: literature reviewing and reflexivity, *Journal of Advanced Nursing*, 60, 3, pp334 - 342

McMenamin I (2006) Process and text: Teaching students to review the literature, *PS: Political Science & Politics,* 39**,** pp 133-135

Merlane H & Cauwood L (2020) Core principles of end-of-life care, *British Journal of Nursing,* 29, 5, pp280 - 282

Merriam SB, Johnson-Bailey J, Lee MY, Kee Y, Ntseane G and Muhamad M (2001) Power and positionality: Negotiating insider/outsider status within and across cultures, *International journal of lifelong education*, 20, 5, pp405 - 416

Methley AM, Campbell S, Chew-Graham C, McNally, R & Cheraghi-Sohi S (2014) PICO, PICOS and SPIDER: a comparison study of specificity and sensitivity in three search tools for qualitative systematic reviews, *BMC Health Services Research,* 14**,** pp579 - 589

Mills J, Bonner A & Francis K (2006a) Adopting a constructivist approach to grounded theory: Implications for research design, *International Journal of Nursing Practice,* 12**,** pp8 – 13

Mills J, Bonner A & Frances K (2006b) The Development of Constructivist Grounded Theory, *International Journal of Qualitative Methods*, 50, 1, pp25 - 35

Mitchinson L, Dowrick A, Buck C, Hoernke K, Martin S, Vanderslott S, Robinson H, Rankl F, Manby L & Lewis-Jackson S (2021) Missing the human connection: A rapid appraisal of healthcare workers' perceptions and experiences of providing palliative care during the COVID-19 pandemic, *Palliative Medicine,* 35**,** pp852 – 861

Moher D, Liberati A, Tetzlaff J & Altman DG (2010) Preferred reporting items for systematic reviews and meta-analyses: the PRISMA statement. *International Journal of Surgery,* 8**,** pp336 – 341

Morgan DL (2014) Pragmatism as a paradigm for social research, *Qualitative Inquiry*, 20, 9 pp1045 – 1053

Morse JM, Noraeger-Stern P, Corbin J; Bowers B, Charmaz K & Clarke AE (2016) *Developing Grounded Theory: The Second Generation*, Oxon: Routledge

Nadeau JW (1998) *Families making sense of death (Vol. 10)*, London: Sage

National End of Life Care Programme (2011) *Talking about end of life care: right conversations, right people, right time*, London: HMSO

National Institute for Health and Care Excellence (2011). *End of Life Care for Adults (Quality Standard 13)* – accessed at https://www.nice.org.uk/guidance/qs13 - 17 April 2020

National Institute of Health and Care Excellence (2017) Care of dying adults in the last days of life (Quality standard 144) – accessed at https://www.nice.org.uk/guidance/qs144 - 17 April 2020

National Palliative and End of Life Care Partnership (2021) Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026 – accessed at https://www.england.nhs.uk/wp-content/uploads/2022/02/ambitions-for-palliative-and-end-of-life-care-2nd-edition.pdf - 6 May 2022

Neuberger JA, Bonser T, Charlesworth-Smith D, Cox D, Guthrie C, Hammed K, Jackson E & Waller S (2013) *More Care, Less Pathway: A review of the Liverpool Care Pathway,* Independent Review of the Liverpool Care Pathway

NHS England and NHS Improvement (2021) *Professional nurse advocate A-EQUIP model: A model of clinical supervision for nurses* – accessed at https://www.england.nhs.uk/publication/professional-nurse-advocate-a-equip-model-a-model-of-clinical-supervision-for-nurses/ 17 December 2021

Nouvet E, Strachan PH, Kryworuchko J, Downar J & You JJ (2016) Waiting for the body to fail: Limits to end-of-life communication in Canadian hospitals, *Mortality*, 21, pp340 - 356

Noyes J (2010) Never mind the qualitative feel the depth! The evolving role of qualitative research in Cochrane intervention reviews, *Journal of Research in Nursing* 15, 6, pp525 - 534

Nursing & Midwifery Council (2018) *The code: Professional standards of practice and behaviour for nurses, midwives and nursing associates.* Accessed at http://www.nmc.org.uk/globalassets/sitedocuments/nmc-publications/revised-new-nmc-code.pdf - 20 February 2019

O'Hara T (2011) Nurses' views on using the Liverpool Care Pathway in an acute hospital setting, *International Journal of Palliative Nursing,* 17**,** pp239 - 244

Office of National Statistics (2021) 2018 Provisional figures on deaths registered in England and Wales – *accessed at https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/datasets/weeklyprovisionalfiguresondeathsregisteredinenglandandwales - 20 November 2020*

Papadatou D (1997) Training health professionals in caring for dying children and grieving families, *Death Studies,* 21**,** pp575 - 600

Papadatou D (2000) A proposed model of health professionals' grieving process, *OMEGA: Journal of Death and Dying,* 41**,** pp59 – 77

Papadatou D, Martinson IM & Chung PM (2001) Caring for dying children: a comparative study of nurses' experiences in Greece and Hong Kong, *Cancer Nursing,* 24**,** pp402 – 412

Papadatou D. & Papadatos CJ (1991) *Children and death*, New York: Taylor & Francis Group

Parahoo K (2014) *Nursing research, principles, process and issues (3rd edition)*, Basingstoke: Palgrave MacMillan

Parliamentary and Health Service Ombudsman (2015) *Dying without dignity: Investigations by the Parliamentary and Health Service Ombudsman into complaints about end of life care*, London: PHSO

Patton (1999) Enhancing the quality and credibility of qualitative analysis, *Health Service Research*, 34, pp1189 - 1208

Peterson J, Johnson MA, Halvorsen B, Apmann L, Chang P-C, Kershek S, Scherr C, Ogi M & Pincon D (2010a) What is it so stressful about caring for a dying patient? A qualitative study of nurses' experiences, *International Journal of Palliative Nursing,* 16**,** pp181 – 187

Peterson JL, Johnson, MA, Halvorsen , Apmann L, Chang, P-C, Kershek, S, Scherr, C, Ogi M & Pincon D (2010b) Where do nurses go for help? A qualitative study of coping with death and dying, *International Journal of Palliative Nursing,* 16**,** pp432 – 438

Reed J & Procter S (1995) *Practitioner research in health care*, Boston, Massachusetts: Springer

Rejnö Å, Silfverberg G & Ternestedt BM (2017) Reasoning about truth-telling in end-of-life care of patients with acute stroke, *Nursing Ethics*, 24, pp100 – 110

Rickerson EM, Somers C, Allen CM, Lewis B, Strumpf N & Casarett DJ (2005) How well are we caring for caregivers? Prevalence of grief-related symptoms and need for bereavement support among long-term care staff, *Journal of Pain and Symptom Management,* 30**,** pp227 – 233

Ritchie J, Lewis J, McNaughton Nicholls C, Ormston R (2014) *Qualitative Research Practice (2nd edition): A guide for social science students and researchers*, London: Sage

Robson C & McCartan K (2016). *Real world research: a resource for users of social research methods in applied settings*, Chichester: Wiley & Sons Ltd

Rolls L & Relf M (2006) Bracketing interviews: addressing methodological challenges in qualitative interviewing in bereavement and palliative care, *Mortality*, 11, 3, pp286 - 305

Rubinelli S, Myers K, Rosenbaum M & Davis D (2020) Implications of the current COVID-19 pandemic for communication in healthcare, *Patient Education and Counseling,* 103**,** p1067

Rui-Shuang Z, Qiao-Hong G, Feng-Qi D & Owens RG (2015) Chinese oncology nurses' experience on caring for dying patients who are on their final days: A qualitative study, *International Journal of Nursing Studies,* 52**,** pp288 – 296

Sabo BM (2006) Compassion fatigue and nursing work: can we accurately capture the consequences of caring work? *International journal of nursing practice,* 12**,** pp136 – 142

Sackett DL, Rosenberg WM, Gray JM, Haynes RB & Richardson, WS (1996) Evidence based medicine: what it is and what it isn't, *British Medical Journal,* 312, 7023, pp71 - 72

Saldana J (2016) *Writing analytic memos*, in The coding manual for qualitative researchers (3rd ed)**,** London: Sage**,** pp32 - 44

Sanders JJ, Paladino J, Reaves E, Luetke-Stahlman H, Anhang Price R, Lorenz K, Hanson LC, Curtis JR, Meier DE & Fromme EK (2020) Quality measurement of serious illness communication: recommendations for health systems based on findings from a symposium of national experts, *Journal of Palliative Medicine,* 23**,** pp13 – 21

Saunders C (1989) *Pain and impending death*, in Wall PD& Melzak R (eds) Textbook of Pain (2nd ed) Edinburgh: Churchill Livingstone, pp624 - 631

Schwandt T (2001) *Dictionary of qualitative inquiry*, London: Sage

Seale C (1999) Quality in Qualitative Research, *Qualitative Inquiry*, 5, 4, pp465 - 478

Selman LE, Chao D, Sowden R, Marshall S, Chamberlain C & Koffman J (2020) Bereavement support on the frontline of COVID-19: recommendations for hospital clinicians. *Journal of Pain and Symptom Management,* 60**,** pp e81-e86

Shannon SE, Sutehall-Long T & Coombs M (2011) Conversations in end-of-life care*, Nursing in Critical Care,* 16, 3, pp124 - 130

Shaver WA (2002) Suffering and the role of abandonment of self, *Journal of Hospice & Palliative Nursing,* 4**,** pp46 – 53

Sixsmith J, Boneham M, & Goldring JE (2003) Accessing the community: Gaining insider perspectives from the outside, *Qualitative Health Research*, 13, 4, pp578 - 589

Strang P, Bergström J, Martinsson L & Lundström S (2020) Dying from COVID-19: loneliness, end-of-life discussions, and support for patients and their families in nursing homes and hospitals. A national register study, *Journal of Pain and Symptom Management,* 60**,** ppe2 - e13

Strauss A (1978) *Qualitative Analysis for Social Scientists*, Cambridge: Cambridge University Press

Strauss A & Corbin J (1990) *Basics of Qualitative Research: Grounded Theory Procedure and Techniques*, London: Sage

Strauss A & Corbin J (1998) *Basics of Qualitative Research: Grounded Theory Procedures and Technique (2nd edition)*, London: Sage

Stroebe MS & Schut HA (1999) The dual process model of coping with bereavement: Rationale and description, *Death studies,* 23**,** pp197 - 224

Stroebe MS & Schut HA (2010). The dual process model of coping with bereavement: Overview and update, *The Australian Journal of Grief and Bereavement,* 11**,** pp4 - 10

Taylor C, Xyrichis A, Leamy MC, Reynolds E & Maben J (2018) Can Schwartz center rounds support healthcare staff with emotional challenges at work, and how do they compare with other interventions aimed at providing similar support? A systematic review and scoping reviews *BMJ Open,* 8, 10:e024254 – accessed at https://doi.org/10.1136/bmjopen-2018-024254 - 6 May 2022

Thomas J & Harden A (2008) Methods for the thematic synthesis of qualitative research in systematic reviews, *BMC Medical Research Methodology,* 8**,** p45

Thompson G, McClement S. & Daeninck P (2006) Nurses' perceptions of quality end-of-life care on an acute medical ward. *Journal of Advanced Nursing,* 53**,** pp169 - 177

Thornberg R (2012) Informed grounded theory, *Scandinavian Journal of Educational Research,* 56**,** pp243 - 259

Tong A, Sainsbury P & Craig J (2007) Consolidated criteria for reporting qualitative research (COREQ): a 32-item checklist for interviews and focus groups, *International Journal for Quality in Healthcare,* 19**,** pp349 – 357

Tornøe KA, Danbolt LJ, Kvigne K & Sorlie V (2015) The challenge of consolation: nurses experiences with spiritual and existential care for the dying-a phenomenological hermeneutical study, *BMC Nursing,* 14

Tyler PA & Ellison RN (1994) Sources of stress and psychological well-being in high-dependency nursing, *Journal of Advanced Nursing,* 19**,** pp469 – 476

Urquhart C (2013) *Grounded Theory for Qualitative Research: A practical guide*, London: Sage

Van Belle E, Giesen J, Conroy T, Van Mierlo M, Vermeulen H, Huisman-De Waal G & Heinen M (2020) Exploring person-centred fundamental nursing care in hospital wards: A multi-site ethnography, *Journal of Clinical Nursing,* 29**,** pp1933 – 1944

Walsh D & Downe S (2006) Appraising the quality of qualitative research, *Midwifery,* 22**,** pp108 – 119

Warnock C, Tod A, Foster J & Soreny C (2010) Breaking bad news in inpatient clinical settings: role of the nurse, *Journal of Advanced Nursing,* 66**,** pp1543 - 1555

Warnock C, Buchanan J & Tod AM (2017) The difficulties experienced by nurses and healthcare staff involved in the process of breaking bad news, *Journal of Advanced Nursing,* 73**,** pp1632 – 1645

Watson J (1988) New dimensions of human caring theory, *Nursing Science Quarterly*, 1, 4, pp175 – 181

Watson J (1997) The theory of human caring: Retrospective and prospective, *Nursing Science Quarterly*, 10, 1, pp49 - 52

Watson J (2002). Intentionality and caring-healing consciousness: A practice of transpersonal nursing, *Holistic Nursing Practice,* 16**,** pp12 - 19

Watson J (2005) *Jean Watson's Theory of Human Caring,* Philadelphia, FA Davies Company

Watson J (2006) *Part one: Jean Watson's theory of human caring*, in. Parker ME (Ed.), Nursing theories and nursing practice**,** Philadelphia: FA Davis Co, pp295 – 302

Watson J & Foster R (2013) *The Attending Nurse Caring Model: integrating theory, evidence and advanced caring-healing therapeutics for transforming professional practice*, in. Smith MC, Turkle MC & Robinson Wolf Z (2013) Caring in Nursing Classics: An Essential Resource, New York: Springer Publishing Company.

Wiener L, Rosenberg AR, Pennarola B, Fry A & Weaver M (2021) Navigating the terrain of moral distress: Experiences of pediatric end-of-life care and bereavement during COVID-19, *Palliative & Supportive Care,* 19**,** pp129 – 134

Wilde V (1992) Controversial hypotheses on the relationship between researcher and informant in qualitative research*, Journal of Advanced Nursing,* 17, 2, pp234 – 242

Wildridge V & Bell L (2002) Brief communication. How CLIP became ECLIPSE: a mnemonic to assist in searching for health policy/management information, *Health Information & Libraries Journal,* 19**,** pp113 – 115

Wilson J & Kirshbaum M (2011) Effects of patient death on nursing staff: a literature review. *British Journal of Nursing,* 20**,** pp559 – 563

Yates PM (2013) Before, during and after: Identity and the social construction of knowledge in qualitative research interviews, *Hydra – Interdisciplinary Journal of Social Sciences*, 1, 1, pp31 – 41

Young J (2005) On insiders (Emic) and outsiders (Etic) views of self, and othering, *System Practice and Action Research*, 18, pp151 – 162

Young R & Collin A (2004) Introduction: constructivism and social constructionism in the career field, *Journal of Vocational Behaviour*, 64, 3

Zheng RS, Guo QH, Dong FQ & Owens RG (2015) Chinese oncology nurses' experience on caring for dying patients who are on their final days: A qualitative study, *International Journal of Nursing Studies*, 52, pp288 - 296.

Zheng RS, Lee SF & Bloomer MJ (2018) How nurses cope with patient death: A systematic review and qualitative meta-synthesis, *Journal of Clinical Nursing,* 27**,** ppe39 - e49

Appendix A – Search Strategy

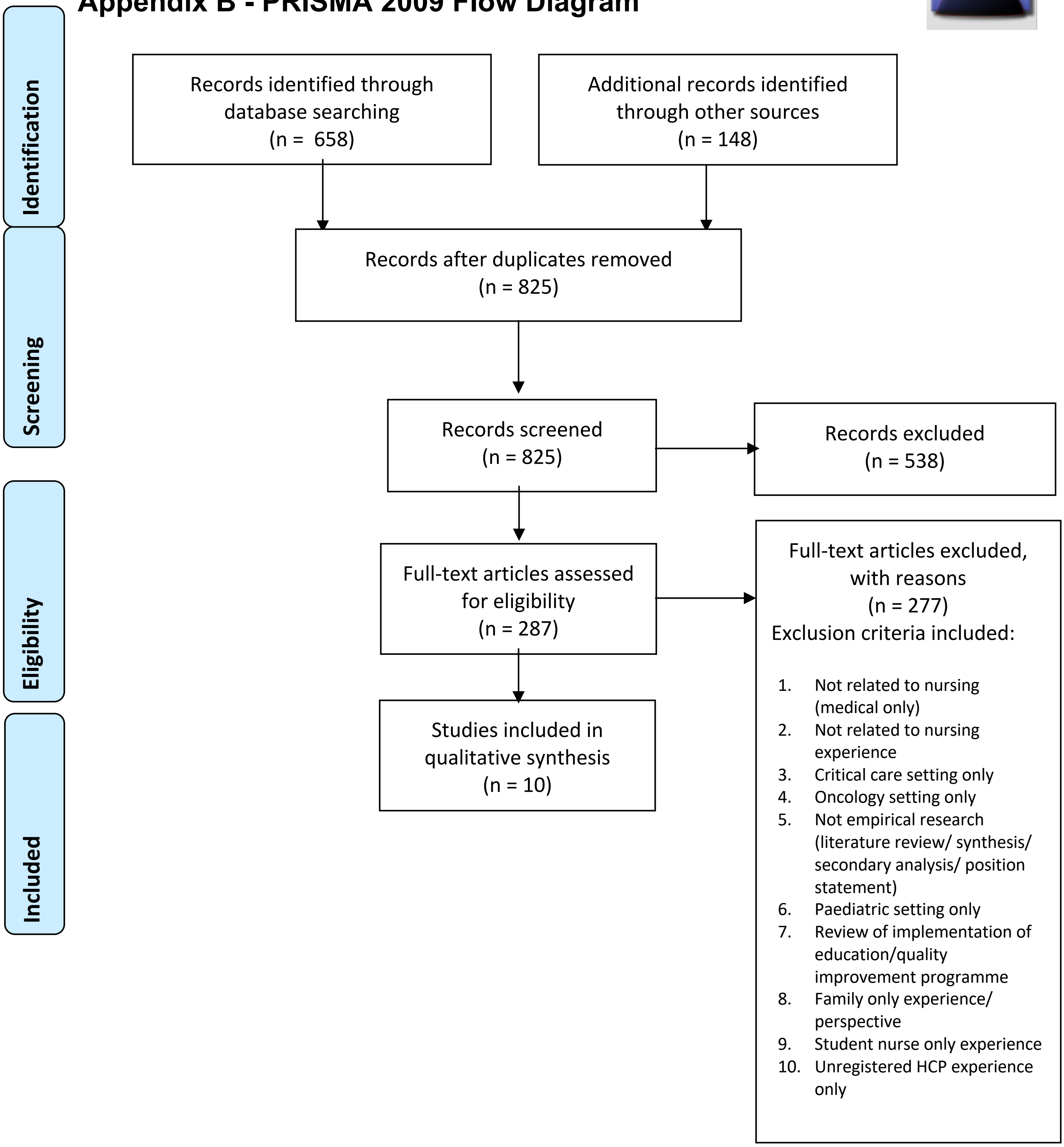
Supportive Literature Review – PICO (Qualitative)

Research Question: What is the impact of end-of-life conversations on nurses working in non-specialist inpatient adult wards?

	Population	Issue	Context	Outcome
PICO Term	"Registered Nurses"	"End-of-life conversations"	"Adult Ward*"	Impact
Alternative terms (synonyms)	Nurs* "qualified nurs*" "sister" "charge nurs*" "matron" "ward manager"	communication* discussion* talk* speak* convers* "breaking bad news" AND dying death "terminal care" "end of life"	"acute care" "secondary care" "tertiary care" hospital* "general ward*" "inpatient ward*"	effect* result* outcome* reaction* perception* though* feeling*

Databases to Search: CINAHL Complete, Medline with Full Text, Web of Science, PsycInfo (all individually)

Appendix B - PRISMA 2009 Flow Diagram



Appendix C – Literature Review summary

Details about the Studies					
Author (year), country, score	**Research question or aim of study**	**Participants & Setting**	**Method**	**Key themes**	**Recommendations/ Results**
Kerr et al (2020), Australia	What communication issues do nurses find challenging when caring for people with life-limiting illness?	39 Nurses (36 registered and 3 enrolled) Surgical, medical and palliative sub-acute ward	Qualitative descriptive study including focus groups (2 per ward). 1 lead facilitator, 1 second facilitator (scribe and provided a verbal summary), 1 research assistant managing recording technology	Staff feel unskilled to have difficult conversations with patients. (sub-theme 1) absence of a communication toolkit and framework inhibits capacity to respond to difficult questions and gather information. (sub-theme 2) Dealing with heightened emotions (Sub-theme 3) Interactions are difficult when there is denial Interacting with family members adds complexity to care of patients who have LLI (sub-theme 1) Unrealistic and mismatched expectations (Sub-theme 2) Balancing relational dynamics with patient values and needs Organisational factors impede nurses' capacity to have meaningful conversations with patients and families	Development of training interventions aiming to improve communication skills for nurses. Increase exposure of communication skills training, including conversation structure, in undergraduate and postgraduate nursing education programmes. Further research to explore the nurses' role in contributing to difficult conversations, including breaking bad news and dealing with prognostic questions.

