A grounded theory study – community palliative care clinical nurse specialists' experiences when fulfilling their role

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Abstract

Background: Community palliative care clinical nurse specialists play a vital role in delivering specialist palliative care in community settings, where continuity and holistic support are critical. While their responsibilities span advanced clinical care, education, and advocacy, the role has evolved significantly in response to increasing patient complexity, changing service models, and policy shifts. This evolution has led to growing role ambiguity, making it harder for community palliative care clinical nurse specialists to navigate expectations and deliver care effectively. Despite their central contribution, there is limited empirical research exploring the lived experiences of community palliative care clinical nurse specialists leaving important gaps in understanding how they perceive, adapt to, and manage the demands of their role

Aim: To develop a grounded theory of clinical nurse specialists' experiences in fulfilling their roles within community specialist palliative care teams.

Methods: A constructivist grounded theory approach guided the study. Participants were community palliative care clinical nurse specialists, working in the Republic of Ireland. A combination of convenience and theoretical sampling strategies was employed to recruit participants who could contribute rich, relevant insights to the developing theory. Participants were invited to take part in the study through established professional networks and service contacts, with subsequent recruitment guided by emerging data needs as per theoretical sampling principles. Data were collected through in-depth, semi-structured interviews. Interviews were transcribed and analysed using constant comparative methods. This iterative process supported the identification of core categories and relationships, leading to the development of a grounded theoretical framework. Ethical approval was obtained.

Results: Nine community palliative care clinical nurse specialists participated in this study. The effectiveness of the community palliative care clinical nurse specialist role is shaped by a complex interaction of personal qualities, organisational support, and external factors, all of which consist of interconnected elements which shape their experience of the role. Empirical and systematic review findings indicate that

community palliative care clinical nurse specialists navigate this balance of personal dedication, organisational challenges, and broader system-level pressures while fulfilling their responsibilities. Facilitators identified include mutual respect among professionals, clear definition of role boundaries, and effective communication networks. In contrast, barriers encompass limited resources, inconsistent understanding of the role among generalist providers, and inadequate succession planning. A theoretical model was developed to illustrate how these personal, organisational, and external factors are interdependent and collectively impact the successful fulfilment of the community palliative care clinical nurse specialist role

Conclusion: This study provides new insights into the realities faced by community-based clinical nurse specialists. The resulting theory emphasises the need for strategic investment in education, role clarity, and resource allocation to effectively support these key professionals. Clinical nurse specialists are instrumental in bridging policy and practice, contributing to service innovation, quality improvement, and patient-centred care delivery. Their leadership and advanced clinical expertise position them as vital agents in shaping responsive, sustainable community palliative care models. These findings have important implications for workforce planning, policy development, and the long-term delivery of high-quality, community-based palliative care

Table of Contents

List of tables

List of figures

List of appendices

List of key terms

Community setting	Indicates the location where the clinical nurse specialist is providing care to the patient within a community setting, such as a community hospital, nursing home, residential care setting, or the patient's own home or that of a relative.
Generalist palliative care. Also called 'General palliative care' or 'Palliative care approach'	Generalist palliative care refers to the work of healthcare professionals who have knowledge and confidence in providing the core palliative care skills (Health Service Executive, 2019). This refers to healthcare professionals who are not part of the specialist palliative care team i.e. oncologists or general practitioners.
Holistic care	Holistic care involves the integration of body, mind, emotion, and spirit, with a focus on the individual's subjective experience and the broader context of their life (Dossey & Keegan, 2008)
Palliative care	Is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification, impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (WHO, 2020)
Public health nurse	Public health nurses are registered nurses who work with communities to improve overall health and prevent disease by addressing factors such as environment, lifestyle, and socioeconomic conditions (Stanhope & Lancaster, 2015). Public health nurses in the UK are called district nurses.
Community palliative care clinical nurse specialists	These nurses play a significant role within specialist palliative care services in the community setting providing direct and indirect services to patients with complex problems associated with their life limiting illnesses (Skilbeck & Payne, 2003).

	These specialists combine a deep, dynamic understanding of clinical expertise with high analytical and intuitive skills (Benner, 1984).
Specialist palliative care	Services are provided in different care settings including hospitals, homes, hospices inpatient units, out-patient and day care settings (Firth et al., 2019). The specialist palliative care team uses in-depth palliative care knowledge and works in collaboration with referring teams to manage current or anticipated complexities relating to symptom control, end-of-life care planning or other physical, psychosocial or spiritual needs that cannot be met by the primary care provider (s) (Health Service Executive, 2019).

1 Background

1.1 Introduction

Palliative care involves the comprehensive, person-centred support of individuals living with life-limiting illnesses, addressing their physical, psychological, social, and spiritual needs. These individuals often require input from a wide range of multidisciplinary professionals across multiple care settings. Within this complex care environment, community palliative care clinical nurse specialists fulfil dynamic and multifaceted roles. These include coordinating with other healthcare providers and external organisations, offering expert guidance on symptom management, providing emotional support, and supporting families and carers throughout the illness trajectory (Connolly et al., 2021). The diverse nature of their responsibilities can sometimes lead to blurred professional boundaries between specialist and generalist services, contributing to uncertainty around roles and responsibilities. Consequently effective communication, collaboration and mutual understanding among team members are essential to navigate these complexities and ensure cohesive, person-centred care.

In this thesis, the experiences of community palliative care clinical nurse specialists fulfilling their roles in the Republic of Ireland are explored. In this chapter, the rationale for exploring the experiences of community palliative care clinical nurse specialists and conducting this research is outlined. Given the study's context, it is also essential to understand the distinction between generalist and specialist palliative care models, as well as the development of the community palliative care clinical nurse specialist role in the Republic of Ireland. The historical and policy-driven evolution of palliative care in the Republic of Ireland will be presented, with a specific focus on the development and progression of the community palliative care clinical nurse specialist role.

1.2 Generalist and specialist palliative care

Palliative care is delivered in two primary forms: generalist and specialist palliative care. Generalist palliative care is typically provided by healthcare professionals who are not exclusively focused on palliative care but incorporate its principles into their

routine practice, such as general practitioners, community nurses, and hospital staff (Department of Health, 2024). In contrast, specialist palliative care is offered by clinicians with advanced training and expertise in managing complex symptoms, psychosocial issues, and end-of-life care (Uitdehaag et al., 2014). The effective provision of both forms of palliative care depends on the availability of adequate resources, comprehensive education, and appropriate training for all healthcare providers involved (Brennan, 2007); Department of Health, 2024). Without these supports the accessibility of generalist and specialist palliative care services may be compromised. These supports are essential to ensure that care is delivered consistently and to a high standard across all settings. Without such infrastructure in place, the accessibility, quality, and continuity of generalist and specialist palliative care services may be significantly compromised (Godrie et al, 2024) . This will impact the well-being and dignity of patients with life-limiting illnesses and their families.

1.3 Specialist and generalist palliative care provision in the Republic of Ireland

The Republic of Ireland was the second European country recognising palliative medicine as a medical speciality in 1995 (Kane et al., 2015). The Republic of Ireland is the setting for this research study. Reports predict an increase of 68-84% in the number of people requiring palliative care between 2016 and 2046 (May et al., 2019). Several national reports and policy documents have influenced how specialist palliative care services should be developed (Department of Health, 2024); Tebbit, 1999); Wilkes, 1980). Although the Report of the National Advisory Committee for Palliative Care (2001) laid a comprehensive foundation for multidisciplinary specialist teams, many of its recommendations remain unimplemented, resulting in continued geographic and resource-based challenges (Department of Health and Children, 2001b); Johnston et al., 2022). The ongoing gap between policy and practice highlights the urgent need for sustained investment and strategic implementation to ensure equitable access to palliative care across the Republic of Ireland.

The recent National Adult Palliative Care policy (2024) emphasises equitable, person-centred and accessible general and specialist palliative care (Department of Health, 2024). It is hoped that the new 2024 National Adult Palliative Care policy, with additional funding support, will bridge this gap between recommendations in policy and availability of resources in the Republic of Ireland. This policy builds on the principles of Slaintecare (2017) which aims to provide care in the right place, at the right time and by the right professionals (Department of Health, 2017). The Health Service Executive in the Republic of Ireland advocates that patients should have access to generalist palliative care from healthcare professionals at home, in an acute hospital, or in their residential care facility, where this care can be provided as part of normal care (Department of Health, 2024). They continue to add that, in addition, access to specialist palliative care should be provided for patients with complex needs in their preferred care setting. In order for these gaps in service availability to be filled adequate funding, resources, education and training is required to meet increasing demands.

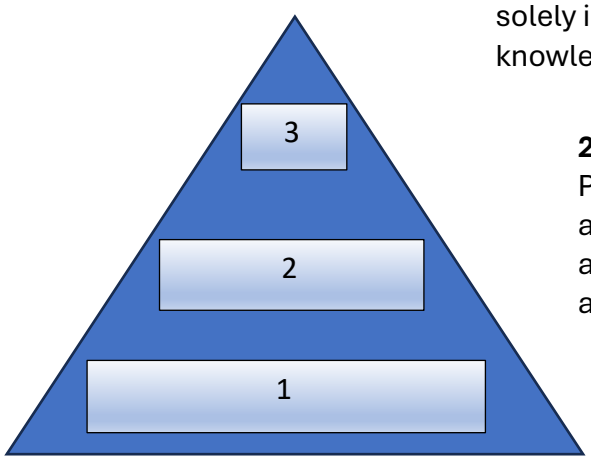
The National Clinical Care Programme for Palliative Care outlined eligibility criteria for access to specialist palliative care services in the Republic of Ireland. For general practitioners or hospital consultants to refer to specialist palliative care services, patients must meet the following criteria having;

- An advanced, progressive, life-limiting condition and
- Current or anticipated complexities relating to symptom control, end-of-life care- planning or other physical, psychosocial or spiritual needs that cannot reasonably be managed by the current care provider(s)

(Department of Health, 2024)

Specialist palliative care services are structured into three levels of specialism and these levels are defined based on the required level of expertise of the healthcare professionals providing the care (Department of Health, 2024); Department of Health and Children, 2001b). See Figure 1 below. The appropriate level of palliative care, it

states, should be available to all patients with malignant and non-malignant life-limiting illnesses.



3. Specialist palliative care
Provided by healthcare professionals who work solely in palliative care and who have extensive knowledge and skills in this specialty

2. Generalist palliative care
Provided in any location, using a palliative care approach by healthcare professionals who have additional knowledge of palliative care principles and use this as part of their role

1.Palliative care approach
Provided in any location or setting by all healthcare professionals as part of their role and using a palliative care approach

(Department of Health and Children, 2001)

Figure 1.1: Levels of Specialist Palliative Care in the Republic of Ireland

1.4 Community based generalist and specialist palliative care

Generalist and specialist palliative care can be delivered within the acute and community care setting. The community setting indicates the location where the patient is, such as a community hospital, nursing home, residential care setting, or the patient's own home or that of a relative. Ensuring equitable access to community-based generalist and specialist palliative care is essential to reducing hospital pressures and improving outcomes for patients with life-limiting illnesses. Given the increased prevalence of older adults with life limiting illnesses requiring palliative care, improving care in the community setting is both a clinical and economic priority (Kane et al., 2015); Yosick et al., 2019). Despite strong evidence that providing community based palliative care reduces admissions and emergency department presentations hospitalisations these community services remain unevenly distributed and often lack

out-of-hours coverage (Kavalieratos et al., 2016); Khan et al., 2019); Youens & Moorin, 2017). Specialist palliative care is primarily provided by community palliative care clinical nurse specialists who play a central role in delivering expert symptom management, care coordination and holistic support in this setting (Mulvihill et al., 2010).

1.5 Historical context of the clinical nurse specialist role

Internationally from as early as 1940 the clinical nurse specialist's role across a range of specialities was characterised by a strong emphasis on consultation, education and the provision of guidance and support to those delivering direct patient care. (Hamric et al., 2013). During the 1980s, the United Kingdom developed the concept of a Central Council for Nursing, Midwifery and Health to support clinical nurse specialists across a range of specialties (Raja-Jones, 2002). In 1994, the (UKCC) defined specialist nursing practice as the exercise of higher levels of judgement, discretion and decision-making in the clinical care (UKCC, 1994). However, the Nursing and Midwifery Council's (NMC) recently updated its standards for specialist practice qualifications in 2024, demonstrating its commitment that specialist nurses possess the necessary competencies to contribute to the advancement of nursing practice (NMC, 2024). These standards enhance clarity by clearly defining the roles, responsibilities, and expectations of specialist nurses, reducing ambiguity in practice, and they improve accessibility by outlining a transparent and structured pathway for nurses to develop and demonstrate advanced competencies, ultimately supporting consistent, high-quality care across healthcare settings.

The National Council for the Professional Development of Nursing and Midwifery was established in the Republic of Ireland in 1999. Its functions included the development of nursing speciality roles, considering service needs, appropriate levels of qualification and competence levels for entry into this practice area. The Health Service Executive identifies clinical nurse specialists across various specialties as having a career pathway incorporating professional development within an inter-professional

team structure (Health Service Executive, 2021). The National Council for the Professional Development of Nursing and Midwifery in the Republic of Ireland differentiated between the role of the clinical nurse specialist across specialties and registered general nurses stating that this clinical nurse specialist role incorporates a major clinical focus of care to patients and their families (National Council for the Professional Development of Nursing and Midwifery, 2008).This foundational work laid the groundwork for a clearly defined, advanced clinical role for clinical nurse specialists across specialties in the Republic of Ireland, ensuring that their contribution is complementary but different to that of registered general nurses.

In the Republic of Ireland, it was not until 2001 before the National Council for Nursing and Midwifery formally defined a Clinical Nurse/Midwife specialist as "a nurse/midwife specialist in clinical practice who has undertaken formal recognised post-registration education in his/her area of specialist practice at higher diploma level"(National Council for the Professional Development of Nursing and Midwifery, 2008). Prior to this, the role existed largely in an informal or aspirational capacity, lacking both a standardised definition and a coherent educational or professional development framework. As a result, the structured development of the clinical nurse specialist role across specialties in the Republic of Ireland occurred considerably later than other jurisdictions such as United States of America and the United Kingdom. In the United States of America, the clinical nurse specialist role evolved within a framework that emphasised the enhancement of patient outcomes through advanced clinical practice, role modelling and the systematic education of the multidisciplinary workforce (Hamric et al., 2013).

Within the Republic of Ireland, the clinical nurse specialist role is underpinned by five core competencies: clinical focus, patient advocacy, education and training, consultancy, audit and research (National Council for the Professional Development of Nursing and Midwifery, 2008). These core competencies were developed through a research-based and policy aligned process aimed at professionalising specialist nursing roles, standardising expectations and enhancing patient care delivery. However, the strategic momentum generated by this framework was disrupted

following the enactment of the Nurses and Midwives Act (2011). The subsequent disbandment of the National Council for the Professional Development of Nursing and Midwifery removed a dedicated national mechanism for the stewardship, evaluation, and iterative development of advanced nursing roles. Oversight of the clinical nurse specialist role was transferred to the Health Service Executive Office of the Nursing and Midwifery Services Directorate, where governance became more closely aligned with service delivery and workforce management imperatives. While this structural realignment may have supported operational integration, it arguably diminished strategic leadership focused on role innovation, career progression, and national coherence. Consequently, the absence of a central, profession-led developmental authority may have contributed to a slowing, or relative stagnation, in the evolution of the clinical nurse specialist role within the Republic of Ireland, particularly when contrasted with the continued advancement observed in international models.

Several critiques can be raised regarding the core competencies scope, implementation and adaptability in a healthcare environment. While the framework defines broad areas of responsibility, in practice there is an overlap of roles with both generalist nurses and advanced nurse practitioners, which can lead to confusion, particularly in multidisciplinary team (Elliott et al., 2013). The scope of clinical nurse specialists across various specialties can vary significantly across services leading to inconsistencies in their role. Clinical nurse specialists across specialties advocate for patients however this work is often unquantified making it challenging to demonstrate its impact in audits. The framework sets educational requirements (higher diploma), but does not specify ongoing continuous professional development or formal mentorship structures, which are essential for sustaining clinical expertise and avoiding role stagnation (National Council for the Professional Development of Nursing and Midwifery, 2008). While clinical nurse specialists across various specialities are expected to contribute to education and mentoring within their role, education roles are often not prioritised due to service demands and pressures. While the core competencies offer a robust foundation for specialist nursing roles their relevance could be strengthened by addressing challenges.

Since the introduction of clinical nurse specialist roles across specialities there are now also advanced nurse and midwifery practitioner roles. There is increasing concern within healthcare systems about the blurring of professional boundaries between clinical nurse specialists and advanced nurse practitioner roles across specialities (Bryant-Lukosius et al., 2017) While both roles are situated within advanced practice and share overlapping competencies such as patient advocacy, education and clinical leadership, they are conceptually and functionally distinct. The clinical nurse specialist role is primarily grounded in competence-based practice, typically aligned with Level 8 of the National Framework of Qualifications, which emphasises the application of specialised knowledge, skills, and professional judgement within a defined scope of practice (National Qualifications Authority of Ireland, 2003). In contrast, the advanced practice role is underpinned by a capability-based model of practice, requiring autonomous decision-making, advanced clinical reasoning, and role expansion across complex and unpredictable clinical contexts, commonly associated with postgraduate education at Level 9 or above. However, in practice, organisational needs, staffing shortages, and evolving models of care have led to role overlap, which can cause confusion among colleagues and diminish role clarity (Hamric et al., 2013). Addressing this ambiguity is essential to ensure that both roles are used effectively and in alignment with their intended purpose.

In palliative care within the Republic of Ireland, the Palliative Care Competency Framework was developed to support community palliative care clinical nurse specialist in their responsibilities by outlining clear, discipline-specific competencies that guide in delivering expert, holistic, and person-centred care (Ryan et al., 2014). It identified six additional domains specific to the field of palliative care including palliative care, communication, comfort, care planning, ethical practice and bereavement. It also fosters role clarity and professional identity, which is essential in community settings where clinical nurse specialists frequently collaborate across boundaries with GPs, public health nurses, and allied health professionals (Bainbridge et al., 2010). Furthermore, the framework supports continuous professional development by identifying skill domains such as leadership, education, and audit areas often under-prioritised in busy community caseloads but essential for sustaining

role effectiveness and career progression. Ultimately, by standardising expectations and promoting reflective practice, the framework helps ensure that clinical nurse specialists in the community are equipped to respond confidently to the growing complexity of palliative care needs. However fulfilment of these criteria and education requirements are challenging when community palliative care clinical nurse specialists have demanding clinical caseloads.

The Report of the National Advisory Committee in Palliative Care (2001) in the Republic of Ireland recognised that specialist palliative care nursing was a new an evolving field and that nursing education in this area was in its early stages (Department of Health and Children, 2001b). Therefore, it had recommended as an interim measure that services should recognise the accrued experience from senior palliative care nurses who did not have post-registration qualifications specific to their role, yet had worked for a minimum of 5 years caring for patients with terminal illness. However from 2010, in the Republic of Ireland, all nurses must have undertaken a post-registration level 8 qualification prior to applying for a community palliative care clinical nurse specialist post. A level 8 post-registration qualification in the Republic of Ireland typically translates to an honours bachelor's degree in many countries such as United Kingdom, United States and Australia (NMBI, 2015). As undergraduate nursing education in Ireland became established at Level 8, the educational preparation for clinical nurse specialist roles has increasingly shifted to Level 9, reflecting the need for advanced knowledge, critical analysis, and enhanced professional judgement consistent with specialist clinical practice as articulated within the NFQ (National Qualifications Authority of Ireland, 2003)

1.6 Synopsis of literature available for community palliative care clinical nurse specialists experiences of their role

Existing international literature about community palliative care clinical nurse specialists predominantly addresses the needs of patients and families, symptom management outcomes, and the experiences of paediatric palliative care. (Bandini et

al., 2022); Chong & Abdullah, 2017); Herbstsomer & Stahl, 2021); Newbury, 2002). While these studies provide valuable insights into the impact of community palliative care clinical nurse specialist roles on direct patient outcomes and caregiver experiences, they tend to be condition or population-specific and often lack generalisability across broader adult palliative care settings. Additionally, much of the available evidence is qualitative in nature, with small sample sizes and limited longitudinal follow-up, which may restrict the applicability of findings to long-term service planning.

Notably absent in the literature is a strong body of evidence exploring the barriers and facilitators that influence community palliative care clinical nurse specialists in fulfilling their specialist roles. Although situated within the acute hospital setting, an evaluation of generalist staff revealed varied understanding of the hospital palliative care clinical nurse specialist role, highlighting that while it was viewed as supportive, significant role ambiguity remained(Bainbridge et al., 2010); Connolly et al., 2021). The limited empirical work in this area represents a significant gap, especially given the increasing demand for specialist palliative care in aging populations and the shifting emphasis from hospital to community-based services (WHO, 2020). Without targeted, contemporary research into community palliative care clinical nurse specialist practice environments and interprofessional dynamics policy-makers and healthcare leaders may lack the insight required to optimise these roles.

This gap underlines the need for robust, high quality studies that can better capture the complex, context-dependent realities of community palliative care clinical nurse specialist roles in palliative care. Such research is essential not only for informing workforce development and policy planning but also for ensuring equitable and effective care for patients with life-limiting illnesses in community settings.

1.7 Personal and professional motivation for the study

With over two decades of experience in specialist palliative care, my professional journey from staff nurse to Director of Nursing has provided me with a unique and

deeply informed perspective on the evolving role of the community palliative care clinical nurse specialist. Having worked across inpatient, acute hospital, and community settings, I have witnessed first-hand how the demands placed on community palliative care clinical nurse specialists has grown increasingly complex alongside the broadening scope of palliative care services. This evolving landscape from a predominantly oncology-focused model to one encompassing a diverse range of life-limiting conditions has underscored the critical need to understand how community palliative care clinical nurse specialists navigate these challenges, particularly within the community.

My interest in this focus stems from my experience and a commitment to improving patient care. I have observed the strain that resource limitations place on specialist services, as well as the resilience and adaptability of community palliative care clinical nurse specialists working in often fragmented and under-resourced community environments. The shift towards integrating specialist palliative care with ongoing treatments such as chemotherapy and immunotherapy presents new clinical and coordination challenges that demand a deeper understanding of community palliative care clinical nurse specialist roles.

Moreover, through my leadership roles, I have become increasingly aware of the strategic importance of workforce planning and service development in ensuring that community palliative care clinical nurse specialists are supported and empowered to deliver high-quality care. This study offers an opportunity to explore the barriers and facilitators impacting community palliative care clinical nurse specialists, insights which I believe are essential for shaping policies that reflect the realities of clinical practice and meet the growing needs of an aging population.

Ultimately, my motivation lies in bridging the gap between frontline experience and organisational decision-making to ensure that the community palliative care clinical nurse specialists role continues to evolve in a way that benefits both patients and healthcare systems. This study represents a crucial step toward that goal, and I am personally invested in contributing evidence that will support sustainable, effective specialist palliative care delivery across community settings.

1.8 Summary

The purpose of this grounded theory study was to examine the experiences of community palliative care clinical nurse specialists within their role in the Republic of Ireland with a particular focus on the barriers and facilitators they encounter in fulfilling their roles. Using the principles of grounded theory, this research sought to generate an in-depth understanding of how community palliative care clinical nurse specialist's navigate their responsibilities in providing specialist palliative care to patients with life-limiting conditions. Given that all healthcare professionals share a responsibility to deliver effective palliative care with specialist input accessed when appropriate, the unique expertise of community palliative care clinical nurse specialists is vital. Existing literature highlights a significant gap regarding the challenges and supports influencing community palliative care clinical nurse specialists role fulfilment. As the demand for specialist palliative care continues to rise, gaining insight into these experiences is essential for informing sustainable service models and ensuring consistent, high-quality care for patients and families. The following methodology chapter will outline the grounded theory approach used to investigate these issues, detailing the research design, data collection, and analysis methods that underpin this study.

1.9 Overview of thesis

In chapter 1 the evolvement of palliative care in the Republic of Ireland was presented with a focus on the clinical nurse specialist role. In chapter 2, the philosophical foundations of the study are described and related to the choice of constructivist grounded theory, which is critically justified. Methods used for the study, design, recruitment, data collection and analysis are presented. In chapter 3, the results of the study are outlined, providing a brief description of the participants' characteristics and giving an in-depth explanation of how each category was constructed. Chapter 4 outlines the systematic review of the literature structured around the categories which emerged from the findings. Delaying the literature review was in accordance with the methodology, supporting a more inductive and unbiased engagement with the data. In

Chapter 5, the final stage of analysis, leading to the construction of a theory outlining the interdependence of personal, organisational and external factors to fulfil the clinical nurse specialist role is outlined. Chapter 6 provides a detailed analysis of the data findings and systematic review, highlighting implications for future practice, policy and research. Hereafter in this thesis clinical nurse specialist(s) refers to the community palliative care clinical nurse specialists role. Any reference to clinical nurse specialist(s) in another specialty will be clearly outlined.

2 Methodology

2.1 Introduction

In this chapter the study's aim, research question, objectives, and rationale for the selected philosophical paradigm and methodology chosen are presented. The methods used to conduct the study are then detailed, including ethical considerations, participant recruitment, data collection and analysis procedures. Finally, concluding with a reflection on the researcher's reflexivity and positionality throughout the research process. Methodology refers to the overarching research strategy that guides how a study is conducted. It encompasses a system of philosophical assumptions and beliefs that shape the researcher's understanding of the research question and inform methodological choices (Melnikovas, 2018). These choices include the selected research design, the approach to the literature review, and the type of data to be collected, analysed and interpreted (Higgins et al., 2019); Imenda, 2014). Together, these elements establish the philosophical and methodological framework that underpins the study and guides each stage of the research process.

2.1.1 Research aim

The aim is to understand how clinical nurse specialists' interpret and give meaning to their role, drawing from their experiences providing specialist palliative care using a grounded theory approach.

2.1.2 Research question

The research question guiding this study is

"What are the experiences of clinical nurse specialists' in fulfilling their role?"

2.1.3 Research objectives

The study's objectives are to

- Examine the experiences of clinical nurse specialists' in fulfilling the core competencies of their role,
- Investigate whether clinical nurse specialists encounter any barriers in fulfilling their role,
- Examine whether there are any factors that support clinical nurse specialists in fulfilling their role.

2.2 Research paradigm

A research paradigm is a set of beliefs and is our way of understanding the world's reality and how we study it. A paradigm is a basic belief system and theoretical framework with assumptions about ontology, epistemology, methodology and methods. One of the first requirements in planning this research was to determine which paradigm could shape the approach to the research and, subsequently, which methodology could best answer the research question (Welford et al., 2011). When choosing a paradigm for this study, it was not about trying to hold one superior to the other. The question was which paradigm was most suitable for the research question. A research question was needed to determine an appropriate ontology, epistemology, and methodology for the study. The research process is an iterative interplay between them all. Ontology refers to the nature of reality while epistemology is the study of knowledge and justified belief (Creswell & Poth, 2016). Ontology serves as the foundation of all research projects, guiding the subsequent development of epistemology and methodological perspectives (Grix, 2010). Some of the positions of research paradigms considered for this study are illustrated in Table 2.1 and outlined below.

Table 2.1: Research paradigms

	Ontology **(Nature of Reality)**	**Epistemology** **(What can be known)**	**Assumption**	**Relevance to my study**
Interpretivism	Based on subjectivist ontological assumptions that reality is socially constructed and evolves constantly (Melnikovas, 2018)	Interpretivists claim that the existence of a world which is independent of human thought is impossible.	Assumes the unpredictable nature of the future	Would focus on pre-existing meanings that clinical nurse specialists attach to their experiences
Relativist	Reality is seen as multiple and constructed through human interactions (Denzin & Lincoln, 2011)	Knowledge is viewed as co-constructed between researcher and participants (Denzin & Lincoln, 2011)	Truth is not absolute but varies depending on context, experience and interpretation (Guba & Lincoln, 1994)	This stance allows the study to explore varied and context specific participant meanings, aligning with qualitative interpretive methodologies (Fetters et al., 2013)
Critical Realism	(Bhaskar, 2020)outlines three levels of ontology in critical realism. They are the empirical, the actual and the real.	A realist epistemology that asserts that the study of the social world should be concerned with the identification of the structures that generate the world.	Assumes the flexibility of the future	That an objective reality exists independently to the clinical nurse specialists experiences, focusing on underlying causes
Pragmatism	Based on the assumption that human	Knowledge is always based on experience	Assumes researchers use the	Focuses on what works in clinical nurse

	actions can never be separated from past experiences (Kaushik & Walsh, 2019)	and ones interpretation of the world is influenced by our social experiences. (Maxcy, 2003)	methodological approach that best fits the research problem	specialist practice as opposed to how knowledge is constructed. It is more outcome driven
Constructivism	Based on the assumption that there are multiple realities (Lee, 2012)	All knowledge is constructed from human and social experience	Assumes reality is a construct of human mind, therefore reality is subjective (Elkind, 2004)	Develops co-construction of clinical nurse specialists experiences

In line with a relativist ontological stance, the assumption within this study is that reality is not singular or objective but instead is socially constructed and context-dependent. An interpretive epistemology complements this by focusing on how individuals make sense of their experiences (Pham, 2018). Rather than seeking universal laws or objective truths, interpretivism prioritises understanding the meanings that people assign to their actions, shaped by their cultural, historical, and social contexts (Pham, 2018) Knowledge is therefore seen as subjective and co-constructed, embedded within lived experiences and personal interpretations (Gray, 2021). The aim of this study is to explore how clinical nurse specialists understand and experience their role. Gaining insight into their perspectives required an approach that values subjective meaning. The interpretive paradigm was chosen for this study as it supports a deep exploration of these personal and contextual understandings (Gray, 2021). Within this framework, my role as the researcher was not to remain detached but to engage empathetically and reflexively with participants, recognizing that meaning is created through interaction and interpretation rather than observation alone.

In contrast, critical realism, while offering valuable tools for uncovering underlying structures rests on a realist ontology that assumes the existence of an objective reality independent of human perception (McEvoy & Richards, 2003). Though it incorporates

aspects of both positivism and interpretivism critical realism ultimately seeks causal explanations and emphasizes mechanisms beyond human experience (Haigh et al., 2019). Its applicability to nursing research has been debated, particularly due to the challenges in demonstrating how it translates into practical or functional insights (McEvoy & Richards, 2003); Ryan, 2022). Some authors argue that the concept of a real world that occurs independently of our reality is a challenge to understand (Williams et al., 2017). Furthermore, its foundational assumption, that a reality exists regardless of human understanding contradicts the relativist ontology underpinning this study.