Details about the Studies					
Author (year), country, score	**Research question or aim of study**	**Participants & Setting**	**Method**	**Key themes**	**Recommendations/ Results**
				(sub-theme 1) Inadequate degree of information (sub-theme 2) Lack of time	
Doubal et al (2018), Scotland	Explore the key learning needs of healthcare professionals when discussing end of life stroke care with patients and families	Combination nursing, medical staff, AHPs (including OT, PT, SALT, Dietician), Social workers, support workers, student Distributed through six national multiprofessional and NHS networks. 599 responses received.	Survey including closed and open questions (using Survey Monkey for closed questions, and NVivo for Open Questions)	Educational resource most valued would be in relation to ensuring consistent messages to families and patients, resolving intrafamily conflict, handling unrealistic expectations, involving families in discussions without making them feel responsible for decisions, discussing prognostic uncertainties, discussing likely mode of death, and discussing oral feeding for 'comfort' in patients at risk of aspiration. Majority of respondents found discussing end of life care with patients and families difficult due to following themes: • uncertainty of outcomes • clinical features of stroke • expectations of families and care teams (leading to angry families and unmet expectations) • a perceived lack of communication skills in self (opening conversations challenging – family understanding) • or deficiencies in services or resources (including layout preventing a private space to conduct conversations).	Survey results identified that HCPs reported discussing issues around palliative and end of life care with patients and families was challenging and that educations support would be welcome. Themes • Ensure consistent messages • Discuss expectations and priorities • Withholding treatment • Discussing prognostic uncertainty • Handling conflicts • Involving families meaningfully in discussions • Discussing the likely mode of death

Details about the Studies					
Author (year), country, score	**Research question or aim of study**	**Participants & Setting**	**Method**	**Key themes**	**Recommendations/ Results**
					An open online learning tool was subsequently developed based on these findings.
Dosser & Kennedy (2012) Scotland	Investigate the current support offered to carers near the end of life in an acute hospital setting, with a view to implementing changes.	5 Carers interviewed Nursing staff and clinical support workers in 2 wards(23 staff) 1 Oncology Ward 1 Cardiorespiratory Ward	Qualitative phenomenological methodology Individual interviews for Carers Focus Groups for ward staff (1 facilitator and 1 silent scribe)	Valuing and respecting, staff recognising the needs of carers but they could not always be addressed. Communication by staff focussed on information giving, although this was not always received by carers as sufficient. Staff may not have felt confident to raise sensitive issues or have recognised that the patient or carer may have wanted as much information as possible. Staff acknowledged lack of skills to deal with direct and difficult questions Ward staff demonstrated a more reactive stance in communication Difficulties in communicating in the ward were linked to the context and events surrounding the situations (including 'busyness' as a barrier). Use of language was important Some staff did not view breaking bad news as their role and so communication may have been lacking Staff recognised that aspects of communication could be improved and was linked to time, context, education and training.	Carers needs are only partially being met in the acute hospital setting. Lack of recognition of carers as partners in care by staff and deficits in communication skills may add to anxiety. Ward staff who work directly with patients and carers also require education and training in communication skills. Communication beyond the spoken word is critical, The palliative care approach is recommended for all patients diagnosed with a life-limiting condition. Health professionals, particularly nurses, need to have sufficient breadth and

Details about the Studies

Author (year), country, score	**Research question or aim of study**	**Participants & Setting**	**Method**	**Key themes**	**Recommendations/ Results**
				Communication was seen as secondary for some against provision of physical care and support of patients. A 'good' and comfortable death was assumed by some to meet the needs of carers and patients.	depth of knowledge of how to support patients and carers at the end of life.
Kryworuchko et al (2016), Canada	Identify factors influencing communication and decision-making, and learn how physicians and nurses view their roles in deciding about the use of life-sustaining technology for seriously ill hospitalised patients and their families	Medical ward staff across 3 Canadian hospitals 9 staff physicians 9 residents 12 nurses	Flanagan's Critical Incident Technique (CIT) – open-ended, in-depth individual interviews (n=30) Saturation achieved when adding 100 critical incidents contributed only 2/3 themes to the analysis.	**Conceptualisations of medical practice as 'saving lives and warding off death.** Death and dying spoken of as largely a culturally taboo topic in hospitals Dominant cultural, economic construction of hospitals, saving lives, warding off death, not overseeing the dying Discussions were avoided until doctors (and sometimes nurses) recognised that life-saving interventions were increasingly futile Communication characterised as difficult and stressful, due to urgency to communicate primarily to prevent delivery of futile care. **Work towards 'making sense of the situation'** Good cases related to dialogue with patients and/or families which created opportunities to construct a shared understanding of the patient's situation. Patient/families not emotionally ready for the discussion led to situations 'getting stuck' – nurses perceived this a missed	Policy and practice recommendations aimed at improving end of life care need to attend to the social factors that shape current attitudes and practices towards death and dying. Physician and nurse training and continuing education need to more explicitly acknowledge clinical uncertainties around end of life. Training needs to explicitly acknowledge and engage dominant if often implicit and taken-for-granted ethical, cultural and professional values and expectations shaping current practices. Training sessions such as these would provide an

Details about the Studies					
Author (year), country, score	**Research question or aim of study**	**Participants & Setting**	**Method**	**Key themes**	**Recommendations/ Results**
				opportunity to ease patient and family suffering **Inherent and systematic tensions in achieving consensus about goals of care** Perceptions of patients/families being emotional and irrational at times. Patients/families described as 'difficult' based on their inability to understand or accept the situation Nurses feeling 'left behind in the wake' of heated discussions Systemic limitations to consensus building and shared decision-making. Consideration that staff unable themselves to diffuse difficult situations if they themselves feel pressure to adjust the care plan Nurses and physicians lacked skill sets to unblock tense disagreements, and lack of time **Approaches to professional work within teams** Description of nursing work largely absent in medical narrative Work done by nurses not recognised as contributing to communication and decision-making. Nursing work described as happening around medical encounters (picking up the pieces).	opportunity to reiterate that such discussions do not and must not make the end of quality care for seriously ill patients.

Details about the Studies					
Author (year), country, score	**Research question or aim of study**	**Participants & Setting**	**Method**	**Key themes**	**Recommendations/ Results**
				Nurses and residents feel isolated in the work they did connected to goals of care. Nurses identified benefits of nurses being more fully informed and included in physician-led goals of care discussions. Mentorship, modelling and support to develop skills mentioned by participants	
Caswell et al (2015), UK	Focus on communication between hospital staff and family carers f patients dying on acute hospital wards, with a focus on the family carers' experience.	Four wards in an English teaching hospital (one acute admission ward, one specialist and mental health unit for older people with cognitive impairment, and two health care of the older people wards. 32 members of staff were interviewed (breakdown not given)	Ethnographic approach, utilising mixed methods of non-participant observation, semi-structured interviews and one focus group with healthcare professionals and bereaved carers, and a review of medical and nursing notes.	**Giving bad news** Whilst death happens on a regular basis, it was not perceived to be the core work of the ward. Nurses felt they need to read medical notes of patient to gain the information required. Nurses were not so ready or bale to discuss aspects of care with family carers **Role of the nurse** 'It's the nurse's job to support the family' Nurses put what the doctor has said into language that the family can comprehend, Nurses' intervention was critical when summoning the family when they recognised that death was imminent. **Perceived limitations to carers' understanding** One conversation with a. doctor was insufficient to allow carers to understand	Factors identified which may have prevented staff from being more effective in their communication included a fear of saying the wrong thing, a lack of confidence in communicating the uncertainty which often accompanied a patient's prognosis, and the institutional nature of an NHS hospital. The culture of the NHS encourages efficiency, and precludes measurements and indicators of efficiency which include the amount of time staff members spend talking to patients and their families.

Details about the Studies					
Author (year), country, score	**Research question or aim of study**	**Participants & Setting**	**Method**	**Key themes**	**Recommendations/ Results**
				that their relative was dying and what the implications of this might be. The onus of understanding was placed on the carers, implying that health professionals have carried out their duty by having the one conversation with the family. It is the carers' responsibility to seek out staff to have further conversations (this was not easy from carers' viewpoint). Lack of contact between family carers and members of staff prohibited the establishment of mutual understanding. Cases evidenced that there was a lack of awareness on the part of staff of the emotional distress that carers keeping vigil for dying patients on the wards may experience. .	Carers were seen to struggle to retain the information they were given, particularly when vague language was used. It was noted this occurred when staff attempted to break potentially painful news. Nurses interpreted information from doctors in way that carers could understand it. However, staff uncertainty and lack of time make communication difficult.
Nouvet et al (2016), Canada	Qualitative part of the DECIDE study to recall and describe hospital-based goals of care communication and decision-making incidents that had gone 'well' or 'unwell' in the acute medical care setting.	30 participants (18 nurses and 12 physicians) from hospitals distributed across three Canadian provinces (French and English speaking).	Interviews were undertaken using Flanagan's Critical Incident Technique. A constant comparative approach was used to analyse data.	**Recognised gap in goals of care discussions with seriously ill hospitalised patients** Discussing end of life goals of care as early as possible is expected but this is rarely enacted in practice and nothing is written in the patient's notes about goals of care. Conversations generally occurred as a last-minute process in the face of fast-approaching death.	Delaying goals of care communication and decision-making was identified as the norm rather than the exception. A complex tangle of assumptions and expected practices is identified that pushes goals of care discussions to the last minute.

Details about the Studies					
Author (year), country, score	**Research question or aim of study**	**Participants & Setting**	**Method**	**Key themes**	**Recommendations/ Results**
				Active avoidance of end-of-life discussions A failure to discuss end of life in the outpatient setting to alert patients to foreseeable decline and death. A focus on getting patients through a life-threatening situation. End of life goals of care discussions were not enjoyable and dreaded by many. Concerns raised that the therapeutic relationship would be broken if such conversations were instigated. Cultural taboos regarding death and dying led these conversations to being inherently ‘difficult’ for some. **Uncertainty about what counts as end of life** Difficulty in judging a patient as ‘end of life’, given the many options for treatment or symptom management. Clinical uncertainty about patient’s risk status **Do everything…..until there is nothing to be done** Physician responsibility to try every possible treatment with a patient Selectivity noted to determine which patients or families were engaged with in goals of care discussions. Nurses identified collision with ideals of care for patients versus ‘do everything’ viewpoint.	Clinically defining patients as being at an increased risk of dying is identified as challenging. A symbolic boundary is identified, which marks the limit of medicine’s power to help. ‘Doing everything’ is the dominant ethic guiding the treatment of seriously ill patients on these wards, creating a barrier to discussion because it devalues non-curative care. Moving to a palliative approach is not valued by the physicians’ paradigm. A perception that this paradigm minimises physician involvement in patient deaths. There is an argument that standard protocols will not fit actual practice, which may provide an opportunity for more clinicians to develop and demonstrate abilities to

Details about the Studies					
Author (year), country, score	**Research question or aim of study**	**Participants & Setting**	**Method**	**Key themes**	**Recommendations/ Results**
					engage patients and families in conversations about goals of care. It should be recognised that providing care that focusses on comfort is not 'nothing'. Policies and guidelines need to attend to the social factors that shape current attitudes and practices towards death and dying. MDT Training and continuing education needs to more explicitly acknowledge clinical uncertainties around end of life. Such training needs to engage dominant ethical, cultural and professional values and expectations shaping current practice.
Rejnö et al (2017), Sweden	Deepen the understanding of stroke team members' reasoning about truth-telling in end-of-life care	15 stroke team members working in stroke units of two associated county hospitals.	Qualitative study based on individual interviews utilising deductive and inductive content analysis.	**Truth above all** Participants highly valued honestly and considered that a reason for always telling the truth without embellishing. A value in itself	The movement between Truth Above All and Hide Truth to Protect was a dynamic process. Staff were striving to be true.

Details about the Studies					
Author (year), country, score	**Research question or aim of study**	**Participants & Setting**	**Method**	**Key themes**	**Recommendations/ Results**
	due to acute stroke.			Honesty was ideal and straightforward and without euphemism the truth should be told It was the best option to prepare the family. <u>To establish trust</u> Truth contributed to a good relation with next of kin. When truth was told, everything was though to be easier and better (including the staff) A mutual understanding of the situation was considered possible, creating a feeling of security and trust. **Hide truth to protect** Carers thought truth could also be harmful Participants would hide the truth of parts of it as part of a strategy, to protect the next of kin <u>Not add extra burden in the sorrow</u> The carers argued withholding truth could be done if next of kin could not deal with whole truth Balance of consequence by telling the whole truth being harmful, aspects would be hidden (such as a difficult death). Giving hope to next of kin was a rationale <u>Awaiting the timely moment</u> Creating possibilities for good care a rationale for delay Carers could have time to arrange for a better meeting, ensuring support in place	Nursing focussed on two subcategories alone (awaiting the right time and not being a messenger of bad news), due to professional and inherent liability of the responsibility for informing next of kin resting on the physicians. Moral imperative was on determining the consequence of action (or not). Due to the uncertainty of care objective vs subjective truth was considered, placing it in time, place and ability. In addition, truth in relation to situations also included relations with organisation structures of care, and the need for support (for staff). Fear of talking of death and dealing with reactions to bad news may contribute the strategy to Hide truth to protect.

Details about the Studies					
Author (year), country, score	**Research question or aim of study**	**Participants & Setting**	**Method**	**Key themes**	**Recommendations/ Results**
				Ensuring strong evidence assessed prior to sharing (including being assured themselves) Not being a messenger of bad news (Nurses particularly) not wanting to impact the bad news to next of kin. Utilise tools to not disclose by not having information themselves (actively not looking) Omission was not considered the same as telling a lie.	Nurses wanted to escape the situation and leave the delivery to someone else. Not wanting to destroy hope was a rationale to not deliver the full-truth. Carers may need support in the form of supervision to be given space to reflect on experience. MDT can be of great value and contribute through inter-professional learning. Recognition of the strain put on the cares to manage the situations will be considerable and call for increased co-operation with next of kin.
Hopkinson et al (2005), UK	To find out how newly qualified nurses cope with caring for dying people in acute hospital medical wards.	28 nurses interviewed from two hospital Trusts in North of England.	Nondirective open style of interviewing. (cross-sectional interview based study). Discovery of patterns identified guided by work of Wolcott	**Relationships** Nurses identified helpful relationships from colleagues to share understanding of experiences. Feedback from patients and relatives were supportive, leading to participatory work with families.	**Development of a theory – the translucent web** Anti-tensions adopted by a nurse worked together as a translucent web to support them through the experience.

Details about the Studies					
Author (year), country, score	**Research question or aim of study**	**Participants & Setting**	**Method**	**Key themes**	**Recommendations/ Results**
			(1994) and Van Manen (1994)	**Resources** Preparation of information supported shaping their own expectations. Anticipation of what was to come allowed them to take action to shape outcomes. Involving others in making clinical judgements helped lessen the burden of responsibility. Escaping the difficulties of caring for dying patients was noted, by undertaking different tasks. Humour was identified as a resource to relieve the burden. Using a structured approach when talking with dying people and families was identified. **Learning from experience** Personal learning occurred as a result of participants own practice and observing/inquiring into others. Knowledge was gained through experience. Experiential learning was deemed to help participants best. **Controlling involvement**	Directional – motivated by a need to sustain or restore a sense of personal comfort Situational – adopted according to circumstance and personal history Dynamic – changed across time with new experiences Translucent – were only partially in a nurse's awareness or control The theory evidences how nurses cope with caring for dying people on acute hospital medical wards. It conceptualises coping as prophylactic as well as restorative, with cognition and behaviour intended to support well-being operating at both an unconscious level and other than in relation to self-perceived stress. Coping was found to be: *The situation specific thoughts and behaviours*

Details about the Studies

Author (year), country, score	**Research question or aim of study**	**Participants & Setting**	**Method**	**Key themes**	**Recommendations/ Results**
				Controlling the amount of emotional involvement was evidenced as a balancing process – ie not to distance themselves too much but not to become too involved. This enabled them to function in their nursing role. **Measuring** Positive feedback from a patient or relative was evidenced as a 'job well done'. Imagining themselves or a member of their family in the patient's position was also identified as way to identify satisfaction. **Revision of the ideal way to die** Participants changed their beliefs about what should happen. **Personal comfort** Anti-tensions were identified as a tool to sustain or restore a sense of personal comfort. Achieving a comfortable death. Identification of various anti-tensions was based upon personal history as well as a specific dying situation.	*engaged by an individual either consciously or unconsciously, with a consequence of sustaining or restoring personal comfort.* A model for supporting nurses would incorporate the needs of the family as well as the needs of the patients. Guidelines in caring for dying people would create markers against which nurses could just their performance.

Details about the Studies					
Author (year), country, score	**Research question or aim of study**	**Participants & Setting**	**Method**	**Key themes**	**Recommendations/ Results**
Warnock et al (2017), UK	To explore the difficulties experienced by nurses and healthcare professionals when engaging in the process of breaking bad news	145 participants in a two-stage study. Participants attended an education day designed to support healthcare staff in the process of breaking bad news. North of England (all healthcare staff)	A descriptive survey design was used. A questionnaire generated qualitative data. Free text descriptions were analysed using framework analysis (Ritchie et al, 2014).	**Roles were categorised into four subject areas:** • Diagnostic and treatment information, including test results. • The impact of illness • Managing reactions • Care at the end of life **Sources of difficulty** Situation Difficult subjects Unexpected news/events Context of communication Tension within the healthcare team Organisation Time and staffing Relationships between departments/services Information systems and processes Services available Patients and relatives Reactions to information and events Family context – disclosure and dynamics Relationship/communication breakdown with healthcare team Communication barriers – physical, language, comprehension	There are multiple moments across the healthcare pathway when significant information is given or managed. Involvement in the process of breaking bad news is not restricted to information provision. Cultural factors can affect the provision of bad news. Staff confidence and congruence between medical and nursing staff can present difficulties. **Results** A structured framework was developed and proposed to have several uses. For nurses and HCPs to reflect on clinical events and practice. The framework highlights the depth and breadth of knowledge and skills required for those involved in the process of breaking

Details about the Studies					
Author (year), country, score	**Research question or aim of study**	**Participants & Setting**	**Method**	**Key themes**	**Recommendations/ Results**
				Individual Individual resources Balancing Emotional consequences	bad news, in order to provide direction to providers for education. The framework suggests the need to look beyond the traditional focus on comms skills in education and include other topics including working with family systems, managing ethical dilemmas, conflict resolution, team working and supporting coping and adaptation. Organisationally, resources need to be reviewed including facilities to support breaking bad news (interpreters, private spaces and provision for structured learning and reflection).

Details about the Studies					
Author (year), country, score	**Research question or aim of study**	**Participants & Setting**	**Method**	**Key themes**	**Recommendations/ Results**
Warnock et al (2010), UK	An exploration of the role of the nurse in the process of breaking bad news in the inpatient clinical setting and the provision of education and support for nurses carrying out this role	236 participants completed a questionnaire (142 staff nurses, 64 ward sisters/charge nurses and 10 nurse specialists),across multiple specialities (medical, surgical, oncology, ICU) in one large NHS Trust in the North of England.	A descriptive survey design was adopted to generate quantitative and qualitative data. Data were analysed using descriptive statistics. Responses to open-ended questions were coded according to their content, and then grouped to form themes. Relationships were explored to develop categories that described the data.	**Barriers to breaking bad news experienced by nurses** How the bad news was broken *Barriers to communication* Practical/physical (lack of privacy, lack of time, method of communication, difficulty contacting family) Language/culture Deficit in nursing knowledge – limited knowledge of events, concerns of own clinical knowledge related to aspects of care. *Information held by patients and relatives* Disclosure – family requested patient not given information leading to impaired nurse/patient communication, nurses feeling dissatisfied about level of care Patient/relative understanding – misunderstand/misinterpreting information given, leading to difficult context for breaking bad news *Unexpected death* Patients dying with no relative present Having to break bad news over the telephone *Reactions to bad news* Complexity and strength of emotions involved when breaking bad news, resulting	For nurses breaking bad news is seen more as a process rather than a consultation. A lack of ability to control the timing of their involvement in breaking bad news was evident. Guidelines already in place to support HCPs when bad news is given, usually focusses on that moment. The study highlights the potential limitations to this approach, for nurses, as they do not acknowledge the ongoing nature of the process. Those involved need to feel confident in their ability to break bad news confidently. 'On the job' training itself is insufficient to meet the educational needs of many nurses. Further research is required.

Details about the Studies					
Author (year), country, score	**Research question or aim of study**	**Participants & Setting**	**Method**	**Key themes**	**Recommendations/ Results**
				in verbal abuse, anger, physical aggression, intimidation, hysteria, and denial. *Significant events* Events leading to enduring effect staying with participants long after the event. *Sources of difficulty* The event itself Relatives' actions Inadequate staffing/services Difficulties with the patient Medical staff Lack of knowledge or expertise **Nurse's experiences of being involved** Mixed response - many thought positive consequences of being involved Experience had encouraged participants to reflect positively on own priorities and what was important Majority felt able to initiate conversations about bad news. **Previous training in relation to breaking bad news** Majority had received little or no formal education on breaking bad news Majority had learned through informal methods such as experience over time Observing the practice of others was felt to be most useful.	

Details about the Studies					
Author (year), country, score	**Research question or aim of study**	**Participants & Setting**	**Method**	**Key themes**	**Recommendations/ Results**
				Majority felt support was available for staff involved in the process of braking bad news – majority informal.	

Appendix D – QARI Tool (Joanna Briggs Institute)

Introduction

JBI is an international research organisation based in the Faculty of Health and Medical Sciences at the University of Adelaide, South Australia. JBI develops and delivers unique evidence-based information, software, education and training designed to improve healthcare practice and health outcomes. With over 70 Collaborating Entities, servicing over 90 countries, JBI is a recognised global leader in evidence-based healthcare.