Pragmatism, often positioned between positivism and constructivism, in terms of mode of enquiry. It has been widely applied in performance measurement, evaluation research (Kelly & Cordeiro, 2020) and is valued for social justice and mixed methods studies (Kaushik & Walsh, 2019). However, pragmatism's emphasis on what works can sometimes sideline deeper interpretive inquiry into meaning-making and context. Many healthcare workers would identify as pragmatists as it focuses on what is practical and achievable as opposed to theoretical or ideal (Long et al., 2018).Given this study's focus on understanding how clinical nurse specialists make sense of their roles from their own perspectives, the philosophical flexibility of pragmatism was less aligned with the study's aims. The interpretive paradigm, grounded in meaning and understanding, offered a more suitable framework.

While constructivist grounded theory also embraces relativism and multiple realities, it places greater emphasis on the co-construction of meaning between the researcher and participants (Charmaz, 2014). In contrast, a more interpretive stance is maintained in this study, where the researcher plays a role in interpreting participant accounts rather than actively co-creating meaning (Timonen et al., 2018). While constructivist grounded theory is rooted in constructivism, its flexible nature allows researchers to adopt interpretivism when they see themselves primarily as interpreting meanings already held by participants, rather than actively shaping those meanings through the research process (Bryant & Charmaz, 2019) The interpretive approach respects the subjective meanings of participants while also allowing the researcher to maintain an analytical distance, focusing on understanding rather than jointly constructing theory.

Examining these philosophical perspectives, alongside reflecting on the research question, helped to clarify the study's ontological and epistemological stance. This process enabled the methodology, ontology and epistemology underpinnings of the study to be defined. The methodological, epistemological and ontological beliefs chosen for this research question including the rationale will now be explained.

2.3 Philosophical foundations of this study

2.3.1 Ontological approach: relativism

The philosophical approach chosen is impacted by the research question. This study seeks to understand the experiences of clinical nurse specialists who work within a team of different multidisciplinary disciplines within a specialist palliative care organisation. These findings will involve nurses' feelings and attitudes about their role. Therefore this study requires an ontological position that is open to understanding the perspectives of all clinical nurse specialists.

A realist approach assumes that reality exists independent of human perception and can be accessed through objective inquiry. Within this ontological position, existence does not deepen on our awareness or knowledge of it (Levers, 2013). In other words, realists maintain that the world exists independently of the human mind. From realist perspective, the aim of research is to understand participants' ideas, assumptions, interpretations and how these interact with one another and with wider social conditions to produce the phenomena under study (Willig, 2016). Examining a phenomena from multiple perspectives enables a more comprehensive understanding, allowing connections to be made between different accounts.

In contrast to realism, relativism acknowledges that there are multiple realities leading to multiple truths. This means that an individual's reality depends on their experiences and the meaning they attribute to those experiences (Charmaz, 2014). From a relativist perspective research takes into account participants' experiences and interpretations of the world. This is done by recognising that these will be unique to that person but

may share commonalities with others (McLeod, 2011). For example, clinical nurse specialists' experiences are individual to that person however there may also be similarities between each other. Individuals who deny the existence of an objective reality assume a relativist ontological position (Guba & Lincoln, 1994). Relativists claim that concepts such as rationality, truth, reality, right, good, or norms must be understood. In other words, the world consists of multiple individual realities.

This research question focuses on developing an understanding of clinical nurse specialists' experiences in fulfilling their role in the community setting. These clinical nurse specialists are human beings who live and work within an organisational culture. This organisation has processes and procedures which the clinical nurse specialists work within. The clinical nurse specialists have job descriptions and core competencies which should be maintained within their day-to-day role. This question requires an ontological perspective that explores a knowable reality of clinical nurse specialists' experiences. However individually these clinical nurse specialists may experience this differently, therefore, this research will be conducted with a relativist ontology.

2.3.2 Epistemological approach: interpretivism

Similarly to ontology, the epistemological foundation for a study influences the research question. Epistemology involves understanding the nature of knowledge, the relationship between the person who seeks to know, the knowledge they construct and the criteria for making claims about the knowledge (Haigh et al., 2019). Epistemology informs the objectivity or subjectivity of research approaches and that of the researcher (Annells, 1996). It provides a philosophical grounding for deciding what kinds of knowledge is possible and how we can ensure that it is legitimate and adequate.

An objective approach aligns with an understanding that the distance between the researcher and the phenomenon under investigation permits objectivity and prevents undesirable researcher influence on the study process and outcomes (Whorley & Addis, 2006). Subjective approaches place value in exploring participants' versions of reality and they are employed within an interpretivist paradigm (Ponterotto, 2005).

Studying these subjective experiences has implications for the researcher also. The researcher cannot behave as a detached observer. Instead through interactions, they gain insight into how and why people behave the way that they do. Within this subjectivism, the researcher is not denying that an external reality exists but instead recognises that this knowledge is value-laden (Levers, 2013). Exploring philosophical underpinnings can help to refine and specify the types of evidence required, and how it should be gathered and interpreted (Markey et al., 2014). The idea of a researcher approaching a subject topic as a blank slate is no longer a realistic proposition.

Interpretivism aims to provide insight and not a prediction. In this study, the research question focuses on developing an understanding of the experiences of clinical nurse specialists in performing their roles in the community setting. An interpretive epistemological position was chosen for this study as it focuses mainly on the construction of narratives and understanding to provide insight into the research question (Collins & Stockton, 2018). An interpretive position will enable these participants' experiences to be explored and recognise the subjective nature of each clinical nurse specialist's experience.

In this study, the clinical nurse specialists' will bring their own experiences of their role to each interview therefore an epistemological view that illustrates the subjective nature of how their knowledge has developed is required. Interpretivist epistemology acknowledges the subjective view of the world and that new understanding can only be created by interpreting individuals' experiences (Charmaz, 2014). This new understanding can be viewed as insight and not a prediction therefore this philosophical approach can be chosen if the research mainly focuses on the construction of future narratives (Melnikovas, 2018). Interpretivist epistemology which encompasses all subjective interpretations that each clinical nurse specialist' brings will be used for this study.

2.4 Research design

A qualitative methodology was required due to the research question and philosophical foundations of this study. In qualitative research, the focus is not on testing a

hypothesis to prove a theory that has already been refined, but instead, its goal is to develop meaning and theory (Strauss & Corbin, 1998). The qualitative approach gives more depth to participants' responses and as a researcher, one feels better able to understand the participants by hearing their own words as opposed to reading their scores (Pistrang & Barker, 2012). Qualitative research describes social phenomena in words rather than numbers and it aims to understand the individual's viewpoint which is why it was chosen for this study. The aim of many qualitative methodologies is to explore interactions and experiences. Qualities of different methodologies considered will now be discussed.

2.4.1 Comparing the diverse approaches of qualitative research

Many qualitative methodologies are designed to explore social phenomena through individuals' interactions and experiences (Cooper et al., 2012); Ritchie et al., 2013). These include narrative analysis, ethnography, phenomenology and grounded theory. However, not all qualitative approaches are equally suited to investigating the kinds of social processes and shared meanings that are central to this study's aim. Understandings and enactments of roles by clinical nurse specialists in community palliative care settings are examined, with emphasis on identifying underlying patterns and social processes. Therefore, it required a methodology that could move beyond individual accounts to develop insights grounded in shared experiences.

Narrative analysis, for example, centres on the individual's story as the unit of analysis, which can yield rich, personal insight but does not typically seek to identify common categories or generate theory (Riessman, 2008). As such, the broader social processes that shape professional roles are not addressed. Ethnography, while valuable for exploring cultural settings and insider perspectives, would have been more appropriate had the study aimed to understand the collective culture of clinical nurse specialists rather than the underlying processes shaping their role perception (Hammersley & Atkinson, 2019). Similarly, phenomenology, is primarily concerned with the essence of lived experience and the meaning of individuals' lived experience (Van Manen, 2023). While this method would have provided rich descriptions of clinical nurse specialists

experiences, this study aims to examine the social construction of their roles and uncover the processes that shape those experiences.

In comparison, grounded theory offers a methodological framework specifically designed to generate theory from data collected from individuals who share a common experience (Charmaz, 2014) . This approach allows for the idea that there are ready-made theories that are applied to each unique situation (Masoodi, 2017). Grounded theory will explain this given social situation which is the work of the clinical nurse specialists in the community setting. The aim of grounded theory should be to generate theory as it is often used when an area is under-researched (Walshe et al., 2020). Grounded theory is used to capture individuals' experiences who share a common circumstance such as common perceptions, thoughts and behaviours which are the essence of grounded theory (Birks & Mills, 2015)). Grounded theory is particularly well-suited to areas where existing literature is limited or fragmented, as it enables researchers to build theory and remain open to new insights rather than being constrained by pre-existing frameworks (Walshe et al., 2020).

In adopting grounded theory, I sought to construct a theoretical understanding of how clinical nurse specialists interpret and navigate their roles in practice. It draws on participants' subjective meanings and acknowledges that knowledge is contextually situated and shaped through social interaction (Charmaz, 2014). It provides a systematic yet flexible approach for exploring the key processes and meanings that define the role of clinical nurse specialists in the community palliative care. It facilitates the development of theoretical and practical insights in a field where limited research currently exists (Birks & Mills, 2015). For these reasons, I identified grounded theory as the most appropriate methodological choice for this study.

2.4.2 Choice of grounded theory research methodology

I used grounded theory to interpret data and did not stop at just reporting it or describing participants' experiences. A theory explains a relationship between

concepts in a way that explains or increases understanding of a phenomenon (Charmaz, 2014). Philosophical foundations have major implications for the methods used in a grounded theory study (Rieger, 2019); Singh & Estefan, 2018). It helps to systematically collect and analyse the data to generate theories about patterns of human behaviour in their social context. It is a method used to create a new theory by interpreting the world either when there isn't any existing theory or you want to challenge what is already there. Grounded theory is a particularly valuable research approach in palliative care for the development of new hypotheses, and inductive theories on key issues and to maximise the chance to apply theoretical sampling (Stiel et al., 2010). Grounded theory offers a robust and appropriate methodological approach for exploring the complex, evolving role of clinical nurse specialists in palliative care.

There are several distinguishing features of grounded theory such as theoretical sampling and using the constant comparative method for data analysis which remain the original and most important criteria across all types and will be discussed further later. However, the fundamental aim is to use methods of induction to explain behaviour, which subsequently leads to the ability to build theories (Rieger, 2019). Grounded theory has evolved over time into several approaches, each underpinned by different philosophical assumptions and methods.

2.4.3 Types of grounded theory

Among the different approaches to grounded theory, constructivist grounded theory, as developed by Kathy Charmaz, is the most appropriate for this study due to its alignment with a relativist ontological and interpretive epistemological stance. This differs from Glaserian grounded theory, which assumes an objective reality discoverable through researcher neutrality (Glaser et al., 1968), and Straussian grounded theory, which employs more structured coding and procedures while retaining some objectivist assumptions (Corbin & Strauss, 2014). In contrast, constructivist grounded theory recognises that both the researcher and participants shape the meaning of the data, making it the best fit for this study's focus on understanding personal and social experiences.

2.4.4 Constructivist grounded theory

Within constructivist grounded theory, reality is understood as plural and constructed through experiential and social interactions (Charmaz, 2014). This approach recognises that data are not simply discovered but are co-created through the interaction between researcher and participant (Chun Tie et al., 2019). The researcher is not a detached observer but an active participant in the research process, shaping the meaning that emerges from the data (Denzin & Lincoln, 2011). This perspective aligns with the aims of this study, which are to understand how clinical nurse specialists in palliative care interpret, negotiate, and give meaning to their roles within a specific social and professional context. In this study literature was not reviewed first to avoid bias. In grounded theory, delaying the literature review helps prevent preconceived notions from influencing data collection and analysis, thereby preserving the emergence of theory grounded in the data (Glaser & Strauss, 2017).

Building on the work of Charmaz, the goal of constructivist grounded theory is to examine the way researchers create their interpretations of theory from the data. It challenges the idea that theory is waiting to be discovered. Instead, it recognises that theory will always be discovered because researchers and participants create their understanding of society and reality (Charmaz, 2014); Mills et al., 2006). Constructivist grounded theory draws attention to the role people's constructions of meaning play in shaping the nature of the social world that they inhabit (Willig, 2016). The research question influences how the data is collected. The final theory is theory which is dependent on the researcher's view. The constructed theory is an interpretation as opposed to an exact representation (Sebastian, 2019). This theory is dependent upon the researcher's view and cannot occur or stand without it.

As constructivist grounded theory is flexible, iterative and a reflexive process it enables the researcher to respond to what emerges in the data rather than being bound by pre-existing theories (Charmaz, 2014). This is particularly important in areas like community palliative care, where there is limited research and a need for contextually grounded theoretical development (Stiel et al., 2010). Constructivist grounded theory emphasises the importance of the researcher's reflexivity, acknowledging how their background,

assumptions, and positioning influence data interpretation (Birks & Mills, 2015). Data collection for this study was continued until the point of data saturation. Theoretical saturation is what grounded theorists aim for and researchers cannot anticipate what sample size will be required to achieve this (Charmaz, 2014). Given the study's focus on interpreting subjective experiences and uncovering the basic social processes that shape professional roles in a community healthcare setting, constructivist grounded theory provided the most philosophically and methodologically coherent approach.

2.4.5 Preliminary scan of the literature

A preliminary scan of the literature was carried out to set the context and establish the rationale for this study. This scan was needed to help to identify a gap in the available research and inform a research proposal and ethical application. Reviewing the literature on a proposed study gives the researcher an idea of the current knowledge and work that has been undertaken in the field (Birks & Mills, 2015). The knowledge building function of evidence-based practice should lead to an understanding that one cannot ignore prior evidence, especially from published literature (Hughes, 2008). A researcher must examine how this evidence and knowledge influences both themselves and their research. In constructivist grounded theory, the outcome of a study is not seen as an objective discovery by the researcher, but rather as a co-constructed understanding shaped through the researchers engagement and analysis in the field (Charmaz, 2014). Therefore, the preliminary scan of the literature served as both a foundation for the study and a reflective process that informed the researcher of an evident gap.

A preliminary scan of the literature revealed extensive research on the role of registered general nurses in delivering palliative care within community settings however very limited evidence was available regarding the role of the clinical nurse specialist in palliative care. Clinical nurse specialists have a particular expertise when it comes to caring for patients who have life limiting conditions in the community. However, the specific contributions and role enactment of clinical nurse specialists working within

these teams remain underexplored (Gardiner et al., 2022); Hart, 2024). This gap highlights the need for further investigation into how clinical nurse specialists understand and perform their roles in this complex and evolving field.

Clinical nurse specialists is a vital resource not only to patients but also to families and health care professionals in order to enable patients to die at home (Tunnah et al., 2012). In a study by (Newton & Waters, 2001) they analysed the lived experience of work stress of twenty one clinical nurse specialists in the UK. They identified three major themes; relationships with health care professionals, impact of the sadness of the client group and the pressure of the workload. The authors acknowledged that this study reflects nurses experiences working in an urban area and therefore cannot reflect an inner city or rural environment. (Mulvihill et al., 2010) conducted a literature review to obtain an improved understanding of the role of the specialist palliative care community nurse. They concluded that changes in palliative care have led to the modification of the community specialist palliative care nursing role and that clarification of the role and appropriate referrals will ensure that a high level of expertise is delivered to those who are in most need of it. Given that there will be an increased demand on specialist palliative care community services in the future it is important to develop a comprehensive understanding of the role of the specialist palliative care clinical nurse specialist role in the community setting.

2.5 Methods

A COREQ (Consolidated Criteria for Reporting Qualitative Research) 32-item checklist was used in this study to assist in improving the quality of reporting and ensure that certain aspects of the study were covered e.g. including research team, study methods, analysis and interpretations (Tong et al., 2007). This study was carried out using a constructivist grounded theory approach and is based on a relativist ontology and interpretive epistemological approach as previously outlined. The methods will now be presented.

2.5.1 Ethics

Ethical approval was obtained from the local research committee on 8th February 2022 (Reference number 012/2022) and Lancaster University (Appendix 2, FHM-2022-0843-ExRev-1).

2.5.2 Setting

The research setting for this study is a specialist palliative care service in the Republic of Ireland at which the researcher was not employed. A single service was chosen as the research site to allow for in-depth exploration of nurses' experiences within a specific organisational and contextual setting. This approach enabled a focused examination of how clinical nurse specialists within one community palliative care team understood and enacted their roles, while maintaining consistency in service structure, policies, and practices. By limiting variability between different organisational contexts, the study can more effectively identify patterns and social processes specific to the setting, which aligns with the interpretive methodological stance and the aim to generate contextually rich insights (Denzin & Lincoln, 2011); Patton, 2014). The service receives 1100 new community patients each year averaging 93 new community patients per month. The service has an average of 500 active community palliative care patients at any one time. The community service operates across both urban and rural areas. Funding for this service is provided by the Health Service Executive (HSE) and through fundraising initiatives carried out by the local community, including donations and bequests.

2.5.3 Population

The population of interest for this study were clinical nurse specialists providing specialist palliative care in community settings. The clinical nurse specialist team has more than 20 nurses. The criteria used to determine eligibility for the study are outlined in Table 2.2.

Table 2.2: Inclusion criteria used

Inclusion Criteria
Clinical Nurse Specialists with a minimum of 12 months' experience were selected to ensure participants had sufficient exposure to the community palliative care setting to meaningfully reflect on their role and contributions.
Clinical nurse specialists' who carry a clinical caseload and visit patients within their place of care in the community setting providing symptom control and advice

2.5.4 Recruitment

A cover letter outlining the study and requesting access to participants (See Appendix 3 for requisition of access letter) was completed and submitted. A gatekeeper was identified at the research site who initially approached potential participants (n=42), informing them about the study's aims and arranged a suitable time for an online information session. Participant packs were distributed, containing an invitation letter (See Appendix 4), consent form (See Appendix 5), information sheet (See Appendix 6) and a stamped addressed envelope. An information session was held via Microsoft Teams to support the recruitment process and address any questions from the clinical nurse specialists.

2.5.5 Sample Selection

Following the information session with 20 potential participants, interested clinical nurse specialists contacted me to express their willingness to take part in the study. Initial recruitment was conducted using convenience sampling, which allowed for the intentional selection of participants based on their experience with the phenomenon under study (Speziale et al., 2011). This approach ensured that those selected could contribute relevant data regarding the social process being investigated. These participants were selected from those who met the inclusion criteria outlined.

In alignment with grounded theory methodology, theoretical sampling was employed following the initial convenience sampling (Cutcliffe, 2000). Theoretical sampling is a central strategy in grounded theory research and involves selecting additional participants based on emerging categories and concepts from the data (Foley et al., 2021); McCrae & Purssell, 2016); Welford et al., 2011). This process allowed me to develop a more comprehensive and theoretically rich understanding of the phenomenon by seeking data that fills conceptual gaps and strengthens developing themes.

An initial sample of six participants, each with a minimum of 16 years of experience, was interviewed in the first phase of data collection. As data saturation had not yet been achieved, and in line with the principles of theoretical sampling, further participants were sought to explore emerging concepts in greater depth. To examine whether variations in experience might influence role perception and contribute to the development of a more robust theoretical understanding, three more clinical nurse specialists with over 16 years of experience were recruited. The data from these interviews contributed to the refinement of initial codes and supported theoretical saturation. Theoretical saturation occurs in grounded theory when additional analysis (and data collection) no longer contributes to discovering anything new about a category (Carmichael & Cunningham, 2017). This is an important element of rigor and it is facilitated by sampling, as qualitative research samples are relatively small therefore, they must be sufficient to adequately allow for replication and are deliberately selected based on participant's expertise in the chosen topic to ensure meaningful and reliable data collection. (Morse, 2015). The process of theoretical sampling and its role in shaping data collection and analysis will be further elaborated upon in the data analysis section.

2.5.6 Consent

Following the information session and expressing their interest to participate the clinical nurse specialists were invited to return their completed demographic questionnaire and written consent forms to the researcher. Informed consent needed to be coercion free and it is an indication that the participants had agreed to be involved

in the study based on full understanding and knowledge of the whole process (Ignacio & Taylor, 2013). Participants verbally re-confirmed their consent before recording the interview. All participants were made aware of their right to refuse participation in the study. (Economic and Social Research Council, 2015) supports this, adding that there should be no unnecessary influence of research participants to participate in the study.

2.6 Data collection

Data were collected using a demographic questionnaire and semi-structured interviews. The demographic questionnaires (See Appendix 7) with range bands (when appropriate) were distributed in the invitation pack, including gender, age, and years working as a clinical nurse specialist in the community palliative care team. This information contributed to the sampling process and information required.

Semi-structured interviews were chosen as they align closely with the principles of constructivist grounded theory (Gibson & Brown, 2009). This approach recognises that knowledge is co-constructed through the interaction between the researcher and participants, making interviews a valuable tool for exploring participants' perspectives and meanings in depth (Charmaz, 2014). Semi-structured interviews strike a balance between flexibility and focus allowing the researcher to guide the conversation about topics while also enabling participants to introduce new ideas or elaborate on their experiences in their own terms (Birks & Mills, 2015). This flexibility supports the iterative and emergent nature of constructivist grounded theory, where initial data guide the direction of subsequent interviews and theoretical sampling (Charmaz, 2014). Semi-structured interviews are not only methodological sound within constructivist grounded theory but also essential for accessing the depth and complexity of participants' experiences.

Due to COVID-19 restrictions in place at the time of data collection, online semi-structured interviews were used as the method for gathering information in this study. This approach allowed for safe, flexible, and in-depth engagement with participants while adhering to public health guidelines. The interviews took place at a time that

suited the participants. The overarching aim of the interviews was to determine the experiences of the clinical nurse specialists in fulfilling their roles.

The language used in the interview guide (Appendix 8) was tailored to match the terminology familiar to clinical nurse specialists, which helped to facilitate a natural and meaningful conversation. The guide was designed to encourage participants to reflect on and discuss their experiences in relation to the key competencies. Upon developing the interview guide I met with an independent group of clinical nurse specialists who were not involved in the study. They recommended including an ice breaker question and advised that the main questions where possible should avoid explicitly using the competency terminology. Instead, they suggested referring to the competencies indirectly through the phrasing of the questions, for example, tell me about working with other teams in your role, to explore the consultancy competency. These competencies are; clinical focus, patient/client advocacy, education and training, consultancy, audit and research (National Council for the Professional Development of Nursing and Midwifery, 2008). A data collection flow chart illustrating the data collection process is in Figure 2.1.

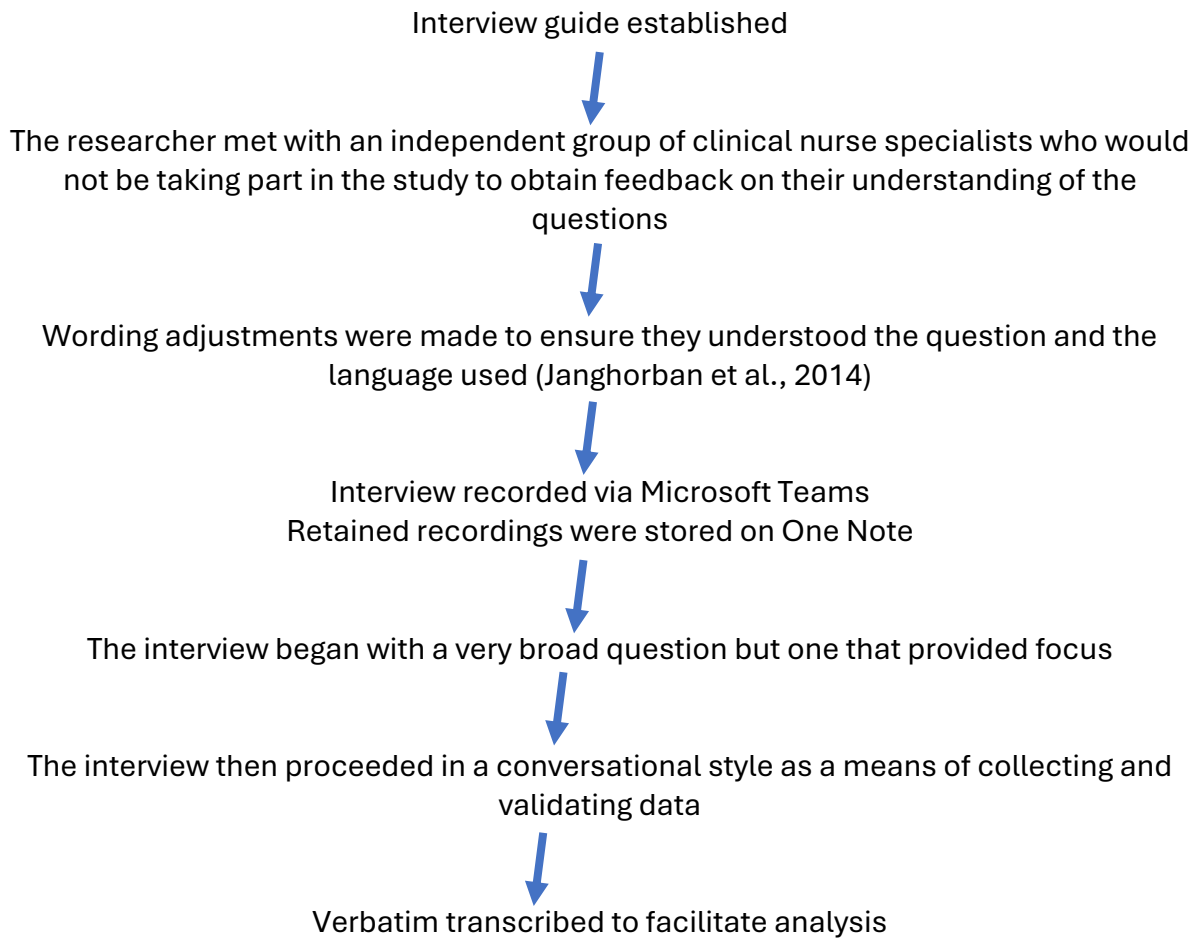


Figure 2.1: Data collection flow chart

During data collection, the researcher's background allowed insight into the participants' experiences during the interview in line with the constructivist approach to create a true dialogue and dismantle power imbalances (McMillen, 2008). It was important to build rapport with the participants approaching their interviews with empathy and respect and this could even be through informal conversation before the interviews began to ease any anxieties for them. The interviews allowed asking a range of in-depth questions, allowing participants to describe their own experiences. This enabled the researcher to assess the participant's personal feelings, thoughts and behaviour, especially the non-verbal which was recorded in memoing. This structured approach to sampling ensured that participant selection was both purposeful and theory-driven, ultimately allowing for the development of a robust and grounded understanding of the clinical nurse specialists' experiences.

2.7 Data analysis

This qualitative research produced a large amount of material for analysis due to the data collection methods such as interviews, field notes and memoing. The approaches to this analysis were conducted in keeping with the epistemological assumptions of grounded theory including an iterative and interpretive process where codes and categories evolved through constant comparison, reflection, and memo-writing, rather than a one-time objective classification The constant comparative method lies at the root of grounded theory analysis and it constantly compares and contrasts the data (Welford et al., 2011). Data analysis emphasizes keeping the researcher close to the participants by keeping their words intact in the process of analysis and it is key to maintain the participants' presence throughout (Charmaz, 2014). The process of data collection and analysis occurred concurrently, which is one of the fundamental aspects of grounded theory (Birks & Mills, 2015); Boeije, 2002). Going back and forth between collecting and analysing data helped to shape and improve ideas as the study progressed, making grounded theory a flexible and effective way to build a new theory. Flawed data analysis can occur if, a researcher focuses on one interview extract without making comparisons to other transcripts that could tell a different story leading to a different outcome (Silverman, 2013). Data collection and analysis occurred until no new information is discovered.

2.7.1 Construction of the categories

A key feature of constructivist grounded theory is constant comparative analysis. This was carried out using memo-writing and field notes by comparing and contrasting codes and categories which led to the discovery of patterns (Boeije, 2002). Comparisons were made within a single interview and then between interviews. Participants' own words were used for some of the codes and constructs to keep their presence throughout. Numerous codes were refined which resulted in a final set of five core categories. Figure 2.2 illustrates the initial process of analysing interviews one to five, followed by the evaluation of the completed 9 interviews.