JBI Systematic Reviews

The core of evidence synthesis is the systematic review of literature of a particular intervention, condition or issue. The systematic review is essentially an analysis of the available literature (that is, evidence) and a judgment of the effectiveness or otherwise of a practice, involving a series of complex steps. JBI takes a particular view on what counts as evidence and the methods utilised to synthesise those different types of evidence. In line with this broader view of evidence, JBI has developed theories, methodologies and rigorous processes for the critical appraisal and synthesis of these diverse forms of evidence in order to aid in clinical decision-making in healthcare. There now exists JBI guidance for conducting reviews of effectiveness research, qualitative research, prevalence/incidence, etiology/risk, economic evaluations, text/opinion, diagnostic test accuracy, mixed-methods, umbrella reviews and scoping reviews. Further information regarding JBI systematic reviews can be found in the JBI Evidence Synthesis Manual.

JBI Critical Appraisal Tools

All systematic reviews incorporate a process of critique or appraisal of the research evidence. The purpose of this appraisal is to assess the methodological quality of a study and to determine the extent to which a study has addressed the possibility of bias in its design, conduct and analysis. All papers selected for inclusion in the systematic review (that is – those that meet the inclusion criteria described in the protocol) need to be subjected to rigorous appraisal by two critical appraisers. The results of this appraisal can then be used to inform synthesis and interpretation of the results of the study. JBI Critical appraisal tools have been developed by the JBI and collaborators and approved by the JBI Scientific Committee following extensive peer review. Although designed for use in systematic reviews, JBI critical appraisal tools can also be used when creating Critically Appraised Topics (CAT), in journal clubs and as an educational tool.

JBI Critical Appraisal Checklist for Qualitative Research

Reviewer______________________________ Date_____23__________April 2021______________________________

Author____ Year_________ Record Number_________

	Yes	No	Unclear	Not applicable
1. Is there congruity between the stated philosophical perspective and the research methodology?	☐	☐	☐	☐
2. Is there congruity between the research methodology and the research question or objectives?	☐	☐	☐	☐
3. Is there congruity between the research methodology and the methods used to collect data?	☐	☐	☐	☐
4. Is there congruity between the research methodology and the representation and analysis of data?	☐	☐	☐	☐
5. Is there congruity between the research methodology and the interpretation of results?	☐	☐	☐	☐
6. Is there a statement locating the researcher culturally or theoretically?	☐	☐	☐	☐
7. Is the influence of the researcher on the research, and vice- versa, addressed?	☐	☐	☐	☐
8. Are participants, and their voices, adequately represented?	☐	☐	☐	☐
9. Is the research ethical according to current criteria or, for recent studies, and is there evidence of ethical approval by an appropriate body?	☐	☐	☐	☐
10. Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data?	☐	☐	☐	☐

Overall appraisal: Include ☐ Exclude ☐ Seek further info ☐

Comments (Including reason for exclusion)

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Discussion of Critical Appraisal Criteria

How to cite: Lockwood C, Munn Z, Porritt K. Qualitative research synthesis: methodological guidance for systematic reviewers utilizing meta-aggregation. Int J Evid Based Healthc. 2015;13(3):179–187.

1. **Congruity between the stated philosophical perspective and the research methodology**

   Does the report clearly state the philosophical or theoretical premises on which the study is based? Does the report clearly state the methodological approach adopted on which the study is based? Is there congruence between the two? For example:

   A report may state that the study adopted a critical perspective and participatory action research methodology was followed. Here there is congruence between a critical view (focusing on knowledge arising out of critique, action and reflection) and action research (an approach that focuses on firstly working with groups to reflect on issues or practices, then considering how they could be different; then acting to create a change; and finally identifying new knowledge arising out of the action taken). However, a report may state that the study adopted an interpretive perspective and used survey methodology. Here there is incongruence between an interpretive view (focusing on knowledge arising out of studying what phenomena mean to individuals or groups) and surveys (an approach that focuses on asking standard questions to a defined study population); a report may state that the study was qualitative or used qualitative methodology (such statements do not demonstrate rigour in design) or make no statement on philosophical orientation or methodology.

2. **Congruity between the research methodology and the research question or objectives**

   Is the study methodology appropriate for addressing the research question? For example:
   A report may state that the research question was to seek understandings of the meaning of pain in a group of people with rheumatoid arthritis and that a phenomenological approach was taken. Here, there is congruity between this question and the methodology. A report may state that the research question was to establish the effects of counselling on the severity of pain experience and that an ethnographic approach was pursued. A question that tries to establish cause-and effect cannot be addressed by using an ethnographic approach (as ethnography sets out to develop understandings of cultural practices) and thus, this would be incongruent.

3. **Congruity between the research methodology and the methods used to collect data**

   Are the data collection methods appropriate to the methodology? For example:

   A report may state that the study pursued a phenomenological approach and data was collected through phenomenological interviews. There is congruence between the methodology and data collection; a report may state that the study pursued a phenomenological approach and data was collected through a postal questionnaire. There is incongruence between the methodology and data collection here as phenomenology seeks to elicit rich descriptions of the experience of a phenomena that cannot be achieved through seeking written responses to standardized questions.

4. **Congruity between the research methodology and the representation and analysis of data**

   Are the data analyzed and represented in ways that are congruent with the stated methodological position? For example:

   A report may state that the study pursued a phenomenological approach to explore people’s experience of grief by asking participants to describe their experiences of grief. If the text generated from asking these questions is searched to establish the meaning of grief to participants, and the meanings of all participants are included in the report findings, then this represents congruity; the same report may, however, focus only on those meanings that were common to all participants and discard single reported meanings. This would not be appropriate in phenomenological work.

5. **There is congruence between the research methodology and the interpretation of results**

   Are the results interpreted in ways that are appropriate to the methodology? For example:

   A report may state that the study pursued a phenomenological approach to explore people’s experience of facial disfigurement and the results are used to inform practitioners about accommodating individual differences in care. There is congruence between the methodology and this approach to interpretation; a report may state that the study pursued a phenomenological approach to explore people’s experience of facial disfigurement and the results are used to generate practice checklists for assessment. There is incongruence between the methodology and this approach to interpretation as phenomenology seeks to understand the meaning of a phenomenon for the study participants and cannot be interpreted to suggest that this can be generalized to total populations to a degree where standardized assessments will have relevance across a population.

6. **Locating the researcher culturally or theoretically**

   Are the beliefs and values, and their potential influence on the study declared? For example:

   The researcher plays a substantial role in the qualitative research process and it is important, in appraising evidence that is generated in this way, to know the researcher's cultural and theoretical orientation. A high quality report will include a statement that clarifies this.

7. **Influence of the researcher on the research, and vice-versa, is addressed**

   Is the potential for the researcher to influence the study and for the potential of the research process itself to influence the researcher and her/his interpretations acknowledged and addressed? For example:

   Is the relationship between the researcher and the study participants addressed? Does the researcher critically examine her/his own role and potential influence during data collection? Is it reported how the researcher responded to events that arose during the study?

8. **Representation of participants and their voices**

   Generally, reports should provide illustrations from the data to show the basis of their conclusions and to ensure that participants are represented in the report.

9. **Ethical approval by an appropriate body**

   A statement on the ethical approval process followed should be in the report.

10. **Relationship of conclusions to analysis, or interpretation of the data**

    This criterion concerns the relationship between the findings reported and the views or words of study participants. In appraising a paper, appraisers seek to satisfy themselves that the conclusions drawn by the research are based on the data collected; data being the text generated through observation, interviews or other processes.

Appendix E – Thematic Analysis of Literature

Details about the Studies					
Author (year), country, score	**Research question or aim of study**	**Participants & Setting**	**Method**	**Key themes**	**Codes and themes**
Kerr et al (2020), Australia	What communication issues do nurses find challenging when caring for people with life-limiting illness?	39 Nurses (36 registered and 3 enrolled) Surgical, medical and palliative sub-acute ward	Qualitative descriptive study including focus groups (2 per ward). 1 lead facilitator, 1 second facilitator (scribe and provided a verbal summary), 1 research assistant managing recording technology	Staff feel unskilled to have difficult conversations with patients. (sub-theme 1) absence of a communication toolkit and framework inhibits capacity to respond to difficult questions and gather information. (sub-theme 2) Dealing with heightened emotions (Sub-theme 3) Interactions are difficult when there is denial Interacting with family members adds complexity to care of patients who have LLI (sub-theme 1) Unrealistic and mismatched expectations (Sub-theme 2) Balancing relational dynamics with patient values and needs Organisational factors impede nurses' capacity to have meaningful conversations with patients and families	**Managing family dynamics x 4** Gaining understanding (from patients) Managing non-compliance (perceived about patients) **Managing other's emotions (feeling unskilled) x2** Developing relationships (with patients) Avoiding the truth Managing patient frustrations Managing multiple families Balancing the flow of information **Managing family understanding x 2** Answering questions Managing unplanned conversations **Managing family emotions x 2** Starting the journey **Identifying (with others) x 2** Feeling upset Advocating **Learning through others x 2** Lacking training Gaining experience **Balancing needs x 2** Managing the context for patients Managing the context for families Battling time

Details about the Studies					
Author (year), country, score	**Research question or aim of study**	**Participants & Setting**	**Method**	**Key themes**	**Codes and themes**
				(sub-theme 1) Inadequate degree of information (sub-theme 2) Lack of time	**Lacking clarity x 2** Acting under tension Being excluded (by others in the team) Not being informed Compromising the plan Expecting to manage **Lacking a structure x 2** Lacking confidence Putting it on (face) Losing resilience Improvising Not having the tools Feeling the fear Nursing closely Having the basics Losing trust
Doubal et al (2018), Scotland	Explore the key learning needs of healthcare professionals when discussing end of life stroke care with patients and families	Combination nursing, medical staff, AHPs (including OT, PT, SALT, Dietician), Social workers, support workers, student Distributed through six national multiprofessional and NHS networks.	Survey including closed and open questions (using Survey Monkey for closed questions, and NVivo for Open Questions)	Educational resource most valued would be in relation to ensuring consistent messages to families and patients, resolving intrafamily conflict, handling unrealistic expectations, involving families in discussions without making them feel responsible for decisions, discussing prognostic uncertainties, discussing likely mode of death, and discussing oral feeding for 'comfort' in patients at risk of aspiration. Majority of respondents found discussing end of life care with patients and families difficult due to following themes:	**Managing expectations x 2** Messaging consistently Prognosticating challenges Future-telling Managing inconsistent messages **Managing different scenarios (deaths) x 2** Managing shock Managing unplanned conversations Timing the conversations **Being honest x 2** Deciding what stops and starts Not raising false hopes Finding the right words Not providing treatment **Managing family dynamics x 2**

Details about the Studies					
Author (year), country, score	**Research question or aim of study**	**Participants & Setting**	**Method**	**Key themes**	**Codes and themes**
		599 responses received.		• uncertainty of outcomes • clinical features of stroke • expectations of families and care teams (leading to angry families and unmet expectations) • a perceived lack of communication skills in self (opening conversations challenging – family understanding) • or deficiencies in services or resources (including layout preventing a private space to conduct conversations).	Challenging conversations Resolving family conflict Managing family responsibilities Managing distress Supporting family emotions Managing family understanding Managing family emotions **Wanting resources** Wanting skills Managing clinical risks Working through team challenges Lacking privacy Wanting training Meeting the challenge
Dosser & Kennedy (2012) Scotland	Investigate the current support offered to carers near the end of life in an acute hospital setting, with a view to implementing changes.	5 Carers interviewed Nursing staff and clinical support workers in 2 wards(23 staff) 1 Oncology Ward 1 Cardiorespiratory Ward	Qualitative phenomenological methodology Individual interviews for Carers Focus Groups for ward staff (1 facilitator and 1 silent scribe)	Valuing and respecting, staff recognising the needs of carers but they could not always be addressed. Communication by staff focussed on information giving, although this was not always received by carers as sufficient. Staff may not have felt confident to raise sensitive issues or have recognised that the patient or carer may have wanted as much information as possible. Staff acknowledged lack of skills to deal with direct and difficult questions Ward staff demonstrated a more reactive stance in communication Difficulties in communicating in the ward were linked to the context and events surrounding the situations (including 'busyness' as a barrier).	**Sharing information x 2** Offering solutions Being interested Communicating Using the right words Answering difficult questions Guiding the way Taking the lead Being sympathetic **Lacking confidence x 2** Lacking skills Reacting to situations Being affected by death Deprioritising communication (physical care priority) **Managing competing priorities x 2** Meeting family needs Providing physical care **Wanting training x 2**

Details about the Studies					
Author (year), country, score	**Research question or aim of study**	**Participants & Setting**	**Method**	**Key themes**	**Codes and themes**
				Use of language was important Some staff did not view breaking bad news as their role and so communication may have been lacking Staff recognised that aspects of communication could be improved and was linked to time, context, education and training. Communication was seen as secondary for some against provision of physical care and support of patients. A 'good' and comfortable death was assumed by some to meet the needs of carers and patients.	Not recognising others (carers) Not seeing others (carers) Not engaging (with carers) Assuming needs (of carers) Increasing knowledge Clarifying role responsibility (doctor v nurse) Lacking privacy Avoiding the conversation
Kryworuchko et al (2016), Canada	Identify factors influencing communication and decision-making, and learn how physicians and nurses view their roles in deciding about the use of life-sustaining technology for seriously ill hospitalised patients and their families	Medical ward staff across 3 Canadian hospitals 9 staff physicians 9 residents 12 nurses	Flanagan's Critical Incident Technique (CIT) – open-ended, in-depth individual interviews (n=30) Saturation achieved when adding 100 critical incidents contributed only 2/3 themes to the analysis.	**Conceptualisations of medical practice as 'saving lives and warding off death.** Death and dying spoken of as largely a culturally taboo topic in hospitals Dominant cultural, economic construction of hospitals, saving lives, warding off death, not overseeing the dying Discussions were avoided until doctors (and sometimes nurses) recognised that life-saving interventions were increasingly futile Communication characterised as difficult and stressful, due to urgency to communicate primarily to prevent delivery of futile care.	**Leaving it too late x 3** Delaying decisions Not starting the journey Avoiding the conversation '**Warding off death' x 2** Focusing on saving lives **Managing difficult situations x 2** Getting stuck Managing family understandings Challenging the medical position Failing to gain consensus Witnessing grief Managing grief Feeling the tension Feeling uncomfortable Judging families

Details about the Studies					
Author (year), country, score	**Research question or aim of study**	**Participants & Setting**	**Method**	**Key themes**	**Codes and themes**
				Work towards ‘making sense of the situation’ Good cases related to dialogue with patients and/or families which created opportunities to construct a shared understanding of the patient’s situation. Patient/families not emotionally ready for the discussion led to situations ‘getting stuck’ – nurses perceived this a missed opportunity to ease patient and family suffering **Inherent and systematic tensions in achieving consensus about goals of care** Perceptions of patients/families being emotional and irrational at times. Patients/families described as ‘difficult’ based on their inability to understand or accept the situation Nurses feeling ‘left behind in the wake’ of heated discussions Systemic limitations to consensus building and shared decision-making. Consideration that staff unable themselves to diffuse difficult situations if they themselves feel pressure to adjust the care plan Nurses and physicians lacked skill sets to unblock tense disagreements, and lack of time **Approaches to professional work within teams**	**Working together x 2** **Understanding the goal (consensus) x 2** Developing a relationship Understanding the context Helping the family Clarifying messages Minimising conflict Preparing self and others Working with others Supporting early conversations **Battling time x 2** Feeling the pressure (time poor) x 2 Feeling a failure Stressing **Constructing meaning/being present x 2** Joint understanding Reflecting Sharing experiences **Working invisibly x 2** ‘Planting the seeds’ ‘Picking up the pieces’ Working alone Wanting support Lacking support Gaining support Lacking experience

Details about the Studies					
Author (year), country, score	**Research question or aim of study**	**Participants & Setting**	**Method**	**Key themes**	**Codes and themes**
				Description of nursing work largely absent in medical narrative Work done by nurses not recognised as contributing to communication and decision-making. Nursing work described as happening around medical encounters (picking up the pieces). Nurses and residents feel isolated in the work they did connected to goals of care. Nurses identified benefits of nurses being more fully informed and included in physician-led goals of care discussions. Mentorship, modelling and support to develop skills mentioned by participants	Gaining training Developing culture
Caswell et al (2015), UK	Focus on communication between hospital staff and family carers f patients dying on acute hospital wards, with a focus on the family carers' experience.	Four wards in an English teaching hospital (one acute admission ward, one specialist and mental health unit for older people with cognitive impairment, and two health care of the older people wards.	Ethnographic approach, utilising mixed methods of non-participant observation, semi-structured interviews and one focus group with healthcare professionals and bereaved carers, and a review of medical and nursing notes.	**Giving bad news** Whilst death happens on a regular basis, it was not perceived to be the core work of the ward. Nurses felt they need to read medical notes of patient to gain the information required. Nurses were not so ready or bale to discuss aspects of care with family carers **Role of the nurse** 'It's the nurse's job to support the family'	**Battling time x 2** Giving time Having multiple conversations **Clarifying care x 4** **Gaining information and understanding x2** Understanding the plan Supporting the team Breaking bad news Communicating with families Understanding roles Managing conversations Positioning End of Life Care

Details about the Studies

Author (year), country, score	**Research question or aim of study**	**Participants & Setting**	**Method**	**Key themes**	**Codes and themes**
		32 members of staff were interviewed (breakdown not given)		Nurses put what the doctor has said into language that the family can comprehend, Nurses' intervention was critical when summoning the family when they recognised that death was imminent. **Perceived limitations to carers' understanding** One conversation with a doctor was insufficient to allow carers to understand that their relative was dying and what the implications of this might be. The onus of understanding was placed on the carers, implying that health professionals have carried out their duty by having the one conversation with the family. It is the carers' responsibility to seek out staff to have further conversations (this was not easy from carers' viewpoint). Lack of contact between family carers and members of staff prohibited the establishment of mutual understanding. **REVIEW** Cases evidenced that there was a lack of awareness on the part of staff of the emotional distress that carers keeping vigil for dying patients on the wards may experience.	Normalising End of Life Care Understanding responsibilities Understanding context Supporting the family Calling the family Managing distress Providing the best experience **Not feeling confident x 2** Moving responsibilities Implying the end Not giving time **Avoiding the family x 2** **Avoiding the conversation x 2** **Failing to empathise x 2** Needing clarity Understanding the plan

Details about the Studies					
Author (year), country, score	**Research question or aim of study**	**Participants & Setting**	**Method**	**Key themes**	**Codes and themes**
				Factors identified which may have prevented staff from being more effective in their communication included a fear of saying the wrong thing, a lack of confidence in communicating the uncertainty which often accompanied a patient's prognosis, and the institutional nature of an NHS hospital. The culture of the NHS encourages efficiency and precludes measurements and indicators of efficiency which include the amount of time staff members spend talking to patients and their families. Carers were seen to struggle to retain the information they were given, particularly when vague language was used. It was noted this occurred when staff attempted to break potentially painful news. Nurses interpreted information from doctors in way that carers could understand it. However, staff uncertainty and lack of time make communication difficult.	
Nouvet et al (2016), Canada	Qualitative part of the DECIDE study to recall and describe hospital-based goals of	30 participants (18 nurses and 12 physicians) from hospitals distributed	Interviews were undertaken using Flanagan's Critical Incident Technique. A	**Recognised gap in goals of care discussions with seriously ill hospitalised patients**	**Communicating late x 7** Being uncertain (prognosis) x 3 Feeling uncertain x 2 **Avoiding x 3**

Details about the Studies					
Author (year), country, score	**Research question or aim of study**	**Participants & Setting**	**Method**	**Key themes**	**Codes and themes**
	care communication and decision-making incidents that had gone 'well' or 'unwell' in the acute medical care setting.	across three Canadian provinces (French and English speaking).	constant comparative approach was used to analyse data.	Discussing end of life goals of care as early as possible is expected but this is rarely enacted in practice and nothing is written in the patient's notes about goals of care. Conversations generally occurred as a last-minute process in the face of fast-approaching death. **Active avoidance of end-of-life discussions** A failure to discuss end of life in the outpatient setting to alert patients to foreseeable decline and death. A focus on getting patients through a life-threatening situation. End of life goals of care discussions were not enjoyable and dreaded by many. Concerns raised that the therapeutic relationship would be broken if such conversations were instigated. Cultural taboos regarding death and dying led these conversations to being inherently 'difficult' for some. **Uncertainty about what counts as end of life** Difficulty in judging a patient as 'end of life', given the many options for treatment or symptom management. Clinical uncertainty about patient's risk status	Breaking the therapeutic relationship Managing difficult conversations Minimising interactions Failing to plan Failing to involve others Shifting responsibilities **Lacking clarity x 2** Needing to be certain **Saving lives first x 4** Doing everything x 2 Minimising end of life care **Choosing** Assuming what is right Providing comfort Providing training Communicating early

Details about the Studies					
Author (year), country, score	**Research question or aim of study**	**Participants & Setting**	**Method**	**Key themes**	**Codes and themes**
				Do everything…..until there is nothing to be done Physician responsibility to try every possible treatment with a patient Selectivity noted to determine which patients or families were engaged with in goals of care discussions. Nurses identified collision with ideals of care for patients versus 'do everything' viewpoint. **REVIEW** Delaying goals of care communication and decision-making was identified as the norm rather than the exception. A complex tangle of assumptions and expected practices is identified that pushes foals of care discussions to the last minute. Clinical defining patients as being at an increased risk of dying is identified as challenging. A symbolic boundary is identified, which marks the limit of medicine's power to help. 'Doing everything' is the dominant ethic guiding the treatment of seriously ill patients on these wards, creating a barrier to discussion because it devalues non-curative care.	