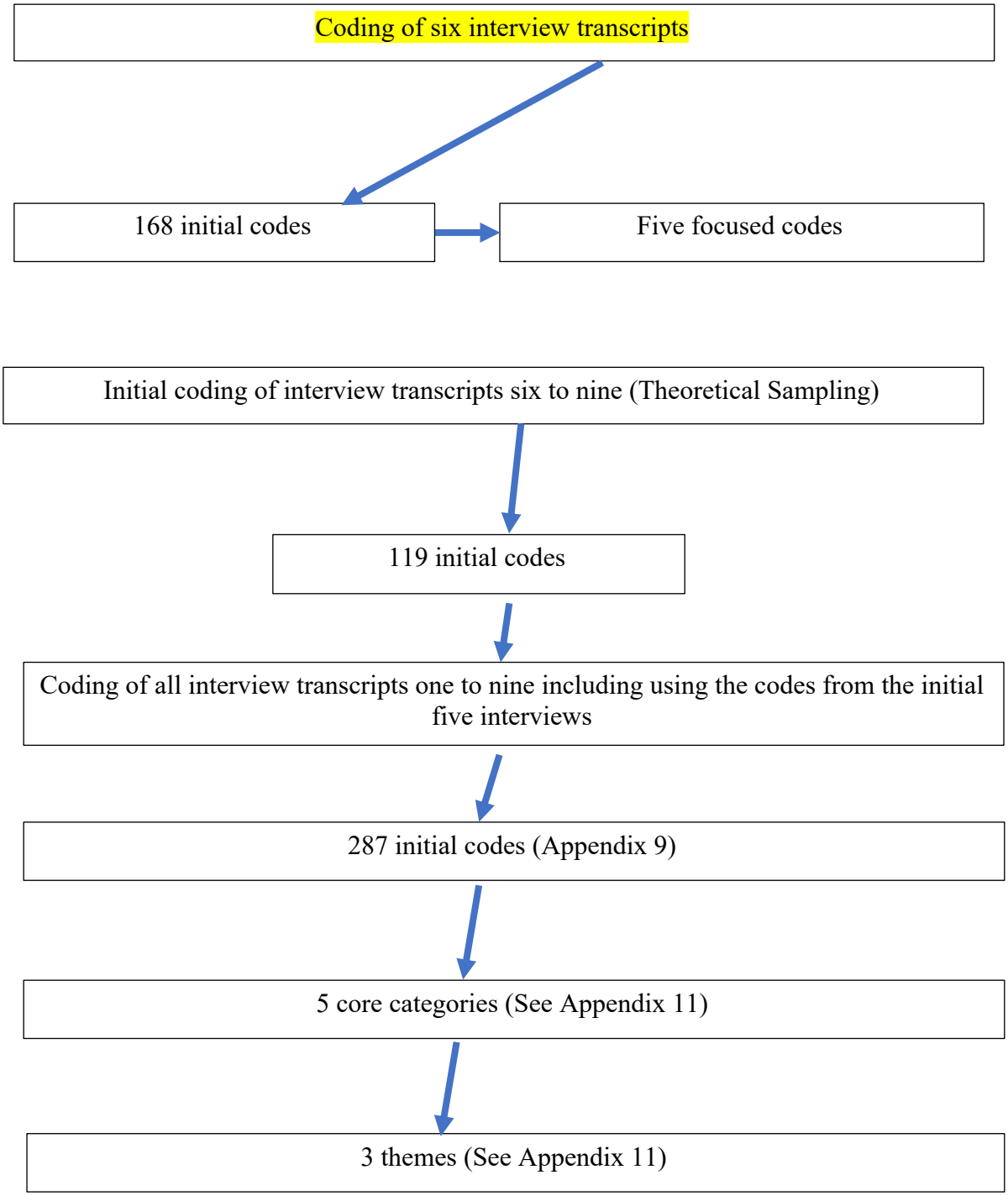


Figure 2.2 : Progression of coding through analysis

2.7.2 Initial coding

The data were collected, coded and analysed data from the beginning of the study. As codes were developed, their relevance to participants' intended meanings was verified through direct questioning, consistent with a constant comparative method of analysis

(Charmaz, 2014). Initially, this coding involved reviewing each transcript line by line and this is the first step in constructivist grounded theory data analysis. Each interview transcript was analysed so that the coded content had relevance to the experiences of the community palliative care team clinical nurse specialists when fulfilling their roles. NVivo was used to assist with the development of codes, categories and related themes of their experiences. The process of data collection and analysis occurred concurrently.

In the initial coding process, direct quotes from participants were used as codes. Using the participant's own words enhanced the credibility of the findings. Data collection continued until I noticed that additional data no longer added any fresh insights, ideas, or themes. In other words, I stopped collecting data when I reached data saturation; a point where further interviews or observations simply confirm what's already been found and don't contribute anything new to the analysis (Charmaz, 2014) . This is in keeping with constructivist grounded theory where data could only be used as long as it is added to the advancement of a particular category (Cutcliffe, 2000). The themes identified from the data were then developed and linked to the research question.

2.7.3 Focused coding

This was the second major phase in coding allowing the sorting, synthesizing and analysing of the data. This step allowed for asking questions of the data like 'What are the circumstances that led to this action' (Charmaz, 2014). Focused coding enabled the most frequently used or significant codes to be used to assist with narrowing larger amounts of data. This coding raised the data analysis to another level. This was carried out manually and also with the support of NVIVO. 5 focused codes were developed (See Appendix 9).

2.7.4 Memo-writing and field notes

Maintaining memo-writing and field notes is a practical way to maintain rigour. Field notes were kept by the researcher during the interviews which commented on the atmosphere and the researcher's feelings. These were used as a useful reference to refer to during analysis and write-up. In addition, the researcher kept memos during the analytical process. Memo-writing helps in constant comparison and acts as a reflective process for the researcher (Ghezeljeh & Emami, 2009). They are supportive of the generation of concepts and categories and serve as a reminder about how certain terms were developed. Furthermore, memo writing is the crucial step between coding and writing as it outlines the grounded theorist's discussions, ideas and comparisons made between data. Memo writing and field notes enabled the researcher to retrace their theoretical trials and assisted (Charmaz & Thornberg, 2020) with the transparency of the study. Memos were written after each interview. An example of a post-interview reflection memo is in Table 4;

Table 2.3: Post-interview reflective memo

Jane Works within healthcare for 40 years and within specialist palliative care for 20 years. I have never met her before. Her word 'anchor' of the role has really struck me. This is such a pivotal position to see herself in. She carried out the interview on her day off as she would never have the time in work. Also added she probably won't get the time back for the interview which however she took great pride in being asked and someone wanting to know about her experiences and seem to enjoy answering the questions. I am aware I am known as the Director of Nursing in my service. The palliative care community in Ireland is a small community. I reassured her regarding my role as a researcher and not a nurse manager. Following her interview I amended the interview guide to ask a question in relation to self-care within the role e.g. do they take lunch

2.7.5 Theoretical saturation

Data collection continued until no new insights were generated that contributed to the development of the emerging theory. Data is valuable only insofar as it advances the understanding of specific categories (Cutcliffe, 2000). When additional data fails to provide new information, the category is considered saturated (Charmaz, 2014). Theoretical saturation occurred when the identified themes became well-developed and no further data added meaningful depth or variation (Firn et al., 2018). Initially, six participants were interviewed each with a minimum of 16 years of experience and their data analysed. As data saturation had not yet been achieved, and in line with the principles of theoretical saturation, a further 3 participants were sought to explore emerging concepts in greater depth. To examine whether variations in experience might influence role perception and contribute to the development of a more robust theoretical understanding, three more clinical nurse specialists with over 10 years of experience were recruited. Saturation was ultimately attained after nine participants, at which point additional data collection was unlikely to generate any new information into the experiences of clinical nurse specialists.

2.8 Ethical considerations

2.8.1 Management of interviews

Consent was obtained from all participants who took part in the interviews (see Appendix 5). Participants were informed that under the Data Protection Act (2018) personal data relating to them from which they could be identified will not be passed between authorities without their permission)Government of Ireland 2018). They were also made aware that under the Freedom of Information Act (2014) they are entitled to access the research study information (Government of Ireland, 2014).

2.8.2 Management of interview data

During the data transcription process, all participant identifiers were anonymised and pseudonyms were used for quotes to protect the participant's identity. All transcribed verbatim interview data was anonymised ensuring there were no personal identifiers at the earliest opportunity following data collection. All personal data was destroyed at the end of the study. All interviews took place online via Microsoft Teams as previously explained. When choosing the platform it was important to consider the functions they had available plus what the participant had access to. All electronic data was transferred to secure and encrypted storage and in keeping with Lancaster University protocol, this was OneDrive.

2.8.3 Confidentiality

Given the Republic of Ireland's small size and the limited geographical distribution of specialist palliative care services, the number of professionals working in this field is relatively low. Therefore, confidentiality was paramount in any documentation or account of this research to protect the identities of participants within such a small professional community. Confidentiality was upheld, and participants were not identified in any write-up or subsequent presentations. All participant identifiers were removed during the data transcription process, and pseudonyms were utilized to protect participant identities. These pseudonyms were selected by the researcher and chosen to reflect common names without revealing any identifying information. All transcribed verbatim interview data was anonymised, ensuring that there were no personal identifiers post-data collection. They were given the opportunity to receive a copy of the findings once the study concluded.

2.8.4 Participants well-being

Building trust and rapport when asking people to talk about themselves raises the possibility that participants reveal stories that are personal and may be distressing, not only for the narrator but also for the listener. If a participant became upset the interview

would be stopped and the participant is given time to consider if they wished to proceed, terminate the interview and resume later, or withdraw from the study altogether. This process would be followed as per Appendix 10, Distress Protocol for Qualitative Data Collection (Haigh & Witham, 2013). Participants' well-being took priority over the study. This protocol did not need to be implemented for this study.

Following all the interviews a debriefing session was offered to allow participants to express feelings and ask questions. If following this participants would have needed further support, relevant local support services information would be given. No participants required the debriefing session or further support as a result of participating in this study. It is the researcher's role to address any issues which may arise during the study with the participants' welfare in mind (Ignacio & Taylor, 2013). Furthermore, all research should protect and defend the rights of others to prevent any harm from occurring (Beauchamp & Childress, 2001). There may be no direct benefit to participation in this study. However clinical nurse specialists may find it a positive experience to participate in the research and share their experiences.

Supporting Documents included in the Research Ethics Committee application

- Access request Letters (Appendix 3)
- Participant invitation letter (Appendix 4)
- Participant consent form (Appendix 5)
- Participant Information Sheet outlining the purpose of the study (Appendix 6)

2.9 Quality in grounded theory

Quality criteria are required for grounded theory designs. Rigour is best achieved by meticulous planning, diligence, reflexivity of the researcher and open communication between the participants and the researcher (Johnson et al., 2011). Validity and credibility are often used interchangeably. Credibility refers to how faithful the description of the phenomena is. A qualitative study is credible when it presents such a faithful description or interpretation of a human's experience that people have had that

experience would immediately recognize it as their own and a method of establishing this is through member checking (Candela, 2019). This is where the study participants were asked through questioning, to check the accuracy of their interview accounts against the descriptions in the research report. The researcher's position and role was made clear to the participants. The researcher's professional background meant the participant's language, professional experiences and potential dilemmas helped to create credible core conditions for the interviews (Crouchman et al., 2022). Quality guidelines developed by (Charmaz & Thornberg, 2020) were used as a checklist resource for this study. This assists in ensuring that there is deep engagement with the method and data during the study.

2.10 Personal influence of the researcher and methodological justification

A key component of the study is my view of reality and the meaning I attribute to its formation in being able to explain and explore the reasons for choosing the research design and methodology. Previous knowledge can strengthen the research study once the researcher is aware not to let it define the project (Charmaz & Thornberg, 2020). Therefore throughout the study, I needed to be cognisant of my own views and perspectives rather than erase or forget them. My interest in this research topic came from my personal, academic and professional interest in this topic having worked for over twenty years within a specialist palliative care service. Field notes acted in a diary format capturing not only observations of the participants but also the feelings and observations of the researcher.

My underlying beliefs were that clinical nurse specialists encountered many barriers and facilitators in fulfilling their roles such as limited time staffing constraints and access to resources. I also held assumptions that organisational culture, leadership support and interprofessional relationships significantly influence how effectively they can practice. While these preconceptions helped guide the areas I explored, I remained reflexive throughout the study to ensure that participant's perspectives, rather than my assumptions directed the findings. However, I needed to be open enough in my

research approach to acknowledge that clinical nurse specialists' had their own experiences. I strongly believe that it is valuable to understand specific contexts in which people live and work which enables a greater knowledge base of their beliefs, motivations and values that underline their behaviour.

By practicing reflexivity, I consistently examined my values, assumptions, and behaviours, along with the participants' experiences, as these could have influenced how I interpreted their responses. I found memoing especially valuable in increasing my awareness of the factors affecting my connection to the research topic, the participants, and the data interpretation process.

At the time of the study, I was working as a Director of Nursing. I remained mindful that my role in this PhD is a researcher and not a Director of Nursing. However, clinicians have advantages as researchers due to their skilled interview techniques, training to follow feedback and unpack meanings, ability to elicit multiple perspectives and their self-awareness as interviewers (Burck, 2005). I needed to be cognisant of my senior management role when interviewing participants outside of my organisation and reassure them regarding the confidentiality aspect of the study. The study was not carried out within my organisation as it would not be appropriate to interview clinical nurse specialists who reported to me however the participants were aware of my substantive role.

Over the course of the thesis, my initial assumptions were both a useful starting point and a lens that required ongoing critical examination. While I began with the belief that structural barriers such as time, staffing, and resources were central to the experiences of clinical nurse specialists, engagement with participants revealed a reality in which individual influence, professional identity and the environmental context played equally significant roles. This process challenged me to reconsider the weight I had initially placed on organisational factors alone and to recognise the interplay between individual and systemic influences. Through sustained reflexivity, memoing, and immersion in the data, my perspective shifted from a largely assumption driven understanding to one that was more grounded in participants' lived experiences. This shift in assumptions not only strengthened the credibility of the findings but also my

appreciation of the complexity of the clinical nurse specialist role and the importance of remaining open to unexpected insights throughout the research process.

Grounded theory was appropriate as it would not start from a formulated hypothesis but instead would formulate hypothesis but instead would formulate a theory based on the results of the research. Nurses have diverse perspectives of their experiences leading to different realities as they fulfil their role. I understand this as I also worked in this role. Constructivist grounded theory is congruent with this study as the philosophical position corresponds with understanding the clinical nurse specialists' reality of their role.

2.11 Summary

This study of clinical nurse specialists' experiences when fulfilling their role was carried out using a constructivist grounded theory approach. It was based on the philosophical foundations of relativism and interpretivism. The aim was to build a grounded theory that would be based on participants' experiences, interpretation of the data and related literature.

3 Results

3.1 Introduction

In Chapter 2 the methodology that guided this study and how interview data would be collected and analysed was described. In this chapter a brief description of the participants' characteristics and an in-depth explanation of how each category was constructed is outlined. These categories were constructed from semi-structured interviews of community palliative care team clinical nurse specialists about their experiences fulfilling their role. In this chapter the participants' characteristics and findings from the interview data are also outlined.

3.1.1 Composition of the participant group

Nine (n=9) female clinical nurse specialists consented to participate in the research study. The community palliative care team had no male clinical nurse specialists on the team. The participants' characteristics are presented in Table 3.1. 44% of the clinical nurse specialists had completed a masters qualification. The question relating to nurse prescribing was omitted from the final data analysis because the results did not contribute meaningfully to addressing the overarching research question.

Table 3.1: Characteristics of participants

Characteristic	Results
Gender	
Female	9
Male	0
Number of years qualified as a nurse	
1-5 yrs	0
6-10 yrs	1
11-15 yrs	2
16 or greater	6
Number of years as a clinical nurse specialist	
1-5 yrs	1
6-10 yrs	4
11-15 yrs	1
16 or greater	3
Number of years working in specialist palliative care	
1-5 yrs	2
6-10 yrs	4
11-15 yrs	0
16 or greater	3
Where does your community palliative care team cover	
Rural Area	2
Urban Area	0
Both	7
Have you completed the Masters in Palliative Care (or equivalent)	
Yes	4
No	5
Have you completed a PhD in Palliative Care (or equivalent)	
Yes	0
No	9

3.1.1.1 Initial and focused coding

The initial coding of all interview transcripts involved examining data line by line. This produced 287 codes (See Figure 2.2 and Appendix 12) using NVIVO. These initial codes are described as actions within each line which stay close to the participants' experiences (Charmaz, 2014). Some in-vivo codes were used to preserve participants' meanings and actions in their descriptions of their experiences. Field notes enriched this stage by providing contextual insights that deepened understanding of participants' meanings (Mulhall, 2003) and memoing captured analytical insights. Together these steps provided a lead to the development of 5 focused codes (See Appendix 10).

Eventually, through continued comparison and memoing, three categories were developed, which explain how codes relate to one another in the context of clinical nurse specialists experiences. In the remainder of this chapter the findings from the analysis of the interview transcripts to support the development of these categories are presented. The three main categories are presented in Figure 3.1 (below). Two of these categories are further divided into subthemes. Quotes from participants will be in italics alongside the number of years they are working within specialist palliative care.

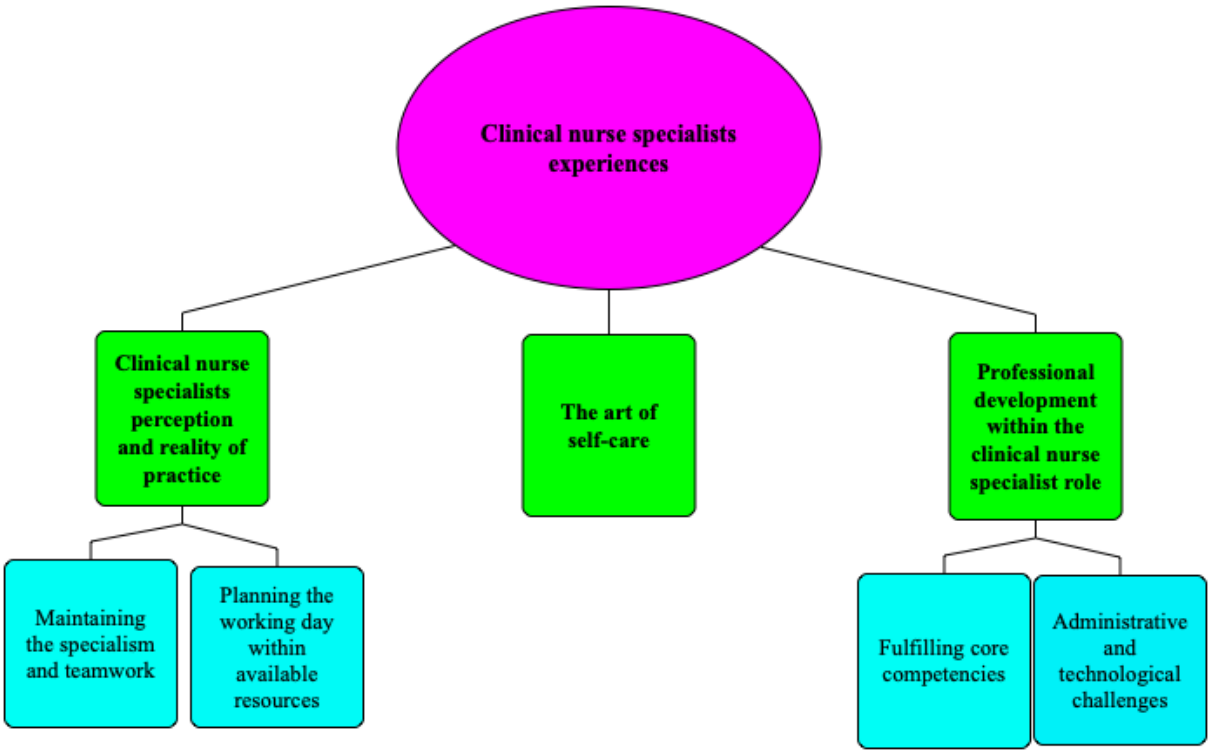


Figure 3.1: 3 final categories

3.2 Clinical nurse specialists' perception versus the reality of their practice

All participant identifiers were anonymised and pseudonyms were used for quotes to protect the participant's identity. This section addresses the idealised or *"romantic"(Ita)* perceptions clinical nurse specialists held about their role before entering the specialist of palliative care. It examines the motivations behind their decision to pursue a career in this speciality. This leads onto the key challenges clinical nurse specialists encounter in practice when working to ensure that specialist palliative care services are both accessible and appropriately prioritised for individuals who require it.

This category also refers to the resourcing and working relationships as part of the multidisciplinary team that clinical nurse specialists perform as part of their role. They act as a *"link" (Ruby, 6-10 years)* between members of their specialist palliative care team and also within the wider acute and primary care services. Clinical nurse specialists perceive that integration and system navigation are central to their role as they liaise with a range of disciplines across various sites. They regard each phone call and interaction as an effort to develop a more comprehensive knowledge and understanding of the patient, their journey and their story.

3.2.1 Maintaining the specialism and teamwork

In this category the motivations that led clinical nurse specialists to pursue this role are explained, including their initial perceptions of what it would involve. Now working in the role, they reflect on the challenges of maintaining their speciality focus amidst the realities of daily practice. In this category clinical nurse specialists identified key areas for improvement that are needed to support their roles and maintain the specialist nature of their work.

Some participants' interest began while working within generalist services alongside specialist palliative care nurses, whom they viewed as role models. '*Seeing the difference they made once a patient was under their care*' *(Sue, 6-10 years)* was a key factor in their pursuit of a career in specialist palliative care. Participants described being *"drawn"(Faye, 1-5 years)* into specialist palliative care as though it were a force beyond their control. Assessing the whole patient and family within the holistic framework that defines the speciality was the main aspect that attracted them. They valued the opportunity to join patients on their journey through their illness to pursue a life focused on living rather than dying. Furthermore, they said that, when the time came, they were comfortable supporting patients through the dying process and felt this to be a privileged position.

> *"There was just something about it. Unfortunately in different areas of nursing. It's very hard to keep care holistic because it is so task-driven. This care was so holistic that it just drew me to it" (Jane, 16 years or more)*

In contrast, some clinical nurse specialists reflected on their experiences of palliative care which they had witnessed within generalist settings. They were disappointed to see poor symptom management or late end-of-life care diagnosis due to the inexperience of staff, including themselves at the time. This led them to pursue a career that would enable them to gain the specialist knowledge which would lead them to address this knowledge and practice deficiency for themselves.

The clinical nurse specialists emphasised the importance of continuing to focus on their specialist role in everyday practice ensuring they are prioritising a response to patients with complex specialist palliative care needs. There can be an over-expectation by other healthcare professionals of what they can do, combined with an inadequate understanding of the role. One key misunderstanding identified by clinical nurse specialists is the consistent failure among some healthcare professionals to distinguish between patients who require generalist palliative care and those who truly need specialist palliative input. This lack of clarity leads to inappropriate referrals, placing unnecessary strain on already stretched specialist services. Clinical nurse

specialists expressed deep concern about the dilution of their role, feeling overwhelmed by a growing volume of general palliative care cases that could and should be managed elsewhere. This blurring of boundaries not only affects service efficiency but also undermines the specialist nature of their work, which requires advanced skills, complex symptom management, and holistic support.

> *"We're being asked to do everything, the generalist and the specialist workload. It's exhausting, and it's not sustainable. If we don't draw the line somewhere, we risk losing what makes specialist palliative care truly specialist. Oftentimes even the specialists finds it challenging distinguishing between generalist and specialist referrrals " (Rita, 16 years or more)*

There was a shared belief among the team that this issue needs to be addressed at a national level**,** with clearer guidelines and greater education across generalist and specialist healthcare settings to protect the integrity and capacity of specialist palliative care services.

The failure to effectively utilise the discharging guidelines for patients under the community specialist palliative care team was deeply troubling for the clinical nurse specialists, who described it as a "disservice" (Faye, *1-5 years*) not only to themselves as professionals, but more importantly, to the patients. There was a shared sense of frustration among the clinical nurse specialists, who felt that patients were being kept on the caseload longer than clinically necessary, often without clear rationale. This prolonged association with the palliative care team could inadvertently result in patients receiving less active management upon hospital admission, an outcome that felt ethically and professionally wrong.

Adding to their frustration was the lack of clarity and consistency within the discharging guidelines themselves. Clinical nurse specialists expressed that these were often ambiguous and open to subjective interpretation, leading to variability in decision-making across the team. This ambiguity made it harder to advocate effectively for appropriate discharge of patients from the specialist palliative care service, leaving

clinical nurse specialists feeling unsupported and sometimes even conflicted in their roles.

While the multidisciplinary team case reviews were acknowledged as a valuable and constructive space to consider discharging stable patients, the reality was often far from ideal. Due to increasing workloads and rising patient numbers, these meetings frequently became dominated by more urgent cases, such as newly assessed patients, those with uncontrolled symptoms, or those requiring end-of-life care. As a result, opportunities to reflect on and manage long-term caseloads were missed, compounding the emotional and operational burden felt by the team.

Ultimately, there was a palpable sense among clinical nurse specialists that their capacity to deliver equitable, high-quality care was being compromised by systemic constraints, leaving them caught between professional responsibility and organisational limitations.

Clinical nurse specialists explain that within their role they bring a wealth of specialist knowledge and skills. Having access to all necessary resources such as equipment and carers means the clinical nurse specialists can implement what is required and subsequently empower the person to remain at home. They see themselves as having an in-depth knowledge of patients, including their beliefs, strengths, weaknesses, and faith. Often, the aim of a visit is to provide psychosocial support rather than physical care. They report adjusting their communication style, balancing their information with what the patient can cope with and hear on a particular day. They say they are consistently guided by the fundamental principles of honesty and truthfulness, adapting to each patients' preference about what they do or do not wish to know. They view bereavement support as a key aspect of the specialist role, however this is often incomplete due to not being able to carry out post-death visits to families routinely which the clinical nurse specialists find frustrating. This is due to service demands.

> *" I spend so long connecting with patients and families I feel we don't do the disconnecting and make sure they are okay afterwards. I think to finish this*

journey you have to exit and know that the family are coping ok or signpost them for further support" (Jane, 16 years or more)

Participants viewed themselves as being the liaison point between all teams, ensuring continuity of care for patients and families. This collaboration was viewed as being between multidisciplinary team members within specialist palliative care, alongside acute and primary care services such as the GP and Public Health Nurse. The clinical nurse specialists perceived that their acting as a link between services enables the patient's story to evolve, ensuring they always have supervised, managed and co-ordinated expert advice.

"I rang the public health nurse. They came out the following day with the OT and reviewed him during a joint visit. I linked in with the GP who was fabulous, he actually would have done locum with us before so he's on the ball" (Faye, 1-5 years)

This co-ordination is carried out as part of clinical nurse specialists' advocacy role, as many times '*patients and families are so frustrated at trying to access services and not being able to get anywhere' (Tina, 6-10 years)*. One participant viewed her role as '*joining the dots between all the services which enabled the patient's journey to be knitted together'(Rita, 16 years or more)*.

Clinical nurse specialists outlined how they act in an advisory capacity only to patients, families and other healthcare professionals. They view their role as being different to that of public health nurses, community intervention teams, nursing home staff and GPs as they never take over the care of the patient but assist and support other healthcare professionals involved. They view this relationship as a collaborative one, with success dependent on interdisciplinary communication and support. They see GPs as the fulcrum of care, since they know the patient well and, in some cases, have built up years of relationships with patients and their families. While the clinical nurse specialists understand this as being a clear policy of practice, they often see *"blurring" (Tina, 6-10 years)* or discrepancies between roles, and sometimes public health nurses or GPs become less involved once the community palliative care nurse starts to visit.

The clinical nurse specialists perceive that other healthcare professionals do not clearly understand the difference between general and specialist palliative care, and that this contributes to misunderstandings including frustrations in everyday practice. Negotiating these complex interactions with other healthcare professionals can be challenging, time-consuming and tiring for the clinical nurse specialists.

> *"What you see is, once you're involved, you become the key person and they can just take a step back from providing their service. That should not be the case. One of the hardest things can be to get a patient medically assessed by their GP at home" (Rita, 16 years or more)*

The clinical nurse specialist's role with the GP is important, and, in general, for the clinical nurse specialists once there is a good working relationship and cohesiveness between them the patient journey is less challenging. One clinical nurse specialist explained that she considers the GP as the gatekeeper of the patient's overall care, and that clinical nurse specialists become frustrated when GPs or public health nurses reduce or withdraw their input (described as "*taking a backseat"*) *(Ita, 16 years or more)* when the specialist palliative care team becomes involved. At times the clinical nurse specialists feel unsupported by GPs and community nurses when some services are reduced in this way. They struggle when this occurs because a collaborative interdisciplinary team effort is always necessary to ensure that the patient and family have the support they need for the patient to remain at home.

The clinical nurse specialists also find it challenging contacting GPs when they need to discuss a patient. They regard secretaries as 'gatekeepers' who won't allow the clinical nurse specialists access to GPs. Frequently, a secretary will ask for details of a prescription regarding a change in medication advised by the clinical nurse specialist. However, if a new medication such as an opioid is being suggested, the clinical nurse specialist feels it warrants a conversation with the GP rather than their secretary. The clinical nurse specialists view trying to access pharmacies, GPs and public health nurses as excessively time-consuming and frustrating. A future goal would be to establish clinics within primary care centres, which would strengthen and enhance

clinical nurse specialists' relationships with GPs and public health nurses. This would also be a new way to deliver specialist palliative care in an "*ever-evolving speciality" (Rita, 16 years or more)*.

Within their clinical workload all clinical nurse specialists referred to the challenges of providing specialist palliative care for children. Upon taking up employment in what they viewed as an adult specialist palliative care service, many had not perceived this to be part of their role. For those transitioning from an in-patient unit to the community team, paediatric admissions had not occurred in that setting. They reported that there was significant anxiety among the community nursing team once they received a community paediatric referral. They identified a lack of knowledge as the cause of this anxiety, since their experience and training had been in the provision of specialist palliative care to adults. They reported that the volume of paediatric referrals can fluctuate, resulting in inconsistent exposure to caring for children. In addition, when looking for advice within their team on caring for a child, they find that the healthcare professionals they turn to in other disciplines are also not paediatric specialists.

> *"It is scary because when you're not confident in the general care of the paediatric, it is extremely hard to be confident in the palliative care of a child. We are expected to look after children but we are not trained to do it" (Maya, 1-5 years)*

Encounters with paediatric patients caused significant anxiety, often resulting in sleepless nights, as nurses grappled with the heightened emotional burden and a perceived lack of sufficient training and skills. This contrast revealed a shift from feeling professionally grounded to feeling disempowered and exposed, highlighting the emotional and professional complexity involved when stepping outside their usual scope of practice. While clinical nurse specialists felt empowered and confident in delivering adult end-of life care, this did not extend to paediatric cases. Access to paediatric specialist expertise varied from phone or email contact however ordinarily the clinical nurse specialist would be often visiting the home alone.

While clinical nurse specialists viewed teamwork as an essential component of fulfilling their role with healthcare professionals outside the service, it was also important for them within their own service. All the clinical nurse specialists mentioned the importance of having good relationships within their specialist palliative care team. They perceived that *'similar souls (Jane, 16 years or more)'* are drawn into this speciality area. Having a supportive working environment was viewed as important in creating and sustaining the clinical workplace.

> *"I've never worked with a team like I have in specialist palliative care. It is the most wonderfully supportive of people. I say that for the whole multidisciplinary team" (Maya, 1-5 years)*

3.2.2 Planning the working day within available resources

Planning a working day with regards to patient care involves working not only in predictable scenarios but also adapting to unexpected situations. Decision-making, although it can be complex, is required on the spot. Clinical nurse specialists often described decision-making as both empowering and demanding. They valued the autonomy their role provided, allowing them to make timely, informed decisions tailored to individual patient needs. However, this autonomy also bought feelings of isolation, particularly when navigating complex cases without immediate support. Many expressed that collaborative decision-making with GPs and other team members strengthened their confidence and ensured more holistic care.