Details about the Studies					
Author (year), country, score	**Research question or aim of study**	**Participants & Setting**	**Method**	**Key themes**	**Codes and themes**
				Moving to a palliative approach is not valued by the physicians' paradigm. A perception that this paradigm minimises physician involvement in patient deaths. There is an argument that standard protocols will not fit actual practice, which may provide an opportunity for more clinicians to develop and demonstrate abilities to engage patients and families in conversations about goals of care. It should be recognised that providing care that focusses on comfort is not 'nothing'. Policies and guidelines need to attend to the social factors that shape current attitudes and practices towards death and dying. MDT Training and continuing education needs to more explicitly acknowledge clinical uncertainties around end of life. Such training needs to engage dominant ethical, cultural and professional values and expectations shaping current practice.	

Details about the Studies					
Author (year), country, score	**Research question or aim of study**	**Participants & Setting**	**Method**	**Key themes**	**Codes and themes**
Rejnö et al (2017), Sweden	Deepen the understanding of stroke team members' reasoning about truth-telling in end-of-life care due to acute stroke.	15 stroke team members working in stroke units of two associated county hospitals.	Qualitative study based on individual interviews utilising deductive and inductive content analysis.	**Truth above all** Participants highly valued honestly and considered that a reason for always telling the truth without embellishing. <u>A value in itself</u> Honesty was ideal and straightforward and without euphemism the truth should be told It was the best option to prepare the family. <u>To establish trust</u> Truth contributed to a good relation with next of kin. When truth was told, everything was though to be easier and better (including the staff) A mutual understanding of the situation was considered possible, creating a feeling of security and trust. **Hide truth to protect** Carers thought truth could also be harmful Participants would hide the truth of parts of it as part of a strategy, to protect the next of kin <u>Not add extra burden in the sorrow</u> The carers argued withholding truth could be done if next of kin could not deal with whole truth Balance of consequence by telling the whole truth being harmful, aspects	**Developing trust x 2** Being honest Promoting trust Preparing the family Developing understanding Understanding family dynamics **Protecting family x 4** Hiding truth Managing details Giving hope **Timing the conversation x 2** Planning the conversation Gaining information Working within context **Avoiding the conversation x 3** Avoiding information x 2 Delaying

Details about the Studies					
Author (year), country, score	**Research question or aim of study**	**Participants & Setting**	**Method**	**Key themes**	**Codes and themes**
				would be hidden (such as a difficult death). Giving hope to next of kin was a rationale Awaiting the timely moment Creating possibilities for good care a rationale for delay Carers could have time to arrange for a better meeting, ensuring support in place Ensuring strong evidence assessed prior to sharing (including being assured themselves) Not being a messenger of bad news (Nurses particularly) not wanting to impact the bad news to next of kin. Utilise tools to not disclose by not having information themselves (actively not looking) Omission was not considered the same as telling a lie. **REVIEW** The movement between Truth Above All and Hide Truth to Protect was a dynamic process. Staff were striving to be true. Nursing focussed on two subcategories alone (awaiting the right time and not being a messenger of bad news), due	

Details about the Studies					
Author (year), country, score	**Research question or aim of study**	**Participants & Setting**	**Method**	**Key themes**	**Codes and themes**
				to profession and inherent liability of the responsibility for informing next of kin resting on the physicians. Moral imperative was on determining the consequence of action (or not). Due to the uncertainty of care objective vs subjective truth was considered, placing it in time, place and ability. In addition, truth in relation to situations also included relations with organisation structures of care, and the need for support needed (for staff). Fear of talking of death and dealing with reactions to bad news may contribute the strategy to Hide truth to protect. Nurses wanted to escape the situation and leave the delivery to someone else. Not wanting to destroy hope was a rationale to not deliver the full truth. Carers may need support in the form of supervision to be given space to reflect on experience. MDT can be of great value and contribute through inter-professional learning	

Details about the Studies					
Author (year), country, score	**Research question or aim of study**	**Participants & Setting**	**Method**	**Key themes**	**Codes and themes**
				Recognition of the strain put on the cares to manage the situations will be considerable and call for increased co-operation with next of kin.	
Hopkinson et al (2005), UK	To find out how newly qualified nurses cope with caring for dying people in acute hospital medical wards.	28 nurses interviewed from two hospital Trusts in North of England.	Non-directive open style of interviewing. (cross-sectional interview-based study). Discovery of patterns identified guided by work of Wolcott (1994) and Van Manen (1994)	**Relationships** Nurses identified helpful relationships from colleagues to share understanding of experiences. Feedback from patients and relatives were supportive, leading to participatory work with families. **Resources** Preparation of information supported shaping their own expectations. Anticipation of what was to come allowed them to take action to shape outcomes. Involving others in making clinical judgements helped lessen the burden of responsibility. Escaping the difficulties of caring for dying patients was noted, by undertaking different tasks. Humour was identified as a resource to relieve the burden.	**Walking alongside x 2** Balancing walking both paths Managing expectations Preparing the way Caring for families Managing family dynamics Sharing understanding Walking in other's shoes Supporting a good death Dealing with multiple deaths **Protecting self x 3** Managing different deaths Escaping burden Moving on Managing distress Putting on the armour Balancing Avoiding **Gaining support x 2** Wanting training Receiving feedback **Gaining experience x 2** Making rules Using a structure Having knowledge Experiencing and learning Self-learning

Details about the Studies					
Author (year), country, score	**Research question or aim of study**	**Participants & Setting**	**Method**	**Key themes**	**Codes and themes**
				Using a structured approach when talking with dying people and families was identified. **Learning from experience** Personal learning occurred as a result of participants own practice and observing/inquiring into others. Knowledge was gained through experience. Experiential learning was deemed to help participants best. **Controlling involvement** Controlling the amount of emotional involvement was evidenced as a balancing process – i.e., not to distance themselves too much but not to become too involved. This enabled them to function in their nursing role. **Measuring** Positive feedback from a patient or relative was evidenced as a 'job well done'. Imagining themselves or a member of their family in the patient's position was also identified as way to identify satisfaction. **Revision of the ideal way to die**	**Aligning to internal model** Sustaining self Gauging own standards Situating self Flexing beliefs

Details about the Studies					
Author (year), country, score	**Research question or aim of study**	**Participants & Setting**	**Method**	**Key themes**	**Codes and themes**
				Participants changed their beliefs about what should happen. **Personal comfort** Anti-tensions were identified as a tool to sustain or restore a sense of personal comfort. Achieving a comfortable death. Identification of various anti-tensions was based upon personal history as well as a specific dying situation. **Development of a theory – the translucent web** Anti-tensions adopted by a nurse worked together as a translucent web to support them through the experience. Directional – motivated by a need to sustain or restore a sense of personal comfort Situational – adopted according to circumstance and personal history Dynamic – changed across time with new experiences Translucent – were only partially in a nurse's awareness or control	

Details about the Studies					
Author (year), country, score	**Research question or aim of study**	**Participants & Setting**	**Method**	**Key themes**	**Codes and themes**
				The theory evidences how nurses cope with caring for dying people on acute hospital medical wards. It conceptualises coping as prophylactic as well as restorative, with cognition and behaviour intended to support well-being operating at both an unconscious level and other than in relation to self-perceived stress. Coping was found to be: *The situation specific thoughts and behaviours engaged by an individual either consciously or unconsciously, with a consequence of sustaining or restoring personal comfort.* A model for supporting nurses would incorporate the needs of the family as well as the needs of the patients. Guidelines in caring for dying people would create markers against which nurses could just their performance.	
Warnock et al (2017), UK	To explore the difficulties experienced by nurses and healthcare professionals when engaging in	145 participants in a two-stage study. Participants attended an education day designed to	A descriptive survey design was used. A questionnaire generated qualitative data.	**Roles were categorised into four subject areas:** • Diagnostic and treatment information, including test results. • The impact of illness	Managing difficult situations Broaching the subject Changing the focus Explaining the process Managing sudden death Managing family expectations Differing opinions

Details about the Studies					
Author (year), country, score	**Research question or aim of study**	**Participants & Setting**	**Method**	**Key themes**	**Codes and themes**
	the process of breaking bad news	support healthcare staff in the process of breaking bad news. North of England (all healthcare staff)	Free text descriptions were analysed using framework analysis (Ritchie et al, 2014).	• Managing reactions • Care at the end of life **Sources of difficulty** Situation Difficult subjects Unexpected news/events Context of communication Tension within the healthcare team Organisation Time and staffing Relationships between departments/services Information systems and processes Services available Patients and relatives Reactions to information and events Family context – disclosure and dynamics Relationship/communication breakdown with healthcare team Communication barriers – physical, language, comprehension Individual Individual resources Balancing Emotional consequences **REVIEW**	Picking up the pieces Observing poor communication Managing medical teams **Lacking resources x 2** Lacking time Battling time **Managing family emotions x 2** Understanding the context Understanding family dynamics Advocating Managing messages Feeling the pressure Feeling responsible Situating self in experience Managing the journey

Details about the Studies					
Author (year), country, score	**Research question or aim of study**	**Participants & Setting**	**Method**	**Key themes**	**Codes and themes**
				There are multiple moments across the healthcare pathway when significant information is given or managed. Involvement in the process of breaking bad news is not restricted to information provision. Cultural factors can affect the provision of bad news. Staff confidence and congruence between medical and nursing staff can present difficulties. **Results** A structure framework was developed and proposed to have several uses. For nurses and HCPs to reflect on clinical events and practice. The framework highlights the depth and breadth of knowledge and skills required for those involved in the process of breaking bad news, in order to provide direction to providers for education. The framework suggests the need to look beyond the traditional focus on comms skills in education and include other topics including working with family systems, managing ethical dilemmas, conflict resolution, team	

Details about the Studies

Author (year), country, score	**Research question or aim of study**	**Participants & Setting**	**Method**	**Key themes**	**Codes and themes**
				working and supporting coping and adaptation. Organisationally, resources need to be reviewed including facilities to support breaking bad news (interpreters, private spaces and provision for structured learning and reflection).	
Warnock et al (2010), UK	An exploration of the role of the nurse in the process of breaking bad news in the inpatient clinical setting and the provision of education and support for nurses carrying out this role	236 participants completed a questionnaire (142 staff nurses, 64 ward sisters/charge nurses and 10 nurse specialists), across multiple specialities (medical, surgical, oncology, ICU) in one large NHS Trust in the North of England.	A descriptive survey design was adopted to generate quantitative and qualitative data. Data were analysed using descriptive statistics. Responses to open-ended questions were coded according to their content, and then grouped to form themes. Relationships were explored to develop categories that described the data.	**Barriers to breaking bad news experienced by nurses** How the bad news was broken *Barriers to communication* Practical/physical (lack of privacy, lack of time, method of communication, difficulty contacting family) Language/culture Deficit in nursing knowledge – limited knowledge of events, concerns of own clinical knowledge related to aspects of care. *Information held by patients and relatives* Disclosure – family requested patient not given information leading to impaired nurse/patient communication, nurses feeling dissatisfied about level of care Patient/relative understanding – misunderstand/misinterpreting information given, leading to difficult context for breaking bad news	**Lacking knowledge x 2** Not being prepared Learning from others **Managing the journey** Managing environment Managing expectations Managing family anxieties Managing family emotions Managing disagreements Strengthening relationships Managing the unexpected Feeling frustrated Worrying Wondering Gaining positives Lacking control Battling time

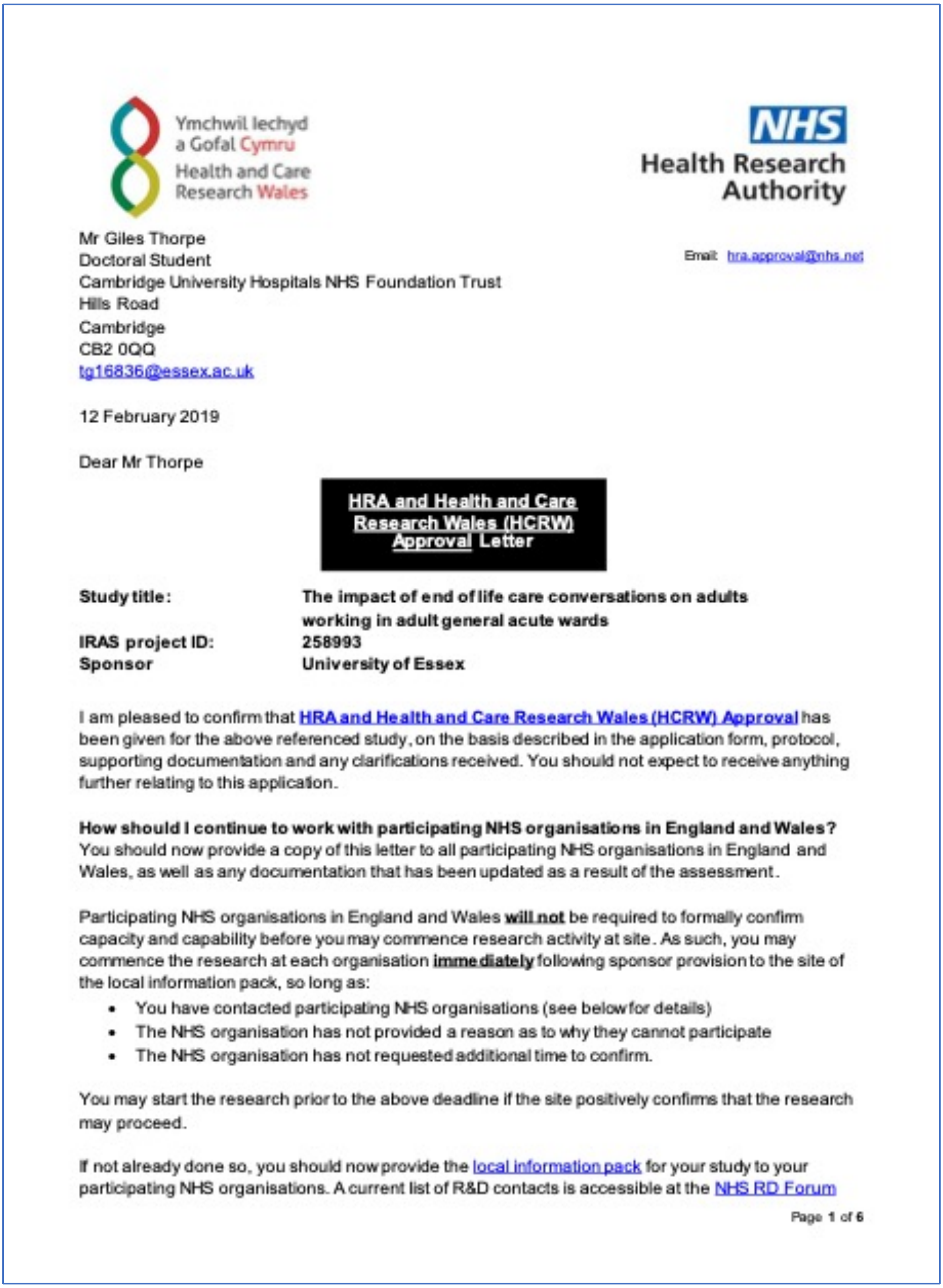
Details about the Studies

Author (year), country, score	Research question or aim of study	Participants & Setting	Method	Key themes	Codes and themes
				Unexpected death Patients dying with no relative present Having to break bad news over the telephone *Reactions to bad news* Complexity and strength of emotions involved when breaking bad news, resulting in verbal abuse, anger, physical aggression, intimidation, hysteria and denial. *Significant events* Events leading to enduring effect staying with participants long after the event. *Sources of difficulty* The event itself Relatives' actions Inadequate staffing/services Difficulties with the patient Medical staff Lack of knowledge or expertise **Nurses' experiences of being involved** Mixed response - many thought positive consequences of being involved Experience had encouraged participants to reflect positively on own priorities and what was important	

Details about the Studies					
Author (year), country, score	**Research question or aim of study**	**Participants & Setting**	**Method**	**Key themes**	**Codes and themes**
				Majority felt able to initiate conversations about bad news. **Previous training in relation to breaking bad news** Majority had received little or no formal education on breaking bad news Majority had learned through informal methods such as experience over time Observing the practice of others was felt to be most useful. Majority felt support was available for staff involved in the process of braking bad news – majority informal. **REVIEW** For nurses breaking bad news is seen more as a process rather than a consultation. A lack of ability to control the timing of their involvement in breaking bad news was evident. Guidelines already in place to support HCPs when bad news is given, usually focusses on that moment. The study highlights the potential limitations to this approach, for nurses, as they do not acknowledge the ongoing nature of the process.	

Details about the Studies					
Author (year), country, score	**Research question or aim of study**	**Participants & Setting**	**Method**	**Key themes**	**Codes and themes**
				Those involved need to feel confident in their ability to break bad news confidently. 'On the job' training itself is insufficient to meet the educational needs of many nurses. Further research is required	

Appendix F – HRA approval



Ymchwil Iechyd a Gofal Cymru
Health and Care Research Wales

NHS
Health Research Authority

Email: hra.approval@nhs.net

Mr Giles Thorpe
Doctoral Student
Cambridge University Hospitals NHS Foundation Trust
Hills Road
Cambridge
CB2 0QQ
tg16836@essex.ac.uk

12 February 2019

Dear Mr Thorpe

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title:	**The impact of end of life care conversations on adults working in adult general acute wards**
IRAS project ID:	**258993**
Sponsor	**University of Essex**

I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

How should I continue to work with participating NHS organisations in England and Wales?
You should now provide a copy of this letter to all participating NHS organisations in England and Wales, as well as any documentation that has been updated as a result of the assessment.

Participating NHS organisations in England and Wales **will not** be required to formally confirm capacity and capability before you may commence research activity at site. As such, you may commence the research at each organisation **immediately** following sponsor provision to the site of the local information pack, so long as:

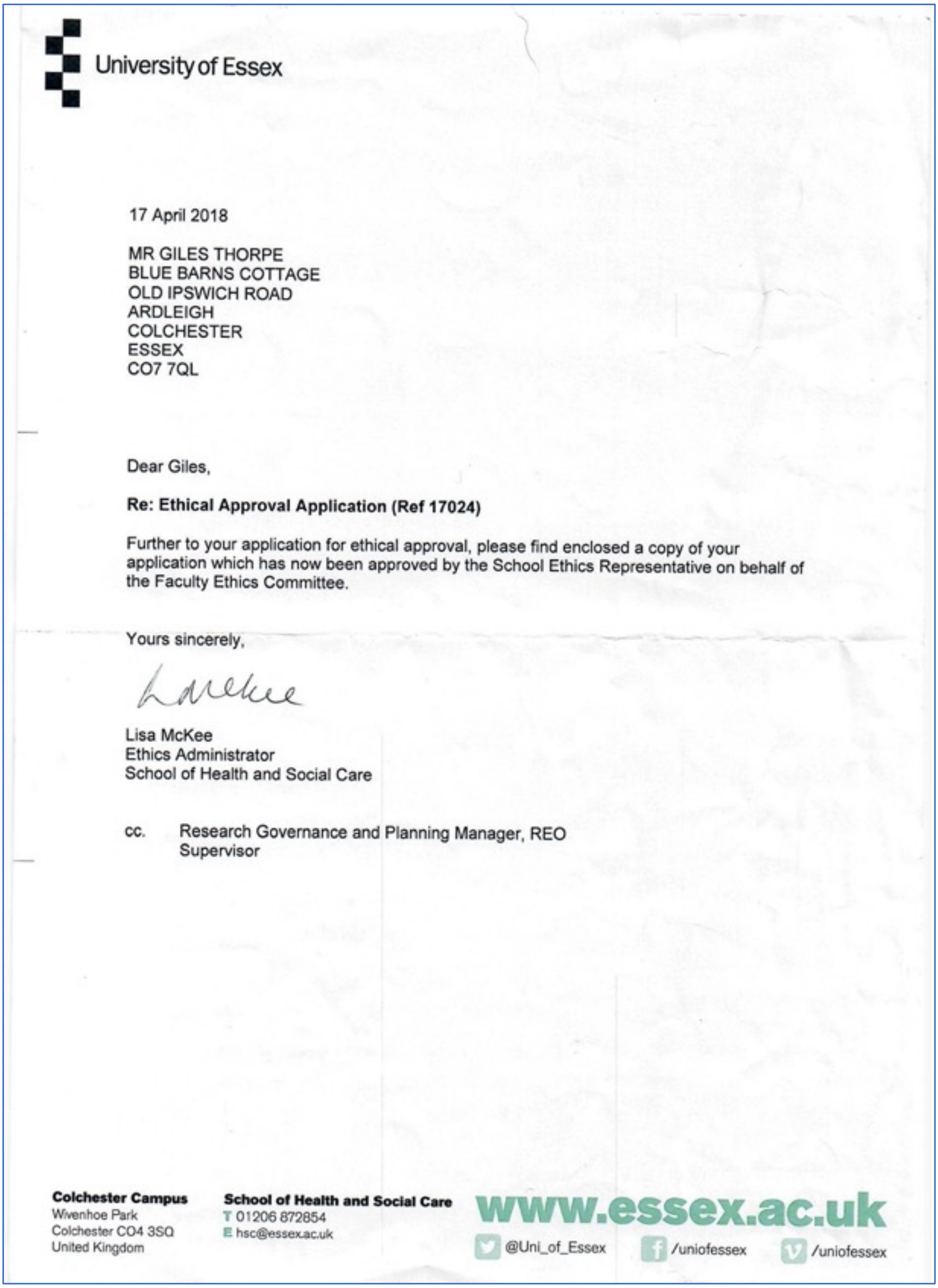
- You have contacted participating NHS organisations (see below for details)
- The NHS organisation has not provided a reason as to why they cannot participate
- The NHS organisation has not requested additional time to confirm.