Clinical nurse specialists anticipate potential eventualities on a patient's journey and plan accordingly for them. This includes having medications and equipment in the home that may be required. During planning, they liaise with other healthcare professionals and services to ensure that any resources needed are available and in place. Aspects of the daily role that are perceived as most stressful and time-consuming are also outlined;

"In pre-empting things, you need to look at the worst-case scenario and be prepared. So if you think someone may deteriorate over the weekend you ensure everything that may be needed is communicated and sourced from the GP and public health nurse" (Tina, 6-10 years)

Anticipating what could happen appears to be intrinsic to the clinical nurse specialist's role. This knowledge is experiential and involves identifying when a patient is deteriorating or approaching an end-of-life situation. Often, they have a '*gut feeling'(Faye, 1-5 years)* that the patient is deteriorating, and know that the care plan is for the patient to remain at home. In these situations, they ensure that the family is aware of what is happening, and try to secure all the resources that will be needed. Preparing the family is important to avoid any panic out-of-hours. The clinical nurse specialists inform families about potential worst-case scenarios to prepare them for these scenarios and help them plan their management effectively.

"If you don't have a plan in place, then we're always worried that an ambulance would be rung. That is the last thing you want to happen when going back to the acute setting is completely inappropriate for that patient and they could end up dying in the emergency department" (Maya, 1-5 years)

A clinical nurse specialist's day commences with phone calls to patients, families, as well as other healthcare professionals. This enables the clinical nurse specialist to prioritise visits and follow up phone calls based on the complexity of needs. While clinical nurse specialists acknowledge this phone support as important, they also regard it as time-consuming, as "*it would be impossible to get to visit everyone who may need a review" (Jane, 16 years or more)*. This is due to patient numbers, staffing levels, volume of daily phone calls and the size of the geographical area.

The frustrations they perceive in planning their day include the fact that 'they are not delivering the level of service they would wish, but are merely 'firefighting' on a daily basis. It often means working beyond their rostered hours, and they find it difficult to receive compensatory hours in return because they are aware that, if they receive it, it

leaves their colleagues short-staffed. They see themselves as responding to needs under great pressure and that it can cause them fear, anxiety and concern that they won't be able to visit a house on time or be in a position to optimally support the patient's journey. They see all their patients' journeys as unique, both for the patients themselves and their families. This results in the clinical nurse specialists feeling responsible and being under pressure to ensure the best outcome for the patient and family. In times of staff shortages, it can be difficult for them to accept the need to be pragmatic and that they can only deliver the care that their staffing levels allow.

> *"It is very hard. You feel like you have done no job properly and you are more firefighting. It's not the kind of palliative care you would like to give. Are patients getting a service? Some are but not all, I would say. It is frustrating and frightening (Ita, 16 years or more)*

The clinical nurse specialists see having insufficient resources such as staffing, within the community team as overwhelming. Sometimes they are aware of staffing shortages the night before they come on duty, which can cause their sleep to be disturbed. Although their priority is always to see patients who require an urgent review, they are frustrated with constantly needing to reschedule other pre-arranged home visits. Working within this stressful and intense environment causes the clinical nurse specialists to be concerned that they will make a mistake or miss something important.

"I think people are burnt out from the firefighting. This also can impact their clinical judgement. I see colleagues needing advice on something I know they know well but they can be so exhausted they are unsure of the decisions they make" (Rita, 16 years or more)

For some patients, dying at home may not be the best or most advisable option especially in the absence of family or home help to support the main carer. When that is the case, the clinical nurse specialists need to be able to offer and guide patients and families to an alternative option. This may be inpatient hospice care to prevent patients from being unnecessarily admitted to an acute hospital or long-term care. For many

patients the reason for a hospice admission may be for symptom management, though frequently, they note that disappointingly it is due to the inadequacy of resources when providing care at home, such as home help.

> *"I do think people romanticise what home will look like when they're dying. It's not always quite so nice. So it's about setting realistic achievements and goals for them. There can be a lot of family disharmony. People can have complicated symptoms. If it's not straightforward, it can be really difficult at home and you have to recognise these limitations" (Tina, 6-10 years)*

Clinical nurse specialists say that providing palliative care to patients is not only necessary during working hours but also around the clock as the specialty cannot stop at 5pm. One participant explained how they make an 'unexpressed contract' within themselves to see a patient's journey through. They may not be on duty when the patient deteriorates or dies so in this instance they rely on their clinical nurse specialist colleagues who are working. They identify that they put much in place during working hours to ensure support and safety for patients. However, when there is no night nurse available or an out-of-hours GP service that would be able to respond by reviewing a patient at home, the quality of the care is uncertain and patients may end up unnecessarily presenting to the emergency department.

> *"For out-of-hours, you can equip them to some extent to manage symptoms in terms of using buccal medications and they can ring into the hospice for symptom control advice. When it's not well managed it's very hard because you have to walk back in the following day and things haven't gone well out of hours (Kate, 6-10 years)*

The weekend service can also prove challenging for the clinical nurse specialists as there are fewer clinical nurse specialists on duty, and, therefore, only a reduced caseload can be sufficiently covered. Some patients and families may not be aware of this and again the availability of a clinical nurse specialist visiting stops at 5pm.

"Some families ring at the weekend expecting that we are an emergency response service but it's not. We have to be honest with families and patients from the first visit as to what we can offer, our service is 9-5pm only (Ruby, 6-10 years)

Despite this, there have been instances where care and advice out of hours work very well as the GP is competent concerning palliative care and may do a home visit or give phone advice supporting the patient and family out of hours to enable them to remain at home. One helpful factor appears to be when the on-call GP has a special interest in palliative care. The general consensus among the clinical nurse specialists is the need for extended nursing hours beyond 5pm however they perceive this would require additional resources.

Another important element of out-of-hours advice is the night nursing service which is funded and provided by the Irish Cancer Society for patients with a malignant diagnosis. This service is provided by the Irish Cancer Society but funded by the Irish Hospice Foundation for patients with a non-malignant condition. It enables patients to receive expert nursing care and support at night in their own homes in their final days. It also provides reassurance and respite for families and loved ones caring for someone at home. These night nurses provided by the Irish Cancer Society were perceived by the clinical nurse specialists as being of vital importance to the specialists when enabling a family to care for someone at the end of their life. However, the availability of night nurses varies according to resources. Clinical nurse specialists dread having to contact family to inform them that a night nurse is unavailable on a given night, with the absence forcing the patient to rely on a busy on-call GP service.

"The night nurses are pivotal to our job. It is great to go off knowing the night nurse is coming and is competent. Just to observe the needs and support the patient. Then you get that hand over in the morning and you get such a snapshot of how the night was. We rely on them." (Faye, 1-5 years).

Despite planning and due care, an acute hospital admission may be beyond the control of the clinical nurse specialist. When it occurs out of hours, it can be distressing for the

clinical nurse specialist to discover when they are next on duty, especially if they have put all the resources possible into the home to prevent that situation occurring. One clinical nurse specialist stated that she "*would be so concerned about a patient [having been admitted to an acute hospital] being on a trolley and in pai*n*" (Faye, 1-5 years)*. Another participant added that this can sometimes reduce them to tears when they have put so much time and effort into trying to avoid an unnecessary hospital admission.

> *"I remember talking to one of the other girls when we found out he'd died the previous night in the emergency department. She was crying, I was crying, we were all crying. We just never want anyone to die on a trolley in an emergency department and he always told us that he wanted to die at home" (Ruby, 6-10 years)*

Sometimes, though, acute hospital admission is necessary. Clinical nurse specialists recognise that some patients will benefit from admission in an acute hospital setting. This will depend on their goals of care, their stage of illness and their personal preference. One patient, admitted to hospital with sepsis, told the clinical nurse specialist when he returned home: 'If you didn't admit me, I would be dead." Accessibility to intravenous antibiotics and therapies at home varies depending on existing resources. Whether or not a patient should be admitted highlights the complexity of clinical decision making required in their specialist role. Although the decision is made in collaboration with the GP and the specialist palliative care multidisciplinary team, the clinical nurse specialists often feel the weight of responsibility, as they are often the only team member who has assessed the patient in person.

Many clinical nurse specialists decided to work in palliative care as they perceived that it would give them more time to be with patients and families and to provide holistic care. They later realised that this can be unrealistic due both to their workload and restricted resources. While in a patient's house, they feel under pressure to leave quickly, being aware of the rest of their workload for that day. This pressure exists alongside their efforts to finish work on time. It is challenging for a clinical nurse

specialist to finish on time if they are in a home and the patient is unwell. In such a scenario, they feel unable to leave without planning for all anticipated needs, as on-call GP services may not have the time or expertise to deal sufficiently with symptom management. Due to the geographical spread of patients and the size of catchment areas, the clinical nurse specialists are unable to return to a patient for a second visit the same day. Some clinical nurse specialists believe that some patients who live nearer the base receive a superior service as they may get a second or even third visit the same day.

> *"It is hard if you're in a house and you're under time pressure. You're trying to fulfil that therapeutic relationship but in your head, you're thinking 'I still have three visits to do.' I'm sure families and patients sense when we are under time pressure, too" (Ita, 16 years or more)*

In addition to difficulties with time and efficient workload management, there is always uncertainty among the clinical nurse specialists as to what awaits them once they enter a patient's home such as, patient that requires personal care, family member requiring additional time to talk or a patient may have deteriorated unexpectedly. These are some of the practical, unanticipated, additional challenges clinical nurse specialists encounter daily that subsequently impact on their scheduling of the rest of their visits that day.

> *"When I arrive at a house I count the cars there. Sometimes huge numbers of cars mean more questions and [more need for] reassurance so I am already stressing that this won't be a visit in the time I have allocated" (Sue, 6-10 years).*

In this category, how clinical nurse specialists navigate the complexities of their working day are explored. It highlights their proactive approach to anticipating patient needs, particularly around end-of-life care, and their reliance on experience, intuition, and coordination with other professionals. Despite best efforts, clinical nurse specialists often feel overwhelmed, working beyond rostered hours, and describe their daily routine as "firefighting." Much of the stress appears to stem from managing high

patient volumes, inadequate staffing, geographic challenges, and time pressures, rather than from the emotional burden of caring for people who are dying. Emotional strain is intensified when hospital admissions occur despite careful planning, especially when these admissions are perceived as preventable.

3.3 The art of self-care

In this category caring for oneself and being able to switch off outside work are discussed. It includes ways in which the clinical nurse specialists have integrated self-care both during and outside of work.

While certain qualifications are necessary to pursue a career in specialist palliative care, one participant explained that, if one "*didn't have a heart" (Tina, 6-10 years)*, it would not be possible to fulfil the role. One clinical nurse specialist *(Kate, 6-10 years)* perceived this "heart" as important to maintain without interruption throughout one's career. Another clinical nurse specialist admitted that *"shedding a tear was ok once you weren't a blubbering heap" (Rita, 16 years or more).* This reminded her that, after all her years in the role, she still had compassion and empathy.

All the clinical nurse specialists referred to eating while working as opposed to having a time-protected lunch break. One of them referred to it as 'dashboard dining,' which involved eating their lunch in the car while they were working which was a frustrating part of the role. The pressure to get out on the road and finish work on time starts as soon as they commence their shift. Stopping for lunch was seen as half an hour wasted when they could have travelled instead to the next patient's house. One clinical nurse specialist reported that she tried not to look at patient charts while she ate her lunch in the car, while another uses this lunch break to read up on the next patient visit.

> *"Dashboard dining sounds fun but it's not and that's the reality. Grabbing something when you can and you're eating alone and you're eating quickly. You're thinking as*

well if I don't stop, there's more chance of me getting off duty on time" (Faye, 1-5 years)

One clinical nurse specialist admitted that she cannot say 'no.' If a late visit is required, she will always forfeit whatever plans she has made in her own life to accommodate the visit. This leads to her missing out on family or pre-planned social events that are important to attend as an aid to 'switching' off from work. But clinical nurse specialists can also feel guilty if they cannot work late due to personal reasons and they feel like they are *"letting the patient down" (Sue, 6-10 years)*. While they often collate time accrued, there is an the understanding among them that they won't be able to take it as it leaves colleagues short-staffed.

Finishing work on time is challenging at times for clinical nurse specialists, who perceived it as a skill that they needed to develop within their workday as *'you could stay on in work all evening and still not be finished' (Kate, 6-10 years)*. They sometimes viewed having energy for their family after work hours as difficult, and some felt guilty about this. The clinical nurse specialists perceived that they "*give so much of themselves in work that sometimes there is no fuel left in the tank when they go home" (Tina, 6-10 years)*. Sometimes, they just want to sit in silence when they go home since they have done so much talking all day. Depending on their circumstances, however, that may not be possible. They also have guilt about that.

"I do feel guilty coming home because I have given so much to my patients and their families that day that I don't have anything to give my own family. That's not right either (Ruby, 6-10 years)

One clinical nurse specialist admitted to 'having bad habits' *(Faye, 1-5 years)* such as checking emails or monitoring her work phone on days off so that she did not miss anything important. Others had successfully developed the skill of switching off once they left the building. Switching off involved them developing healthy boundaries such as turning of work phone, exercising, focusing on family time or using mindfulness or relaxation techniques to decompress. Most of the clinical nurse specialists viewed

camaraderie within the office as very important for support and debriefing among themselves. They perceived black humour as important, which they used as a mechanism to *"let off steam" (Jane, 16 years or more)*. Having this sense of humour for the job was perceived as important not only for switching off but also for relationship building with the team. The clinical nurse specialists described the office space as 'the best therapy at the end of a busy day'. And, although formal staff support is available to them within the organisation, *"ironically there is no time to attend it" (Faye, 1-5 years)*. The clinical nurse specialists have adopted self-care strategies over the years such as watching documentaries, yoga, mindfulness, eating a balanced diet and exercising. One clinical nurse specialist admitted that, as a mode of self-preservation, she always leaves her work phone on her desk and takes pleasure in activating her out-of-office voicemail. Having a colleague to hand over to before a day off also helped to *"clear the head" (Ita, 16 years or more)* before going home. One clinical nurse specialist recommended a mandatory sabbatical for staff working in specialist palliative care, e.g., every ten years they should have to take a year off to work in another field.

Oftentimes, returning to the office to chat about a bad day was important both for debriefing and receiving support. The clinical nurse specialists used these discussions as a forum for sharing advice about a patient's care among themselves . One participant said the team made her '*never feel alone even though I'm deemed a lone worker' (Ita, 16 years or more)*.

> *"It is good to have a platform to talk it through with colleagues who were not associated with this patient and to just get objective views on the plan of care" (Sue, 6-10 years)*

3.4 Professional development within the clinical nurse specialist role

In this category, the challenges of fulfilling the core competencies of a clinical nurse specialist - clinical focus, advocacy, consultancy, audit, training, education and research - are discussed. It also examines the technological skills that are now required

as a clinical nurse specialist. It discusses some challenges regarding facilities, and infrastructure.

3.4.1 Fulfilling core competencies

All clinical nurse specialists referred to the core competencies of their role in the interviews without being prompted to do so. They were all aware of what these competencies entail, but were also aware that, for many reasons, they were not fulfilling all of them. The clinical nurse specialists felt that these aspects of the core competencies were being fulfilled as far as possible given the available resourcing, and they considered them as a priority. One clinical nurse specialist viewed the other core competencies as '*luxury add-ons'(Rita, 16 years or more)*, describing them as being fulfilled only in cases where no urgent patient reviews were required.