You may start the research prior to the above deadline if the site positively confirms that the research may proceed.

If not already done so, you should now provide the local information pack for your study to your participating NHS organisations. A current list of R&D contacts is accessible at the NHS RD Forum

Page 1 of 6

Appendix G – University of Essex Ethical Approval



University of Essex

17 April 2018

MR GILES THORPE
BLUE BARNS COTTAGE
OLD IPSWICH ROAD
ARDLEIGH
COLCHESTER
ESSEX
CO7 7QL

Dear Giles,

Re: Ethical Approval Application (Ref 17024)

Further to your application for ethical approval, please find enclosed a copy of your application which has now been approved by the School Ethics Representative on behalf of the Faculty Ethics Committee.

Yours sincerely,

Lisa McKee
Ethics Administrator
School of Health and Social Care

cc. Research Governance and Planning Manager, REO
Supervisor

Colchester Campus
Wivenhoe Park
Colchester CO4 3SQ
United Kingdom

School of Health and Social Care
T 01206 872854
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Appendix H – Exemplar Letter of Approach Regarding Research Study

GILES THORPE, RN, MSC

University of Essex, Wivenhoe Park, Colchester CO4 3SQ | 07788 275121 |
tg16836@essex.ac.uk

20th September 2018

[redacted]
Chief Nursing Officer
[redacted]

Dear [redacted]

Re: Qualitative research proposal – the impact of end of life care conversations on nursing professionals – working with Basildon University Hospitals NHS Foundation Trust, Mid Essex Hospital NHS Trust and Southend University Hospital NHS Foundation Trust

I hope that my letter finds you well. I am writing to you today to seek permission to contact nursing staff working in your organisations to be participants in a qualitative research study. This study forms part of my doctoral research programme, conducted at the University of Essex.

The research title is '*The Impact of End of Life Care conversations on nurses working in adult general acute wards*'. The purpose of this doctoral research study is to explore the impact end of life care conversations have on nurses working in adult general (non-specialist) acute wards. It is recognised that more patients die in non-specialist areas and the specialist support and skill required when managing end of life care settings is not always available in general adult ward environments. Healthcare regulators (Care Quality Commission, 2016) have identified that the support provided to patients and relatives at, or near, the end of life, is not consistent, and must improve. This research will aim to elicit what the key issues are that impact upon this area of practice for nurses, and what support could be provided to nursing staff working with patients and families. Current evidence has focused on nurses working in specialist areas, primarily in critical care, paediatrics or oncology settings. However, the specialist nature of these settings is not easily translatable to other clinical areas of nursing, within which the majority of the workforce work. The ultimate goal is to contribute to staff and patient experience at such a critical time in patients' journeys.

I have been granted ethical approval by the University of Essex to proceed with the research study (approval form attached to this letter) and can confirm that I am not required to have received NHS Research Authority approval (decision-forms attached to this letter). This is because the research is focused on NHS staff alone and will not involve patients or relatives.

The study's methodology is based on Constructivist Grounded Theory, which will involve undertaking individual interviews with staff, and then analysing the data. I recognise that the research topic is emotive in nature, so will ensure that if any participant appears to be negatively affected by being part of the research then they will be signposted to the relevant Occupational Health support available in the Trust. If they feel that this is not an appropriate course of action to take, then a list of national organisations that are available to provide support and guidance will be shared. The health and well-being of participants is of paramount importance whilst undertaking this research study and beyond.

The potential benefits of participating will be to help develop a greater understanding of how nurses manage end of life care conversations with patients and families, and the potential impact it has on their professional practice. As there is little research exploring this specific area of clinical practice, participation may also help generate potential solutions to improve support to nursing practice and identify where further research is required. I have attached the participant information sheet and consent form for your information. As the professional lead for nursing and midwifery in your organisation I wished to contact you first to seek your views, as I would very much welcome the opportunity to work with your Trusts in undertaking this research study.

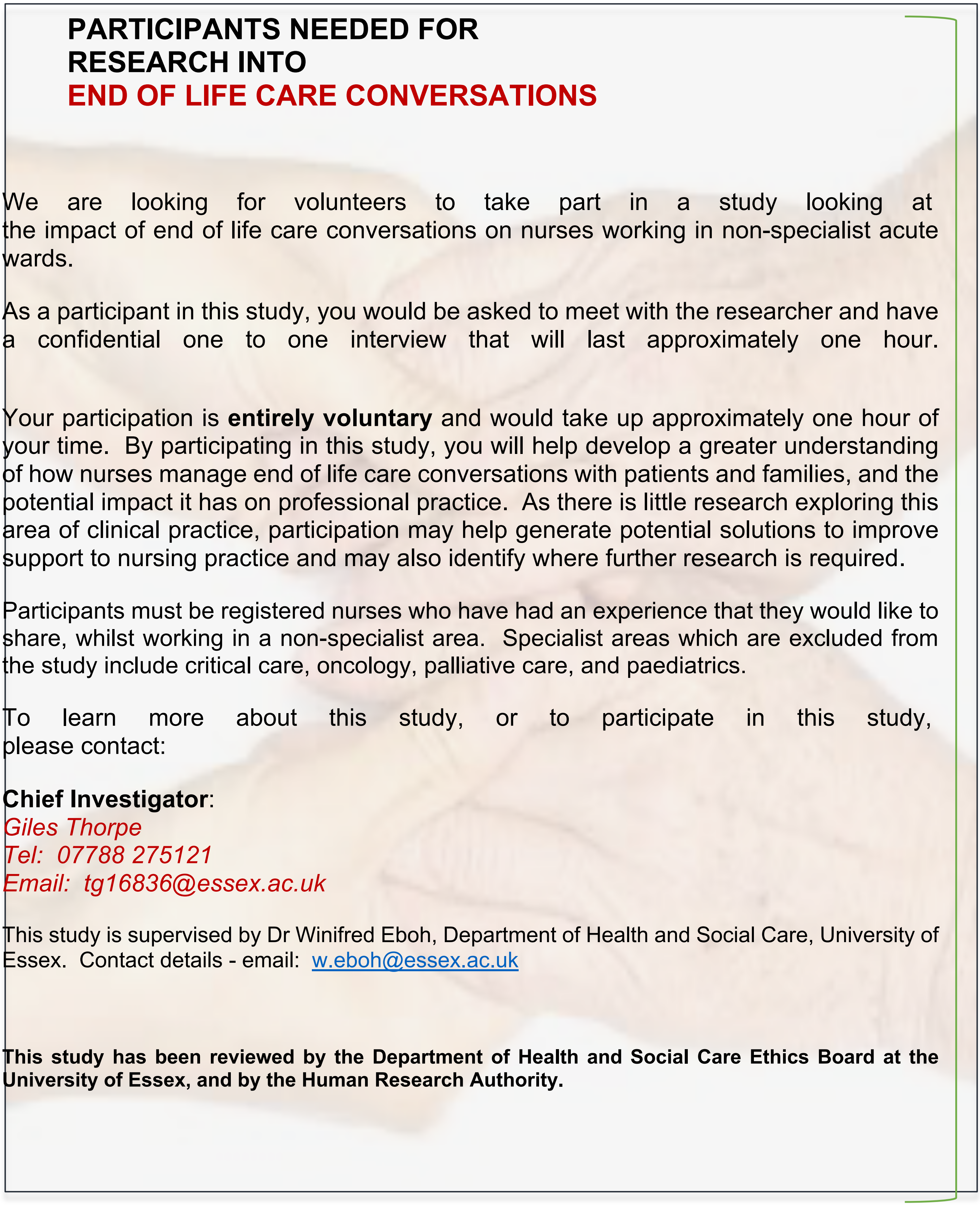
If you feel that this study is something that your nursing workforce would be interested in participating in, I would welcome the opportunity to discuss this with you further in terms of communication strategies to seek participant involvement and to agree next steps in terms of local research approval, where this is required.

Many thanks for taking the time to read my proposal and I look forward to hearing from you in due course with your decision.

Yours sincerely,

Sent Electronically
Giles Thorpe, RN, MSc

Appendix I – Communication Poster for the Research Study



PARTICIPANTS NEEDED FOR RESEARCH INTO
END OF LIFE CARE CONVERSATIONS

We are looking for volunteers to take part in a study looking at the impact of end of life care conversations on nurses working in non-specialist acute wards.

As a participant in this study, you would be asked to meet with the researcher and have a confidential one to one interview that will last approximately one hour.

Your participation is **entirely voluntary** and would take up approximately one hour of your time. By participating in this study, you will help develop a greater understanding of how nurses manage end of life care conversations with patients and families, and the potential impact it has on professional practice. As there is little research exploring this area of clinical practice, participation may help generate potential solutions to improve support to nursing practice and may also identify where further research is required.

Participants must be registered nurses who have had an experience that they would like to share, whilst working in a non-specialist area. Specialist areas which are excluded from the study include critical care, oncology, palliative care, and paediatrics.

To learn more about this study, or to participate in this study, please contact:

Chief Investigator:
Giles Thorpe
Tel: 07788 275121
Email: tg16836@essex.ac.uk

This study is supervised by Dr Winifred Eboh, Department of Health and Social Care, University of Essex. Contact details - email: w.eboh@essex.ac.uk

This study has been reviewed by the Department of Health and Social Care Ethics Board at the University of Essex, and by the Human Research Authority.

Appendix J – Participant Information Sheet

Information Sheet for The Impact of End-of-Life Care conversations on nurses working in adult general acute wards

- This doctoral research study is being undertaken at the University of Essex, within the School of Health and Social Care. Before taking part in this study please read the information sheet below to ensure that you are fully informed about the research study and why it is being undertaken.

- The purpose of this doctoral research study is to explore the impact that end of life care conversations has on nurses working in adult general (non-specialist) acute wards. It is recognised that more patients die in non-specialist areas and specialist support and skill required when managing end of life care settings is not always available in general ward environments. Healthcare regulators (Care Quality Commission) have identified that the support provided to patients and relatives at, or near, the end of life, is not consistent, and must improve. This research hopes to help identify what the key issues are that impact upon this are of practice, and what support may be required for nursing staff working with patients and families. The ultimate goal is to contribute to staff and patient experience at such a critical time in patients' journeys.

- Participants who are being invited to contribute to this research study are registered nurses who have had experience of managing end of life care conversations with patients and/or families, whilst working in an acute (non-specialist) environment. Inclusion criteria include holding a current registration with the Nursing and Midwifery Council, who were working with adult patients at the time of an experience in an NHS hospital Trust in the United Kingdom, and are currently working in the National Health Service. Exclusion criteria include: participants who have been recently bereaved (within the past year), staff whose experience involves children, staff whose experience occurred whilst working in Intensive Care, an oncology ward, within a hospice environment or within primary care, or staff whose experience occurred whilst working in a private healthcare setting. Other exclusion criteria include nursing students and staff who have retired from practice, or work in roles without a current registration.

- Participants are being asked to share their experience with the Chief Investigator (Giles Thorpe) in a semi-structured interview, which will be audio recorded, on a one-to-one basis. The interview should last between thirty and ninety minutes at a location at your place of work. The location will ensure confidentiality.

- It is recognised that talking about such experiences may be emotionally difficult and challenging. Having gained consent from the participating Trusts who have supported the study, they have highlighted support services available as part of employer Occupational Health organisations. However, if this is something that participants would not feel comfortable accessing, a list of national organisations that can provide support and guidance are provided separately. The doctoral research student is a qualified nurse with substantial experience in managing end of life care conversations and will ensure that participants are provided with a safe environment to talk and explore their experiences.

- The potential benefits of participating will be to help develop a greater understanding of how nurses manage end of life care conversations with patients and families, and the potential impact it has on professional practice. As there is little research exploring this area of clinical practice, participation may help generate potential solutions to improve support to nursing practice and may also identify where further research is required.

- All interviews that are recorded will be stored securely by the doctoral research student and held electronically – electronic data will be 256-bit encrypted on removable storage devices which are securely locked. Passwords to access these devices are stored separately with 256-bit encryption. Personal details such as names, phone numbers, employing organisations and addresses will not be revealed to those outside the project. Participants rights to anonymity and confidentiality will be maintained. Participation will remain confidential, and all personal data (as outlined above) will be held securely by the doctoral research student and not included in any publications, reports, web pages or other research outputs. Participants words may be quoted in publications, reports, web pages, and other research outputs, but they will not be identifiable.

- If, as part of the interview process, it is identified that patients or relatives have come to harm, then the interview will be terminated. As a registered nurse, the doctoral research student has a professional responsibility and accountability (as outlined in the Nursing and Midwifery Code of Conduct (2015)) to ensure that any potential harm is fully investigated and appropriate support is provided to those affected through employing Trusts – therefore, confidentiality cannot be maintained at this point. Should this occur, then any data provided at this point will not be used as part of the research process and excluded from use.

- Anonymised data will be shared with the UK Data Archive only following the express consent of participants as outlined in the consent form. If participants agree for their data to be stored in the UK Data Archive other authenticated researchers will have access to this data only if they agree to preserve the confidentiality of the information as requested in the participant consent form. Other authenticated researchers may use participants' words in publications, reports, web pages, and other research outputs, only if they agree to preserve the confidentiality of the information as requested in the participant consent form.

- Participation in this study is completely voluntary and any decision not to participate will not prejudice their professional or academic progress in any way in the future. Participants can ask any questions before agreeing to take part in the research. This can be done by contacting the doctoral research student via the numbers below.

- Participants have the right to withdraw at any time for whatever reason and without explanation or penalty. They are able to do this by contacting the doctoral research student via contact details below.

- If you have any concerns or complaints about this project in the first instance you can contact the doctoral research student via the numbers below. If you are not satisfied with the response you have gained from the doctoral research student in the first instance, please contact their Supervisor, Dr Winifred Eboh via the number below. If you remain unsatisfied and wish to complain formally, you can do this by contacting the Research Governance and Planning Manager, Research Office, University of Essex, Wivenhoe Park, Colchester, CO4 3SQ, by emailing sarahm@essex.ac.uk.

- The University of Essex is the sponsor for this study based in the United Kingdom. We will be using information from you in order to undertake this study and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly. The University of Essex will keep identifiable information about you for 1 year after the study has finished.

- Your rights to access, change or move your information are limited, as we need to manage your information in specific ways in order for the research to be reliable and accurate. If you withdraw from the study, we will keep the information about you that we have already obtained. To safeguard your rights, we will use the minimum personally identifiable information possible.

- You can find out more about how we use your information by contacting the University of Essex Information Assurance Officer, Sara Stock at sstock@essex.ac.uk .

- The Chief Investigator (Mr Giles Thorpe) will keep your name and contact details confidential and will not pass this information to the University of Essex or your employing organisation. The Chief Investigator will use this information as needed, to contact you about the research study, and make sure that relevant information about the study is recorded, and to oversee the quality of the study. Certain individuals from the University of Essex may look at your research records to check the accuracy of the research study. The University of Essex will only receive information without any identifying information.

- The Chief Investigator will keep identifiable information about you from this study for 1 year after the study has finished.

Contact details:
Mr Giles Thorpe – Doctoral Research Student – telephone: XXXX XXXXXX – email: tg16836@essex.ac.uk
Dr Winifred Eboh – Primary Supervisor – email: w.eboh@essex.ac.uk

Appendix K – Participant Consent Form

Consent Form for The Impact of End-of-Life Care conversations on nurses working in adult general acute wards

Taking Part	**Please initial box**
I have read and understood the project information sheet dated DD/MM/YYYY. I have had the opportunity to consider the information, ask questions and have had these questions answered satisfactorily	
I agree to take part in the project. Taking part in the project will include being interviewed and recorded (audio).	
I understand that my participation is voluntary and that I am free to withdraw from the project at any time without giving any reason and without penalty.	
I understand that the identifiable data provided will be securely stored and accessible only to the members of the research team directly involved in the project, and that confidentiality will be maintained.	
I understand that, due to the nature of the project, being interviewed in relation to this topic may not be suitable for individuals who have been recently bereaved (within the last year), that I am aware of the potential risks associated with that, and I confirm that, to the best of my knowledge, I have not been recently bereaved.	

Use of the information I provide beyond this project

I understand that data collected in this project might be shared as appropriate and for publication of findings, in which case data will remain completely anonymous.	
I agree for fully anonymised, typed transcriptions of interview I participate in to be archived at the UK Data Service.	
I agree for audio recording of interviews I participate in to be archived at the UK Data Service.	
I understand that other researchers, as defined in the participant information sheet, will have access to this data only if they agree to preserve the confidentiality of the information as requested in this form.	
I understand that other researchers, as defined in the participants information sheet, may use my words in publications, reports, web pages, and other research outputs, only is they agree to preserve the confidentiality of the information as requested in this form.	

______________________	______________________	__________
Name of participant [printed]	Signature	Date
______________________	______________________	__________
Researcher [printed]	Signature	Date

Project contact details for further information:
Mr Giles Thorpe – Doctoral Research Student – telephone: XXXX XXXXXX – email: tg16836@essex.ac.uk
Dr Winifred Eboh – Primary Supervisor – email: w.eboh@essex.ac.uk

Appendix L – Interview Guide

Interview Guide for

The Impact of End-of-Life Care conversations with nurses working in adult general acute wards

Primary questions will elicit information regarding length of time working as a nurse, date of qualification, career history

Initial questions

1. Can you tell me about an experience you've had when you were involved in having or managing an end-of-life conversation? By this I mean when you had a conversation with either a patient or a relative/carer, about the patient's prognosis and/or plans of care.
   - When was this?
2. What were the events that led up to the conversation taking place?
   - What were the conditions like on the ward? (e.g. were there any events occurring on the ward at the time/how busy was the ward?)
   - How many other patients were you caring for?
   - How did you prioritise what to do?
3. How did you feel as the conversation was happening?

Intermediate Questions

1. What, if anything, did you know about managing end of life care conversations?
2. What happened next (after the conversation ended)?
3. Who else, if anyone, was involved?
   - How were they involved?
4. How did you feel you handled this experience?
5. Who was the most helpful to you during/following your experience?
   - How were they helpful?
   - What did they do?
6. If no-one – What would have been helpful?
7. Did your manager/leadership team/organisation provide any support?
   - How were they helpful?
8. How, if at all, have your thoughts and feelings about having end of life care conversations changed since your experience?
9. What changes have occurred in your professional practice since this experience, either positively or negatively?
10. How do you go about managing end of life conversations now? What do you do that's different following your experience(s)?
11. How would you describe the person you are now after your experience? What do you think has most contributed to this change?
12. As you look back on your career are there any other events that stand out related to end of life?
    - Could you describe it to me?
    - How did you respond to [the event; the resulting situations]?

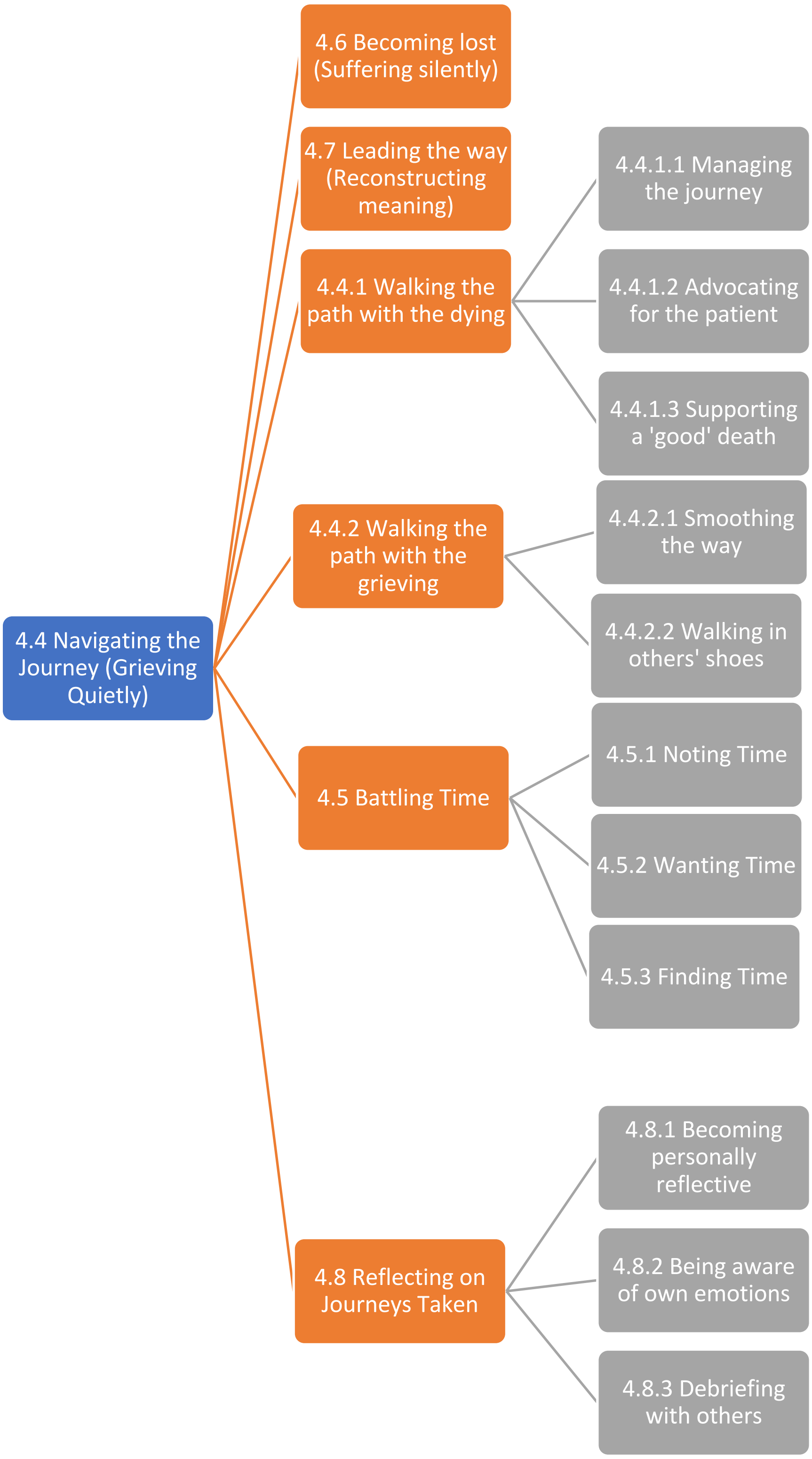
13. What would you describe as the most important lessons you have learned through your experience(s) of managing end of life conversations in your career?
14. How has your experience influenced the professional practice of others (if at all)?
15. What helps you manage similar experiences now?
    - What challenges might you encounter?
    - What do you think are the sources of these challenges?
    - How do you overcome these problems?

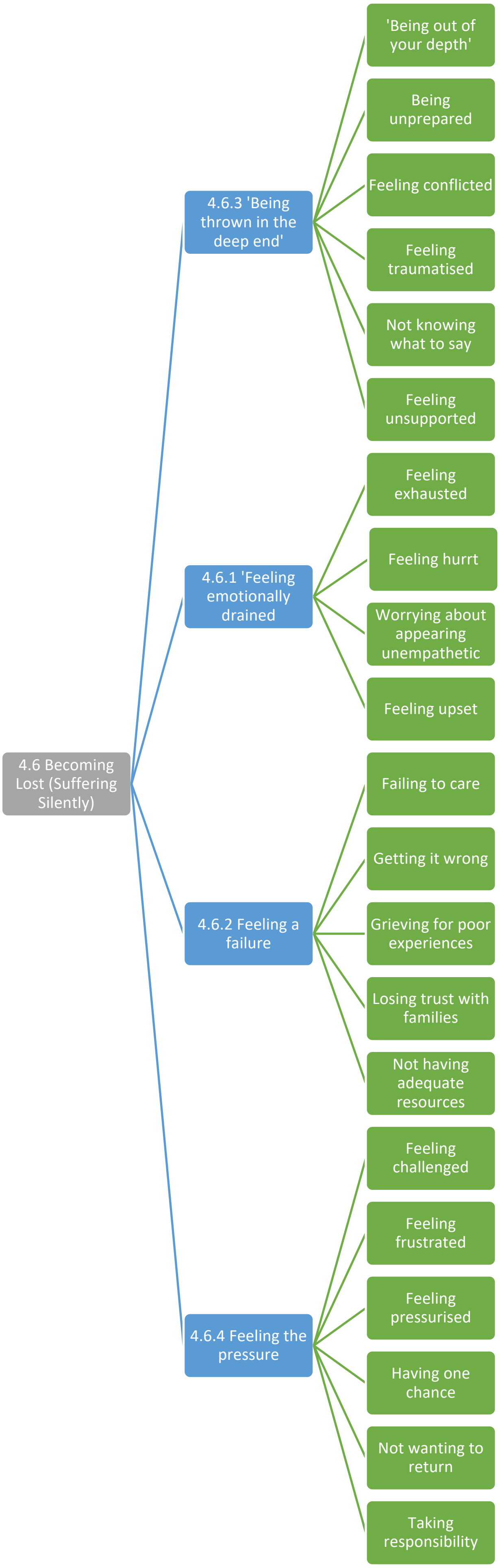
Ending Questions

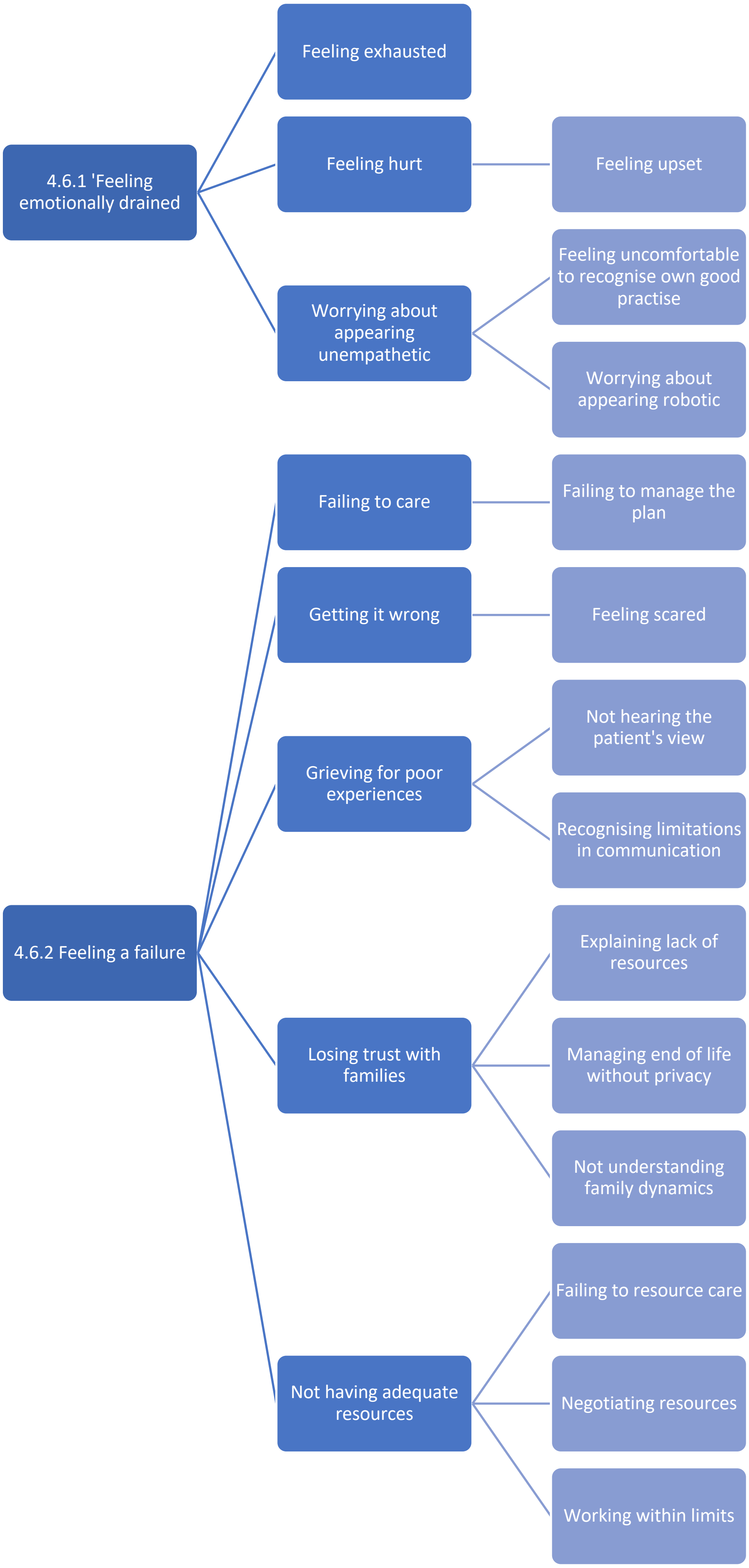
1. What do you think are the most important things to do when managing end of life care conversations now?
    - How did you discover [or create] these strategies?
    - How has your previous experience affect~~ed~~ the way you handle similar situations now?
2. How have you changed/grown as a nurse since your experiences?
    - What do you think are the changes/strengths that you discovered or developed?
3. What do you most value about yourself now as a professional in managing end of life care conversations?
    - What do others most value in you?
4. After having these experiences, what advice would you give to another nurse who may be involved in managing end of life care conversations?
5. What would you say would be the most important things needed to help nurses who become involved in end-of-life conversations?
6. Is there anything that you might not have thought about before that has occurred to you during this interview?
7. Is there anything else you think I should know or understand better?
8. Is there anything you would like to ask me?
9. Is there anything that you think I should have asked you?

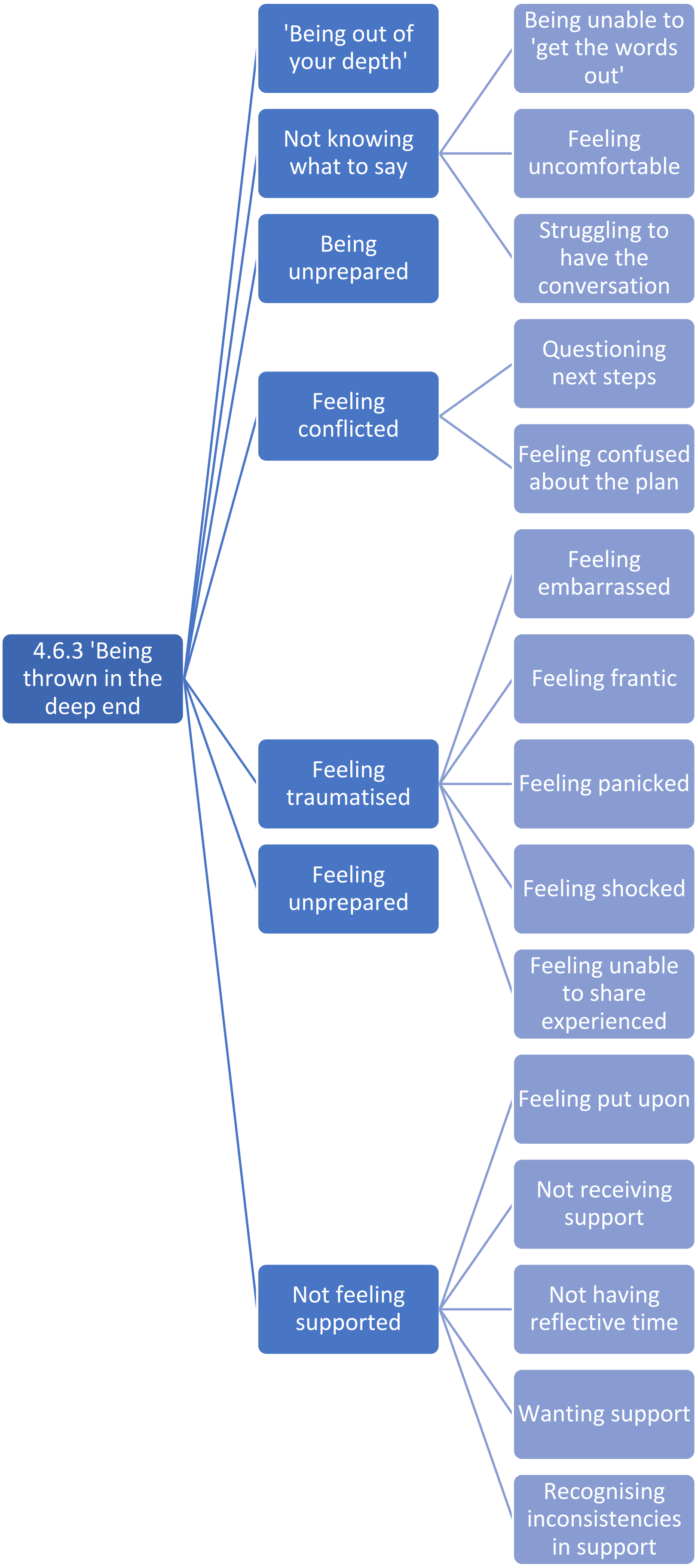
Checks will be made with participants to ensure that they are feeling psychologically safe following the interview, and if there is on-going evidence of distress, sufficient time is planned to debrief following the recording being stopped. Information will be provided about occupational health services within employing hospitals and national charities/organisations that are available to provide independent support (details will be provided).

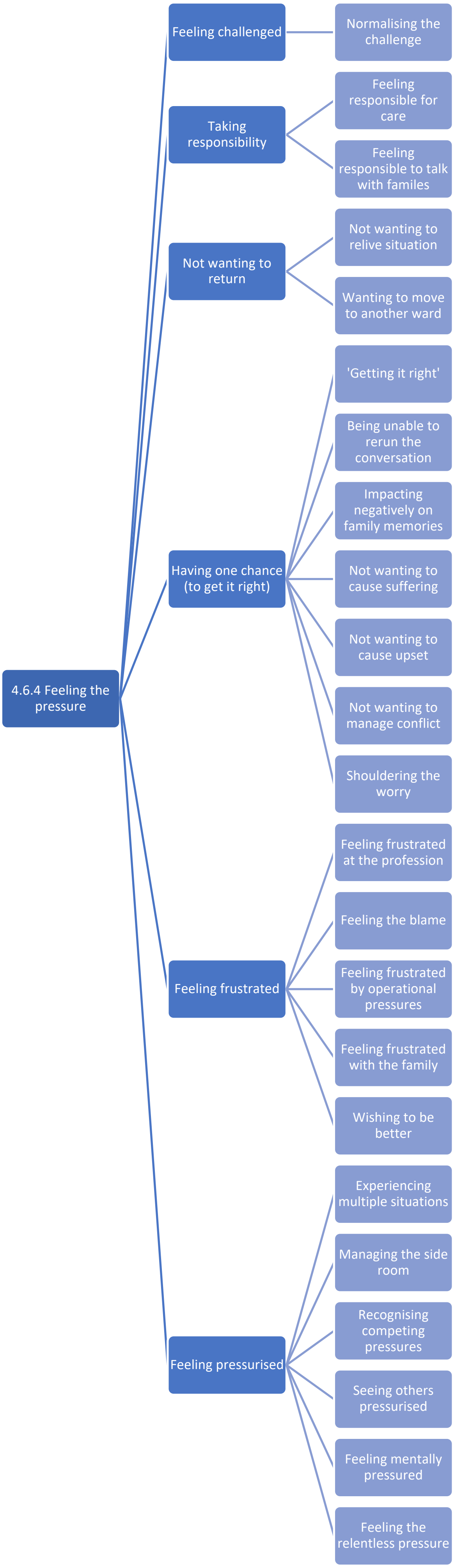
Appendix M – Coding Schema

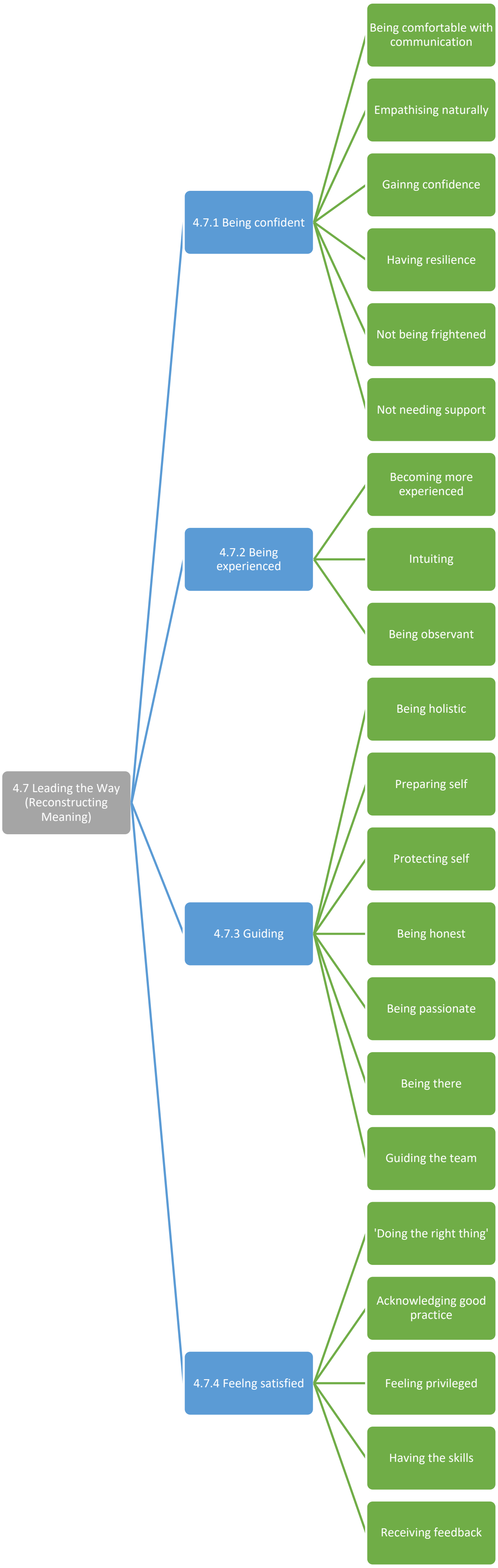



'Being out of your depth'
Being unprepared
Feeling conflicted
Feeling traumatised
Not knowing what to say
Feeling unsupported
4.6.3 'Being thrown in the deep end'
Feeling exhausted
Feeling hurrt
Worrying about appearing unempathetic
Feeling upset
4.6.1 'Feeling emotionally drained
4.6 Becoming Lost (Suffering Silently)
Failing to care
Getting it wrong
Grieving for poor experiences
Losing trust with families
Not having adequate resources
4.6.2 Feeling a failure
Feeling challenged
Feeling frustrated
Feeling pressurised
Having one chance
Not wanting to return
Taking responsibility
4.6.4 Feeling the pressure

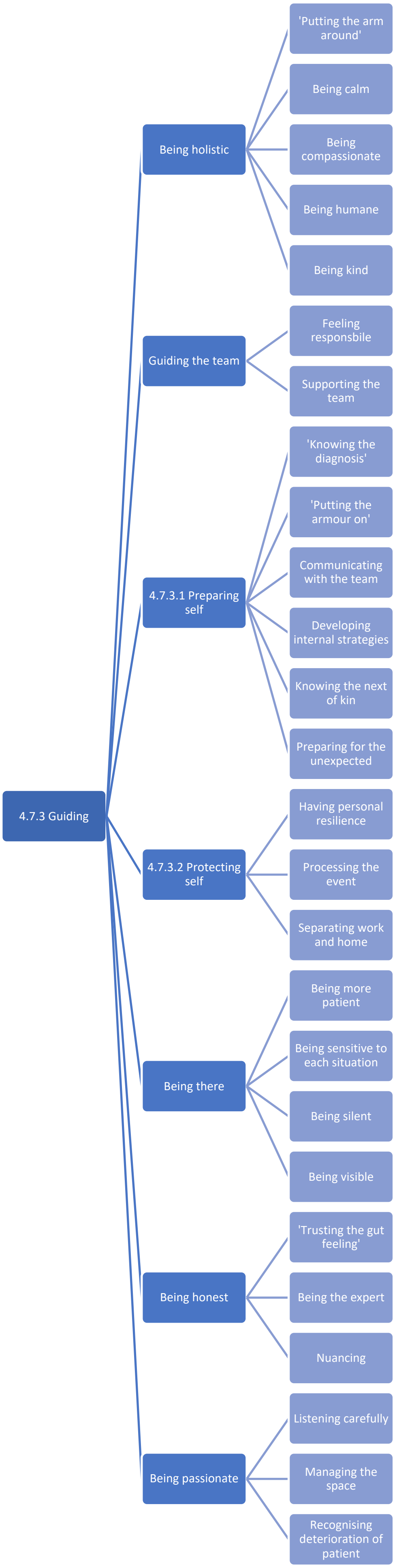

4.6.1 'Feeling emotionally drained
Feeling exhausted
Feeling hurt
Feeling upset
Worrying about appearing unempathetic
Feeling uncomfortable to recognise own good practise
Worrying about appearing robotic
4.6.2 Feeling a failure
Failing to care
Failing to manage the plan
Getting it wrong
Feeling scared
Grieving for poor experiences
Not hearing the patient's view
Recognising limitations in communication
Losing trust with families
Explaining lack of resources
Managing end of life without privacy
Not understanding family dynamics
Not having adequate resources
Failing to resource care
Negotiating resources
Working within limits

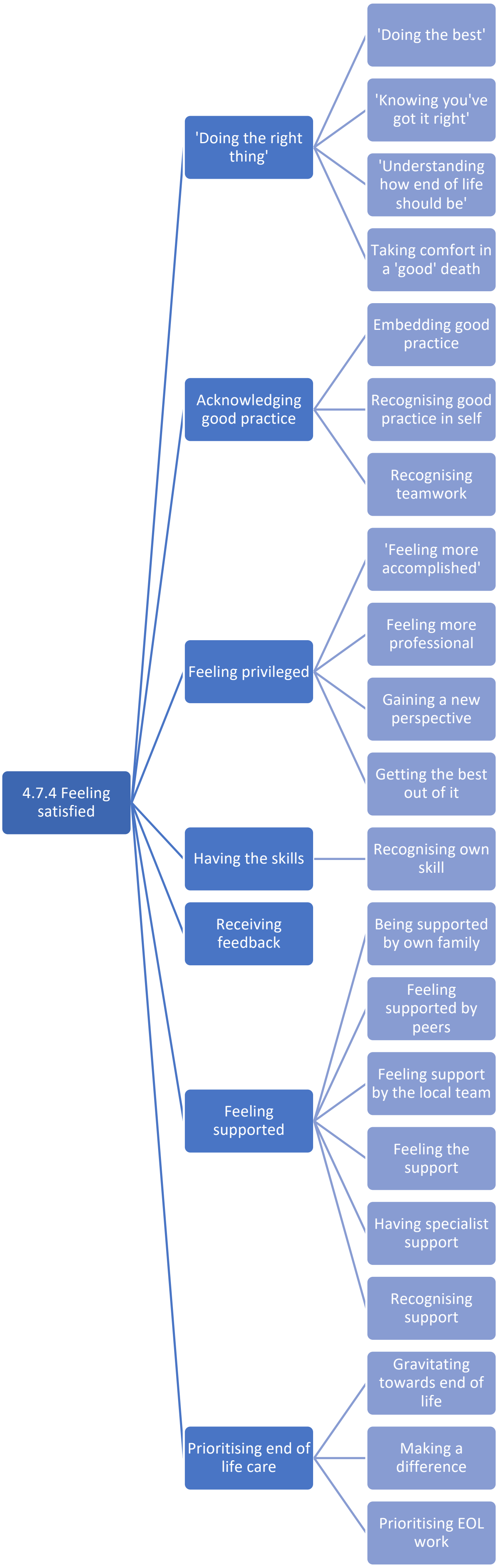

4.6.3 'Being thrown in the deep end
'Being out of your depth'
Not knowing what to say
Being unable to 'get the words out'
Feeling uncomfortable
Struggling to have the conversation
Being unprepared
Feeling conflicted
Questioning next steps
Feeling confused about the plan
Feeling traumatised
Feeling embarrassed
Feeling frantic
Feeling panicked
Feeling shocked
Feeling unable to share experienced
Feeling unprepared
Not feeling supported
Feeling put upon
Not receiving support
Not having reflective time
Wanting support
Recognising inconsistencies in support

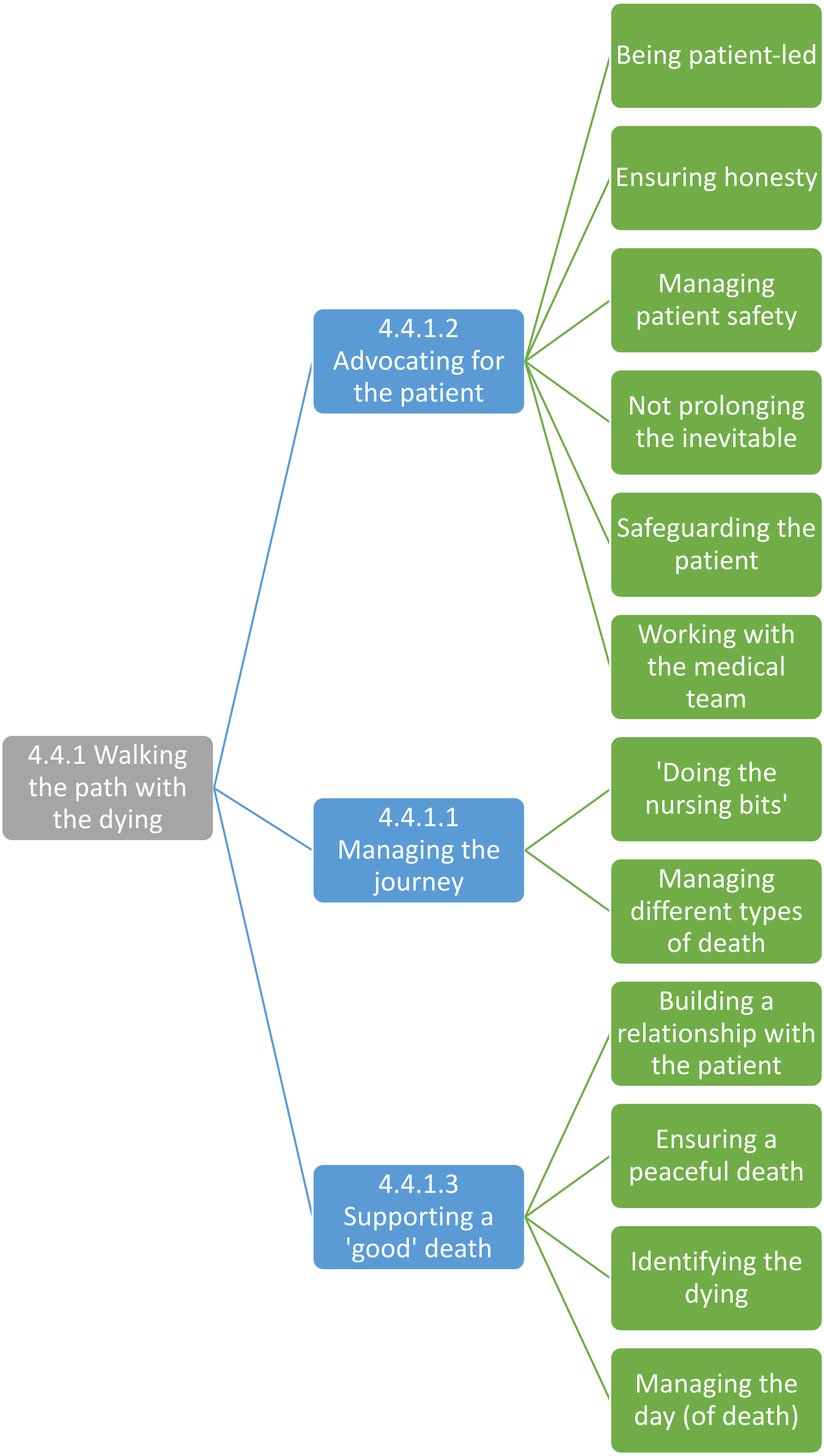

4.6.4 Feeling the pressure
Feeling challenged
Normalising the challenge
Taking responsibility
Feeling responsible for care
Feeling responsible to talk with familes
Not wanting to return
Not wanting to relive situation
Wanting to move to another ward
Having one chance (to get it right)
'Getting it right'
Being unable to rerun the conversation
Impacting negatively on family memories
Not wanting to cause suffering
Not wanting to cause upset
Not wanting to manage conflict
Shouldering the worry
Feeling frustrated
Feeling frustrated at the profession
Feeling the blame
Feeling frustrated by operational pressures
Feeling frustrated with the family
Wishing to be better
Feeling pressurised
Experiencing multiple situations
Managing the side room
Recognising competing pressures
Seeing others pressurised
Feeling mentally pressured
Feeling the relentless pressure

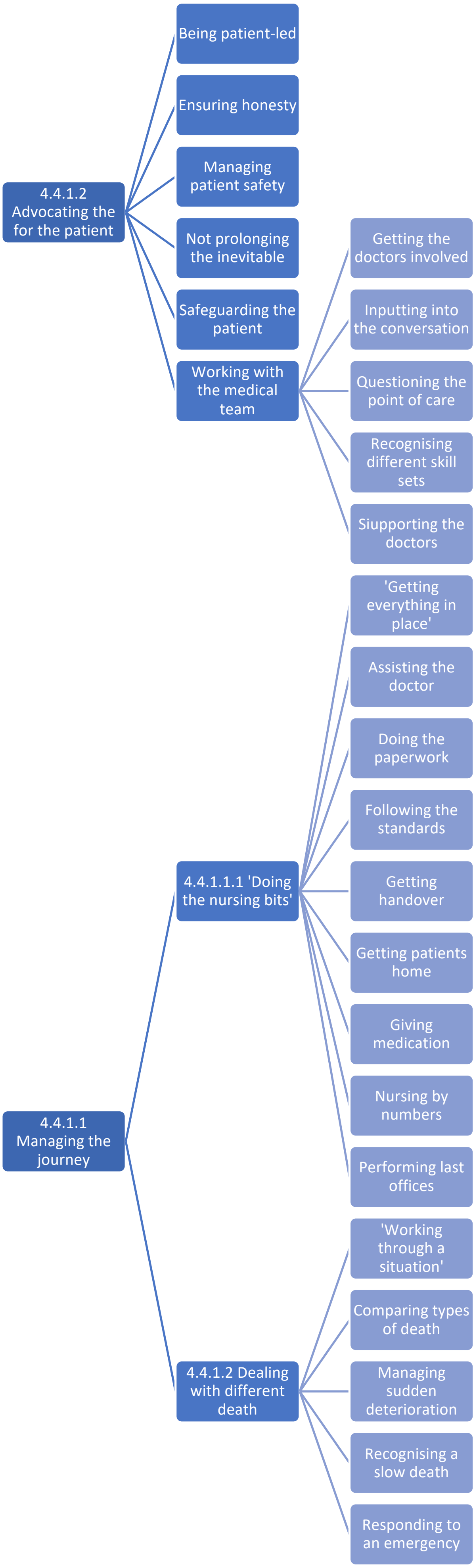

4.7 Leading the Way (Reconstructing Meaning)
4.7.1 Being confident
Being comfortable with communication
Empathising naturally
Gainng confidence
Having resilience
Not being frightened
Not needing support
4.7.2 Being experienced
Becoming more experienced
Intuiting
Being observant
4.7.3 Guiding
Being holistic
Preparing self
Protecting self
Being honest
Being passionate
Being there
Guiding the team
4.7.4 Feelng satisfied
'Doing the right thing'
Acknowledging good practice
Feeling privileged
Having the skills
Receiving feedback

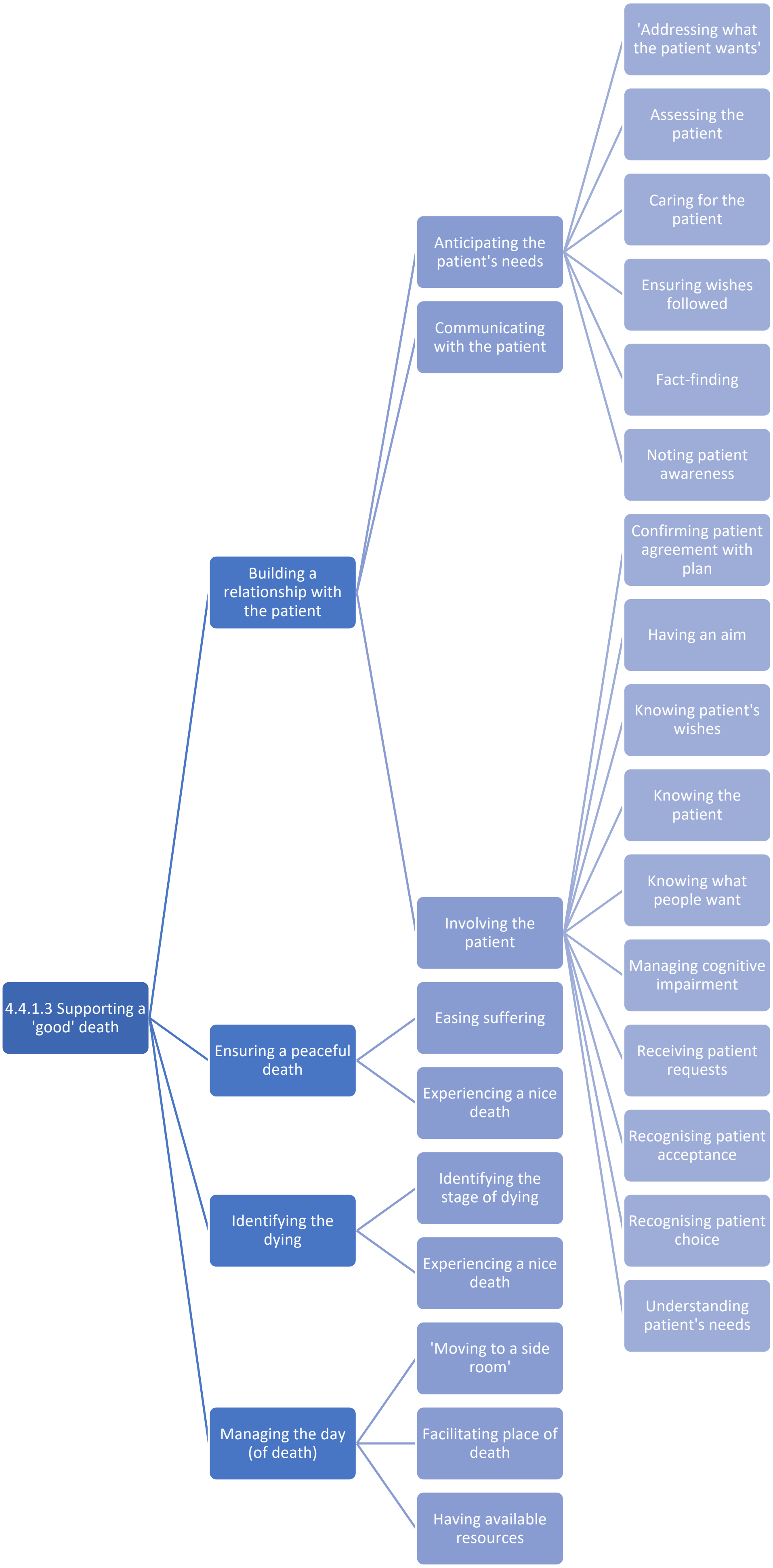

4.7.1 Being confident
Being comfrotable with communication
'Knowing what you're talking about'
'Understanding importance of language'
Explaining things better
Having a good conversation
Empathising naturally
Feeling naturally
Sitting with feelings
Gaining confidence
Becoming more confident
Becoming more involved
Having resilience
'Going through the tough situations'
Coping better
Having to have the conversation
Not being frightened (of death)
Not worrying
Not needing support
4.7.2 Being experienced
Becoming more experienced
Gaining experience
Intuiting
'Trusting the gut feeling'
Being the expert
Nuancing
Being observant
Listening carefully
Managing the space
Recognising deterioration of patient

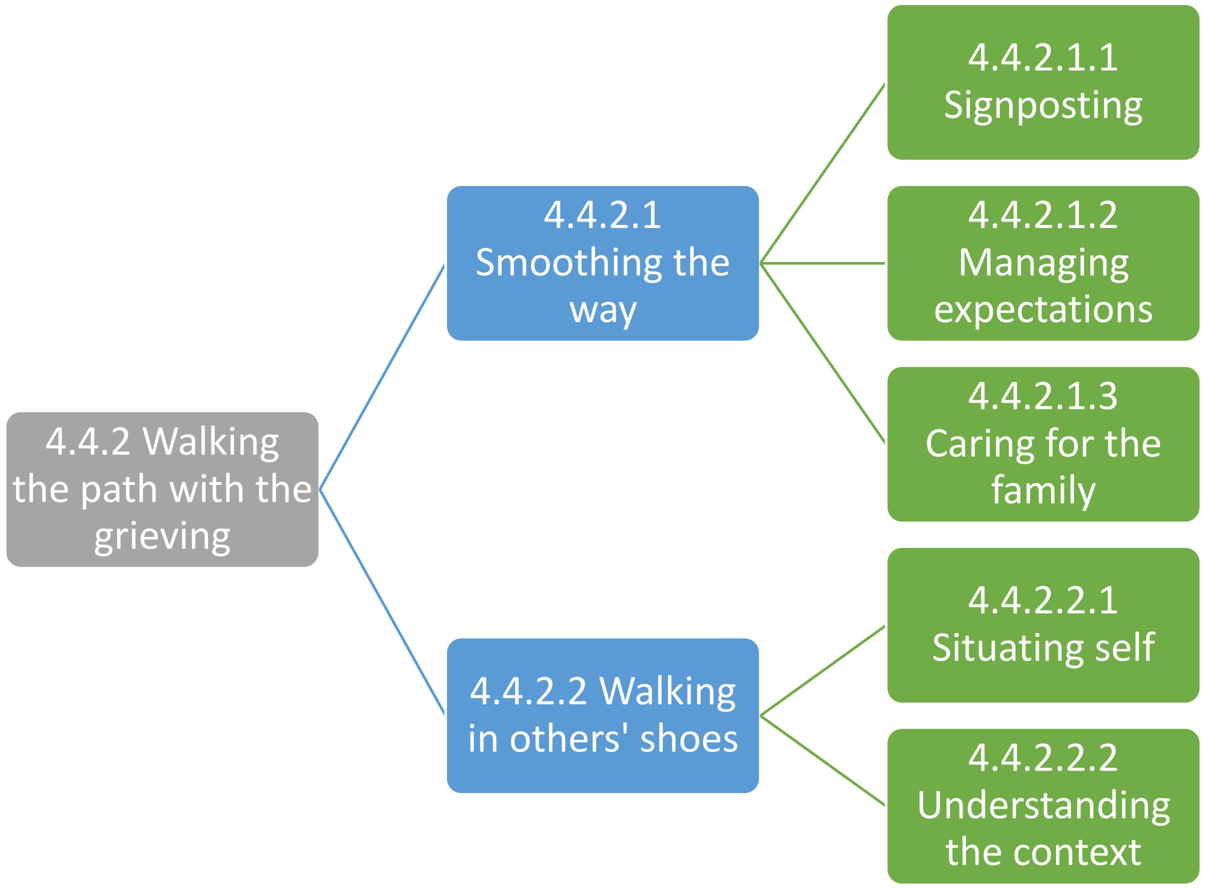

4.7.3 Guiding
Being holistic
'Putting the arm around'
Being calm
Being compassionate
Being humane
Being kind
Guiding the team
Feeling responsbile
Supporting the team
4.7.3.1 Preparing self
'Knowing the diagnosis'
'Putting the armour on'
Communicating with the team
Developing internal strategies
Knowing the next of kin
Preparing for the unexpected
4.7.3.2 Protecting self
Having personal resilience
Processing the event
Separating work and home
Being there
Being more patient
Being sensitive to each situation
Being silent
Being visible
Being honest
'Trusting the gut feeling'
Being the expert
Nuancing
Being passionate
Listening carefully
Managing the space
Recognising deterioration of patient

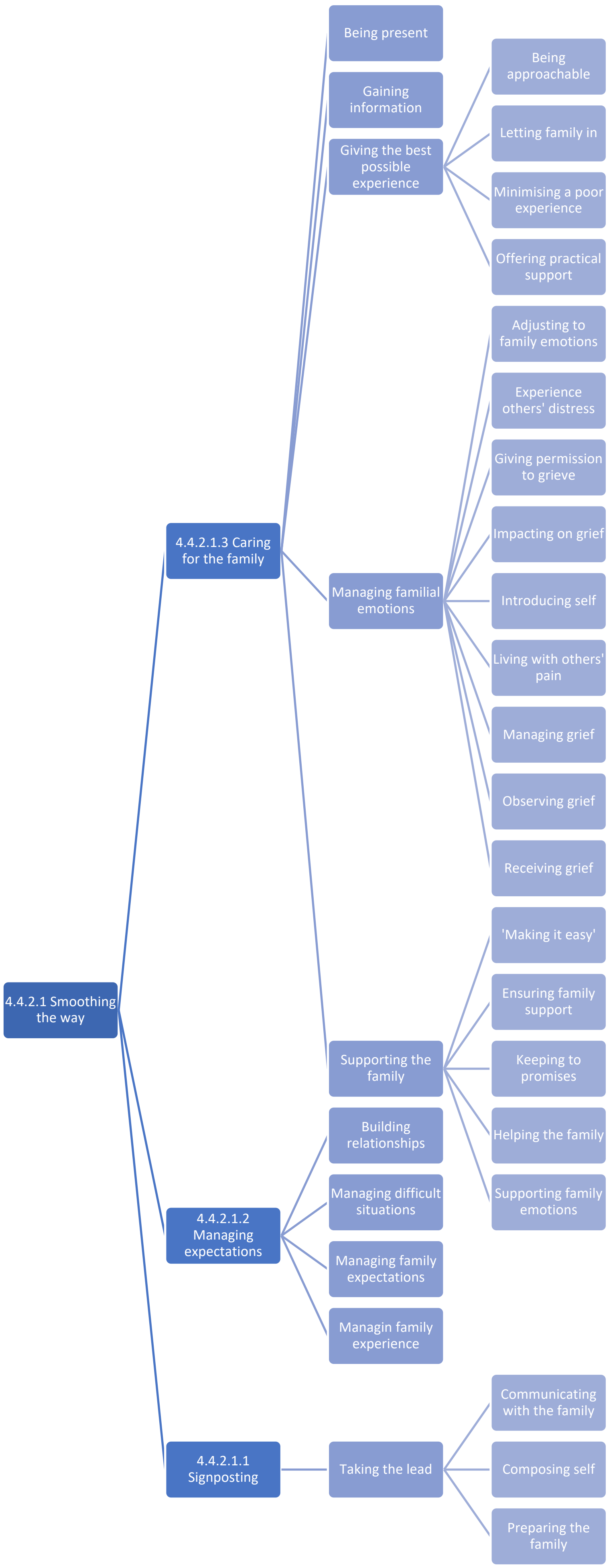

4.7.4 Feeling satisfied
'Doing the right thing'
'Doing the best'
'Knowing you've got it right'
'Understanding how end of life should be'
Taking comfort in a 'good' death
Acknowledging good practice
Embedding good practice
Recognising good practice in self
Recognising teamwork
Feeling privileged
'Feeling more accomplished'
Feeling more professional
Gaining a new perspective
Getting the best out of it
Having the skills
Recognising own skill
Receiving feedback
Feeling supported
Being supported by own family
Feeling supported by peers
Feeling support by the local team
Feeling the support
Having specialist support
Recognising support
Prioritising end of life care
Gravitating towards end of life
Making a difference
Prioritising EOL work

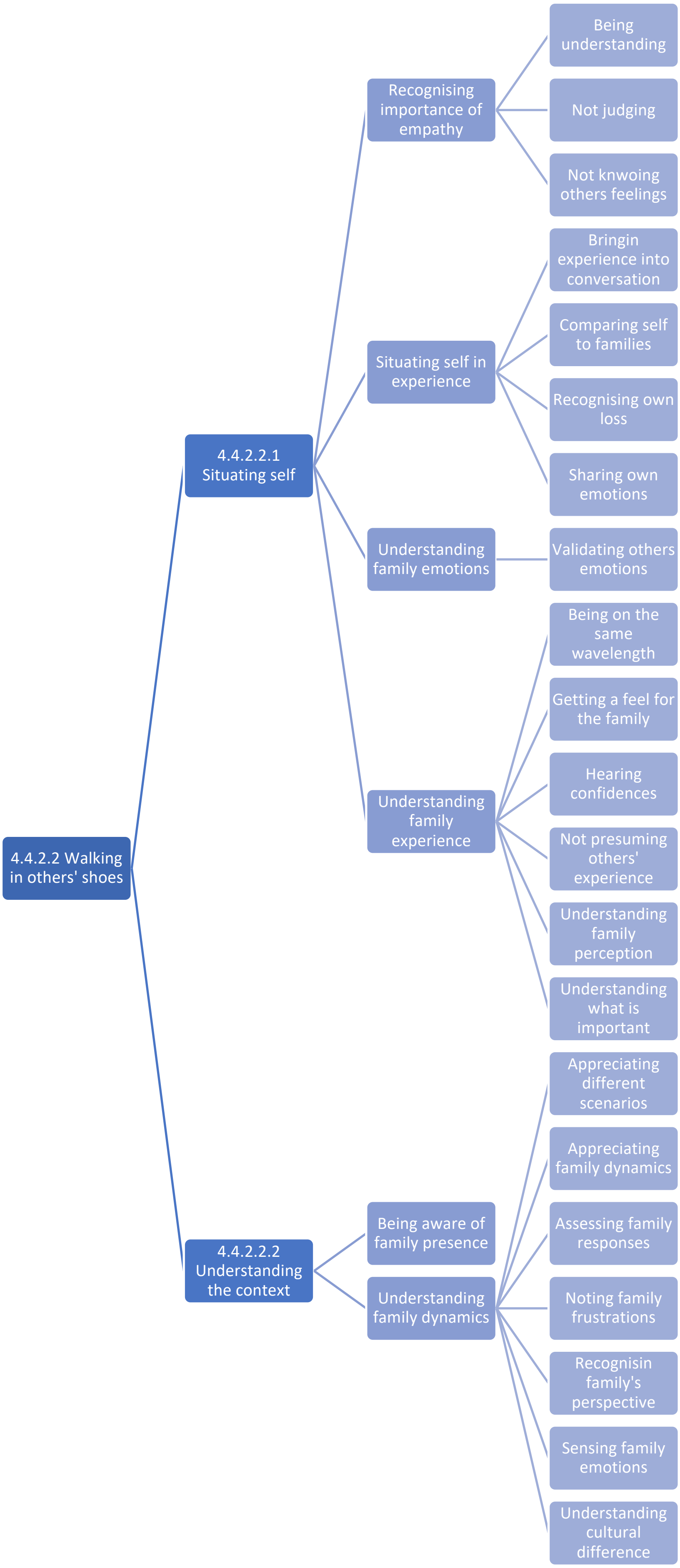

4.4.1 Walking the path with the dying
4.4.1.2 Advocating for the patient
Being patient-led
Ensuring honesty
Managing patient safety
Not prolonging the inevitable
Safeguarding the patient
Working with the medical team
4.4.1.1 Managing the journey
'Doing the nursing bits'
Managing different types of death
4.4.1.3 Supporting a 'good' death
Building a relationship with the patient
Ensuring a peaceful death
Identifying the dying
Managing the day (of death)

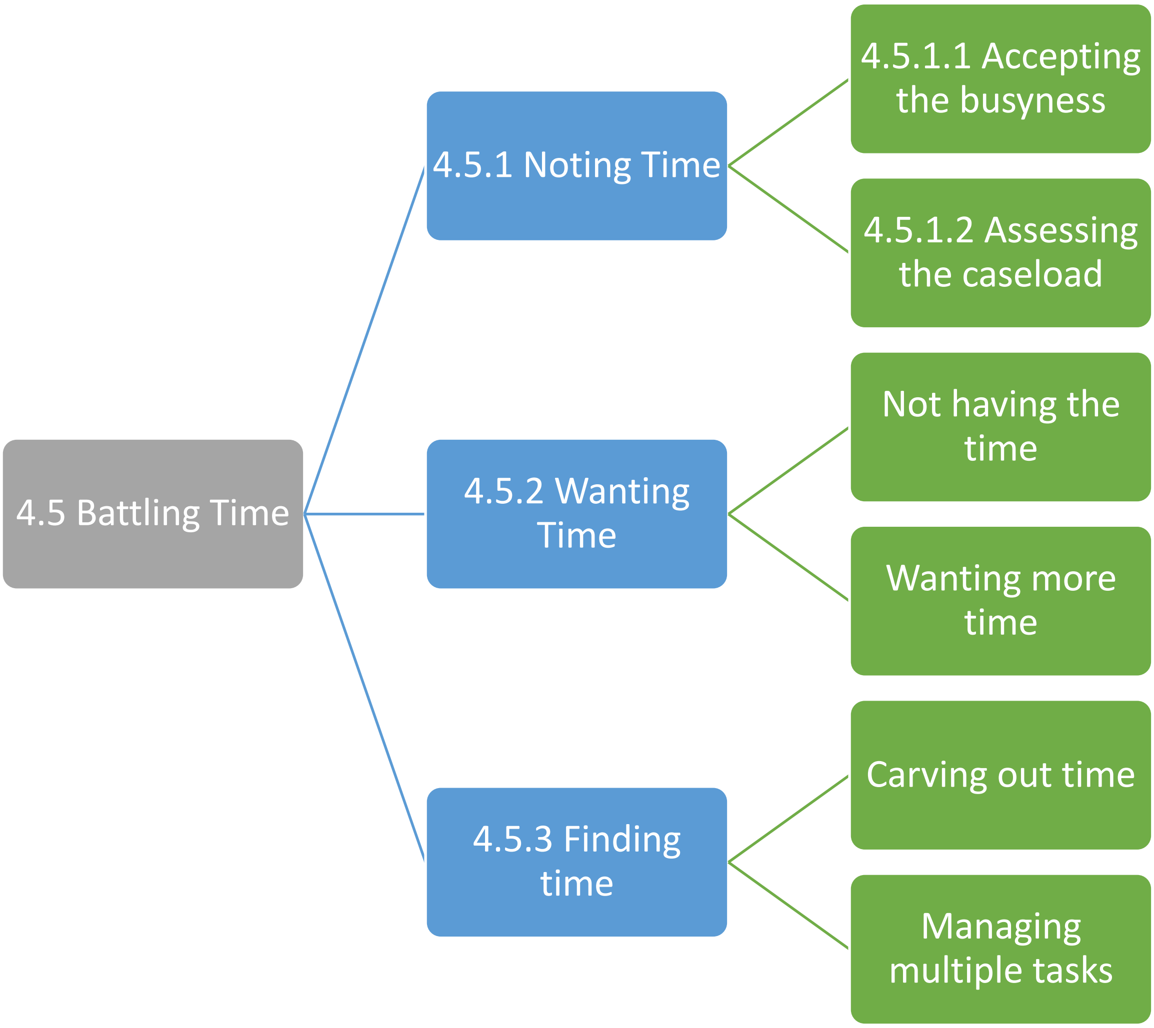

4.4.1.2 Advocating the for the patient
Being patient-led
Ensuring honesty
Managing patient safety
Not prolonging the inevitable
Safeguarding the patient
Working with the medical team
Getting the doctors involved
Inputting into the conversation
Questioning the point of care
Recognising different skill sets
Siupporting the doctors
4.4.1.1 Managing the journey
4.4.1.1.1 'Doing the nursing bits'
'Getting everything in place'
Assisting the doctor
Doing the paperwork
Following the standards
Getting handover
Getting patients home
Giving medication
Nursing by numbers
Performing last offices
4.4.1.2 Dealing with different death
'Working through a situation'
Comparing types of death
Managing sudden deterioration
Recognising a slow death
Responding to an emergency


4.4.1.3 Supporting a 'good' death
Building a relationship with the patient
Anticipating the patient's needs
Communicating with the patient
Involving the patient
'Addressing what the patient wants'
Assessing the patient
Caring for the patient
Ensuring wishes followed
Fact-finding
Noting patient awareness
Confirming patient agreement with plan
Having an aim
Knowing patient's wishes
Knowing the patient
Knowing what people want
Managing cognitive impairment
Receiving patient requests
Recognising patient acceptance
Recognising patient choice
Understanding patient's needs
Ensuring a peaceful death
Easing suffering
Experiencing a nice death
Identifying the dying
Identifying the stage of dying
Experiencing a nice death
Managing the day (of death)
'Moving to a side room'
Facilitating place of death
Having available resources

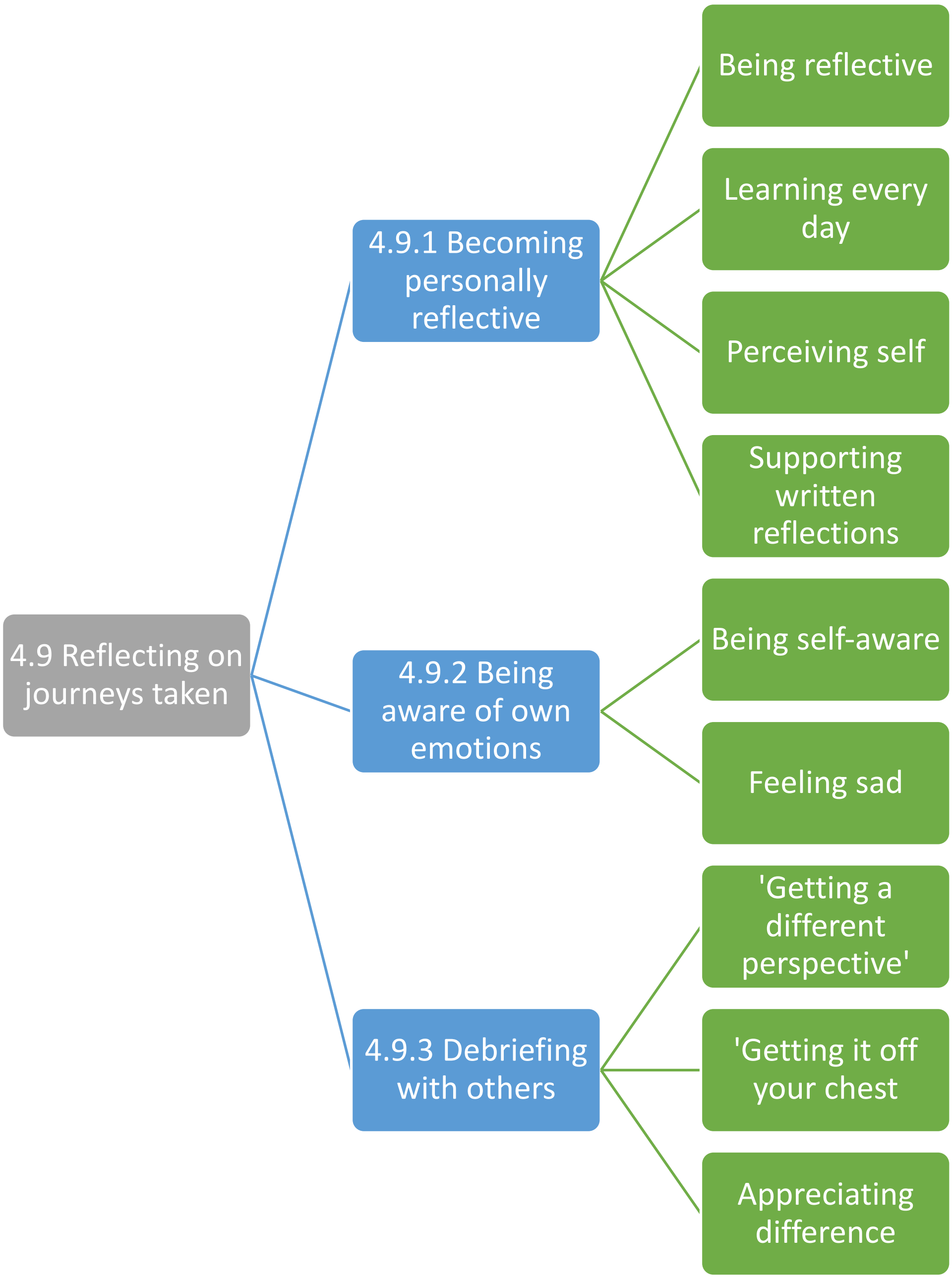

4.4.2 Walking the path with the grieving
4.4.2.1 Smoothing the way
4.4.2.2 Walking in others' shoes
4.4.2.1.1 Signposting
4.4.2.1.2 Managing expectations
4.4.2.1.3 Caring for the family
4.4.2.2.1 Situating self
4.4.2.2.2 Understanding the context

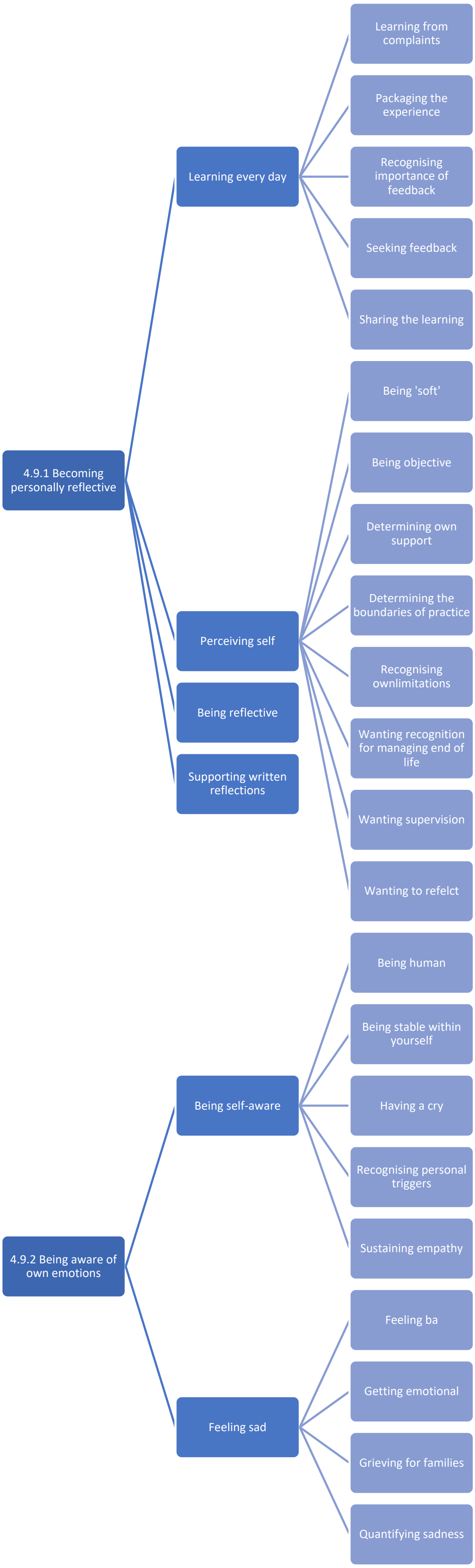

4.4.2.1 Smoothing the way
4.4.2.1.3 Caring for the family
Being present
Gaining information
Giving the best possible experience
Being approachable
Letting family in
Minimising a poor experience
Offering practical support
Managing familial emotions
Adjusting to family emotions
Experience others' distress
Giving permission to grieve
Impacting on grief
Introducing self
Living with others' pain
Managing grief
Observing grief
Receiving grief
Supporting the family
'Making it easy'
Ensuring family support
Keeping to promises
Helping the family
Supporting family emotions
4.4.2.1.2 Managing expectations
Building relationships
Managing difficult situations
Managing family expectations
Managin family experience
4.4.2.1.1 Signposting
Taking the lead
Communicating with the family
Composing self
Preparing the family

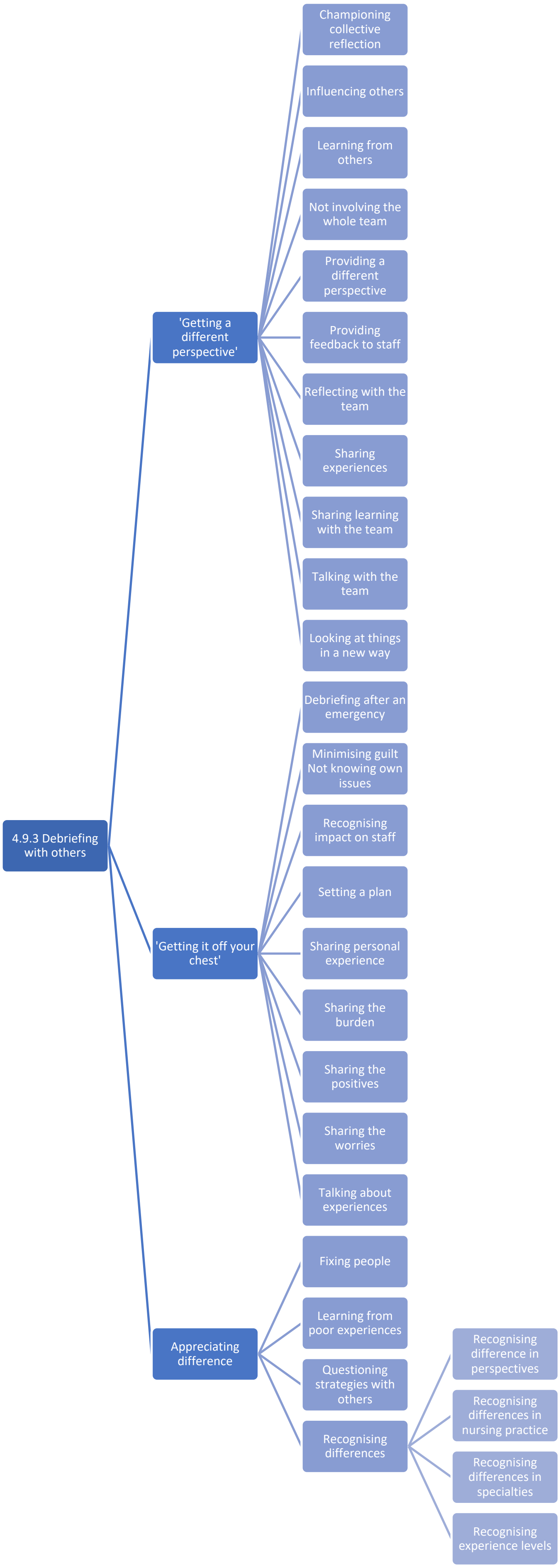

4.4.2.2 Walking in others' shoes
4.4.2.2.1 Situating self
Recognising importance of empathy
Being understanding
Not judging
Not knwoing others feelings
Situating self in experience
Bringin experience into conversation
Comparing self to families
Recognising own loss
Sharing own emotions
Understanding family emotions
Validating others emotions
Understanding family experience
Being on the same wavelength
Getting a feel for the family
Hearing confidences
Not presuming others' experience
Understanding family perception
Understanding what is important
4.4.2.2.2 Understanding the context
Being aware of family presence
Understanding family dynamics
Appreciating different scenarios
Appreciating family dynamics
Assessing family responses
Noting family frustrations
Recognisin family's perspective
Sensing family emotions
Understanding cultural difference


4.5 Battling Time
4.5.1 Noting Time
4.5.1.1 Accepting the busyness
4.5.1.2 Assessing the caseload
4.5.2 Wanting Time
Not having the time
Wanting more time
4.5.3 Finding time
Carving out time
Managing multiple tasks


4.5.1 Noting time
4.5.1.1 Accepting the busyness
Appreciating busyness
Differentiating busyness
4.5.1.2 Assessing the casload
Appreciating time needed
Having multiple patients
Managng competing priorities
Providing equity in care
4.5.2 Wanting time
Not having the time
Being interrupted
Feeling frustrated by lack of time
Not having time for support
Wanting more time
Wanting people to have more time
Wanting more time for self
4.5.3 Finding time
Carving out time
'Having all the time in the world'
Finding the time by others
Finding time for families
Giving the team time
Taking the time
Managing multiple tasks
'Making a special effort' 'Working your way around'
Dealing with things at the same time
Deprioritising other tasks
Managing the time


4.9 Reflecting on journeys taken
4.9.1 Becoming personally reflective
Being reflective
Learning every day
Perceiving self
Supporting written reflections
4.9.2 Being aware of own emotions
Being self-aware
Feeling sad
4.9.3 Debriefing with others
'Getting a different perspective'
'Getting it off your chest
Appreciating difference


4.9.1 Becoming personally reflective
Learning every day
Learning from complaints
Packaging the experience
Recognising importance of feedback
Seeking feedback
Sharing the learning
Perceiving self
Being 'soft'
Being objective
Determining own support
Determining the boundaries of practice
Recognising ownlimitations
Wanting recognition for managing end of life
Wanting supervision
Wanting to refelct
Being reflective
Supporting written reflections
4.9.2 Being aware of own emotions
Being self-aware
Being human
Being stable within yourself
Having a cry
Recognising personal triggers
Sustaining empathy
Feeling sad
Feeling ba
Getting emotional
Grieving for families
Quantifying sadness


4.9.3 Debriefing with others
'Getting a different perspective'
Championing collective reflection
Influencing others
Learning from others
Not involving the whole team
Providing a different perspective
Providing feedback to staff
Reflecting with the team
Sharing experiences
Sharing learning with the team
Talking with the team
Looking at things in a new way
'Getting it off your chest'
Debriefing after an emergency
Minimising guilt Not knowing own issues
Recognising impact on staff
Setting a plan
Sharing personal experience
Sharing the burden
Sharing the positives
Sharing the worries
Talking about experiences
Appreciating difference
Fixing people
Learning from poor experiences
Questioning strategies with others
Recognising differences
Recognising difference in perspectives
Recognising differences in nursing practice
Recognising differences in specialties
Recognising experience levels