Clinical nurse specialists acknowledged that on a daily basis they use clinical focus and autonomy in their work which empowers them to implement a patient-centred plans of care. They play a crucial role in empowering patients and families regarding their illness; however, to achieve this, they need to be proficient, confident and competent in their skills. These skills range from clinical assessment to symptom management, encompassing patient advocacy, system navigation, time management, knowing what to say and how to say it, or simply being able to sit with someone in silence.

> *"I have to be competent and confident in what I do and I have to leave the patient and family feeling that way, too. On each visit, I build on that. I have to know what is the right thing to say and also when is the right time to say nothing and be silent. This helps to develop our nurse-patient connection. This connection may be in a very short or long period but either way, it can be intense" (Kate, 6-10 years)*

Clinical nurse specialists discussed the job satisfaction they got from sharing this journey with patients and their families. They found it rewarding to care for and support patients and families living and dying in their preferred place of care.

"I feel I do the best every day that I possibly can and you know people say how do you do palliative care. I always think if this was my mom, dad, brother, or sister, I'd want the best for them so that is what I do - my best (Ita, 16 years or more)

Once in the role, participants described the experience of caring for patients in their home environment. They regarded themselves as a "*guest in their home*" *(Kate, 6-10 years),* and that this was something that must not be forgotten while in a patient's house.

Many participants referred to end-of-life care planning as *"roping in everyone" (Rita, 16 years or more),* to facilitate the patient and family being cared for and supported at home. They felt that these end-of-life care scenarios worked well because the healthcare professionals they contacted responded and attended the patient quickly.

"I think there was an acknowledgement that we only had a small window to get it right for them, and it was a case of everyone rolling in because it was only going to be a very short period" (Sue, 6-10 years)

Providing end-of-life care was described as a central and routine aspect of the clinical nurse specialist's clinical role, involving the continuous balancing of expertise in symptom management alongside the advocacy work of supporting patients' preferences regarding their place of care.

Clinical nurse specialists acknowledge their responsibility in delivering education while also receiving education to maintain their own continuous professional development and specialist skills. Through informal and formal education there is an expectation being placed on them to educate families, patients and generalist staff as and when the need arises. Most formal educational preparation is carried out in a clinical nurse specialist's free time or ah-hoc during a home visit as they struggle to find or be allocated protected time while on duty. One of the clinical nurse specialists used the

phrase that they ‘firefight education’ as there is no time or resources to allow them to plan and carry it out formally.

While clinical nurse specialists acknowledge the need to maintain their continuous professional development they struggle in completing their mandatory training, such are the challenges their view their workload as.

> *“Besides mandatory training, I haven’t furthered my education in the last few years. You aren’t given the time or support to do it so until they do I will just come to work and visit patients” (Kate, 6-10 years)*

Insufficient focus and support by management to fulfil education needs was a recurring theme highlighted by the clinical nurse specialists. They suggested that protected rostered time for informal or formal education was required. They see it as unfair to expect healthcare professionals to have to attend education or complete mandatory training on their personal time. Clinical nurse specialists hope that, now that the pandemic workload has lessened, education will become a priority again. Doctors are allocated a certain amount of study leave per year to fulfil continuous professional development points for registration, and many of the clinical nurse specialists felt that leave should also be introduced for nurses.

> *“Medics are very good at having protected time for education and when that is on we do not ring them unless it’s an emergency. Nursing should do something similar” (Ita, 16 years or more)*

A recurring tension for clinical nurse specialists was the gap between their recognition of professional development needs and the limitations that constrained their ability to meet them. Although the initiatives they identified such as in-house education sessions, reflective case reviews, and clinical supervision were not seen as resource-intensive in terms of preparation, the nurses repeatedly emphasized the necessity of protected time to engage in them meaningfully. This reveals an underlying process

of negotiating time and space for professional growth within a role already consumed with clinical, administrative, and emotional demands.

Communication was viewed not as a skill where you reach a competency but more so as a competency that requires continuous development and reinforcement. They perceived ongoing communications training as essential since it is a constant requirement of their role. Case reviews following a patient's death emerged as a valuable opportunity for learning and for processing the complexities of symptom management and end-of-life care. However access to these supports was often dependent on capacity within the service and individual effort.

Clinical nurse specialists were frustrated at the underutilisation of peer expertise. The data suggests that clinical nurse specialists saw one another as rich sources of knowledge and support, but there was a lack of opportunities to facilitate this exchange which led to a sense of missed opportunities. This leads to potential present that is not capitalised due to the absence of time.

> *"It's such a pity because we have clinical nurse specialists who have so much experience and knowledge and, unfortunately, we don't have the platform to share that because we would learn so much from each other. Time is a massive element for that" (Ruby, 6-10 years).*

The clinical nurse specialists viewed audit as a lower priority than education and training. Audits were only undertaken when their clinical workload allowed it. They saw having a colleague to work with when completing an audit as beneficial, especially when reviewing practice within their own field. Encouragement is needed to participate in audits, with the clinical nurse specialists stating that, even when there is time, they often do not want to do them. Another frustration that the clinical nurse specialists reported was that, even after they had completed an audit and made recommendations, none of the proposed changes were implemented due to their not having time to do so. This led to tensions between their sense that they are providing excellent care alongside time to complete audits to evaluate the care they provide.

The clinical nurse specialists viewed their career path as limited. Some of them wished to remain in their current role. Others said they would welcome the opportunity to complete a course to become a registered nurse prescriber or progress to an Advanced Nurse Practitioner role. However, these opportunities are limited within specialist palliative care nationally and the clinical nurse specialists felt aggrieved that consultants had the final decision as to whether these nursing roles progressed to advanced nurse practitioner training as the consultant's consent is required to sign off as mentors. By contrast, one clinical nurse specialist said that she would not be interested in pursuing nurse prescribing as an extension of her role as there is no extra remuneration given in recognition of achieving the qualification.

3.4.2 Administrative and technological challenges

Clinical nurse specialists recognise documentation as an necessary aspect of their role, but highlight that it has become increasingly time-consuming and complex. While various strategies are used to manage the workload such as making brief notes during visits or completing records at the end of the day, this often occurs under cognitive strain. They all acknowledged that, with all the phone calls and patient visits on any given day, they return to base '*with a lot of information in their head'*.

> *"So you always have to come back to the office every evening to get your notes done. At that stage, you're swamped with information. If you don't do it on the day you will lose it" (Kate, 6-10 years)*

The preference for more efficient documentation methods was evident, particularly given the current lack of supportive technology such as online patient clinical notes. Some clinical nurse specialists find it challenging to capture every detail from every visit and express frustration that, in *"this day and age" (Ita, 16 years or more)*, there is still no IT system such as voice recognition systems to streamline the documentation process.

Much of the administrative burden was seen to stem from non-clinical tasks, including sourcing reports, reviewing laboratory results, and completing manual documentation tasks. Difficulties in accessing hospital information and the absence of streamlined communication channels contributed to delays and inefficiencies. One clinical nurse specialist described being '*bogged down in a sea of paperwork'*. Several clinical nurse specialists expressed the view that additional administrative support would help free up time to engage in core clinical and professional responsibilities, such as audit and education.

> *"Additional administrative support would be helpful. At the end of the day when you're doing a lot of administration, it is time you are not with a patient" (Faye, 1-5 years)*

While some welcomed advances in digital systems, particularly those introduced during the pandemic, concerns were raised about training needs and the uneven ability to engage with new technologies. The transition to digital documentation was acknowledged as beneficial in principle, but practical challenges—such as limited IT support and poor internet connectivity in rural areas which presented ongoing barriers. These issues were further compounded by inadequate physical working environments, including shared office spaces that compromised confidentiality and concentration.

Learning new technology skills requires time and patience, causing one clinical nurse specialist to want to "*hold onto paper for as long as possible" (Jane, 16 years or more)*. The knowledge base required for new technology is ever-evolving and cannot be learned simply from a book or during one education session. Instead, it requires the practical use of patient information computer databases. The long-term clinical nurse specialists see the benefit for patients and healthcare professionals of having home visits for patients, as well as assessments, Palliative Care Outcomes Collaboration scoring and medication lists all at the touch of a button, especially out of hours. Converting to online systems will be challenging for clinical nurse specialists, especially those who work in rural areas with poor internet connectivity.

"None of us are opposed to it, we're very open to it, because this is the way of the future and it'll be much faster for communication. It is getting us to that point that will be challenging" (Rita, 16 years or more)

While the integration of digital technologies was largely welcomed, clinical nurse specialist experienced varying degrees of frustration adapting to new IT systems as time was always required for adequate training. These challenges were compounded by limitations in their physical working environment, which hindered their ability to engage with their clinical, administrative and training responsibilities. Clinical nurse specialists were frustrated at the lack of adequate space to allow for quiet and confidential conversations, leading some to seek privacy by sitting their cars to make a phone call. The nurses in this study were all based in a room together, and one of them reported that working in these open office spaces causes continuous disturbance. Nationally, office spaces are designed in this way for community palliative care teams.

"Even when you are on the phone people just keep coming up to you and even try to converse with you. You could have a relative crying at the other end of the phone and in the office, someone is trying to give you a message" (Ita, 16 years or more)

While they welcome some developments in information technology, the clinical nurse specialists work within office spaces that were not suited to the sensitive and often emotionally charged nature of their work. Together the digital and physical constraints highlighted a broader issue; the lack of environments for both technological and physical, that support the complex and information sensitive work of the clinical nurse specialist role including time they could spend otherwise fulfilling their competencies.

Overall, the combination of digital and physical constraints was seen as limiting the capacity of clinical nurse specialists to carry out essential elements of their role effectively. The need for an organisational culture that supports learning, professional development, and appropriate infrastructure, both technological and physical was identified as critical for sustaining specialist practice within community palliative care

3.5 Conclusion

In this chapter, the findings of nine semi-structured interviews have been presented. Initial coding was completed to determine the content's fit and its relevance to the study. The themes developed were: *Clinical Nurse Specialists' Perception and Reality of Practice, The Art of Self-Care and Professional Development within the Clinical Nurse Specialist Role*. In this chapter the findings from the analysis of the clinical nurse specialists' transcripts to support the development of these themes are presented. In Chapter 4, a systematic review of the literature will be presented structured around one theme that emerged from the results. Chapter 5 will discuss in depth the interview data findings and the systematic review, culminating in a final theory relating to the experiences of specialist palliative care clinical nurse specialists when fulfilling their role.

4 Systematic review of the literature

4.1 Introduction

This systematic review was conducted using a critical interpretive synthesis method originally developed by (Dixon-Woods et al., 2004).It uses a broad sample of relevant research from qualitative methodologies that will contribute to the construction of a theory and the development of new concepts to gain an understanding of the experiences of the clinical nurse specialists (Aveyard et al., 2016).

This systematic review was undertaken to critically examine and deepen understanding of a key category that emerged from participants interviews; *Clinical Nurse Specialists' Perception and Reality of Practice*. This theme was selected due to its centrality in reflecting the tensions and inconsistencies between how clinical nurse specialists conceptualise their professional role and the realities they navigate in daily community-based palliative care practice. Selecting a single, analytically rich theme allowed for depth over breadth and ensured the review remained closely aligned with the study's aims and epistemological positioning.

This theme outlined the core tensions, ambiguities, and professional challenges experienced by clinical nurse specialists working in community palliative care. This thematic focus served a dual purpose. Firstly, it provided a targeted synthesis of existing evidence, which enabled a comparison between the lived experiences of participants in this study and what has been reported elsewhere in the literature. Secondly, and more importantly, the review was used as a tool to interrogate, refine, and test the emerging theory being constructed through grounded theory methodology.

4.2 Formulating the review question

There is a wide range of evidence-based frameworks to choose from for structuring and directing the review questions. The SPIDER tool was used to assist with refining the research question for this study ensuring the inclusion of all essential components. This tool informs a qualitative framework where a research question can be established

based on the relevant sample, phenomenon of interest, design, evaluation and research type (Cooke et al., 2012). “Spider” is an acronym that combines the following elements:

S (Sample) – Clinical nurse specialists
P (Phenomenon) – Working in the community specialist palliative care setting
D (Design) – Critical interpretive synthesis
E (Evaluation) – Role
R (Research Type) – Qualitative research, including mixed methods

4.3 Review question

How does the everyday reality experienced by specialist palliative care community clinical nurse specialists compare with their prior conceptions of the role?

4.4 Justification for delaying the literature review

A distinguishing feature of some grounded theory approaches directs researchers to delay a literature review until after data collection and analysis. Arguments for postponement often rest on concerns that early exposure to existing theories may bias the researcher, making them uncritical of what they read or too easily swayed by dominant ideas (Charmaz, 2014). However such arguments miss a crucial point: the researchers must adjust the final version of a literature review to fit the purposes and aims of their research (Charmaz, 2014) . Ultimately, the timing and function of the literature review should serve the integrity of the research, supporting rather than constraining the development of theory grounded in data.

In broader terms, literature reviews commonly serve to identify gaps in knowledge**,** situate research within an existing empirical and theoretical context**,** and assess the methodological landscape of a field. In grounded theory, however, the function of the literature review is more nuanced. Grounded theory researchers cannot predict the direction their data will take in advance, and therefore cannot know which aspects of the literature will become relevant (Bryant & Charmaz, 2019). Delaying the

literature review helps maintain theoretical sensitivity and openness**,** key tenets of grounded theory, and prevents premature theoretical closure.

An in-depth literature review for this study was deliberately conducted after the data collection had been completed and analysed. This enabled findings from the literature to be woven into the developing theory. It also ensured that literature relating to relevant existing theories did not influence the researcher when conducting interviews or writing up the data. This delay ensured that the researcher remained open to any findings that emerged from the theory.

This is supported by openness on the part of the researcher as they cannot know in advance which direction their data will take and therefore cannot know which aspects of the literature are relevant to their study. (Bryant & Charmaz, 2019). Conducting the literature review after the preliminary formulation of categories enabled data analysis to guide the selection of literature that would either concur with or challenge the categories.

4.5 Review design

Choosing an appropriate approach to data synthesis will depend upon the review question, the review purpose and the outcome that one seeks to achieve (Schick-Makaroff et al., 2016). Although most forms of synthesis have considerable areas of overlap, they can be characterised as being primarily interpretive or integrative in form and process (Dixon-Woods et al., 2004). Integrative synthesis involves summarising data by pooling data findings together, and is rooted in a positivist paradigm (Dixon-Woods et al., 2004); Noblit & Hare, 1988). Integrative data synthesis involves techniques such as meta-analysis and mixed-method reviews (Hong et al., 2017). They require basic comparability between phenomena so that data can be aggregated for analysis (Dixon-Woods et al., 2004). Since this review synthesises information that is based on clinical nurse specialists' experiences and perceptions, the use of any quantitative integrative data synthesis was not appropriate.

This systematic review aimed to interrogate and enhance elements of the theory developed from the empirical work carried out for this study. The synthesis for this review was guided by the epistemological and ontological assumptions of the overall research study, which are underpinned by a relativist ontology and interpretive epistemology.

Table 4.1: Types of Interpretive Review Synthesis Methods

Interpretive review synthesis methods	Underpinnings	Purpose and rationale for not using this method
Thematic synthesis	Developed out of a need to conduct reviews that address questions relating to interventions (Barnett-Page & Thomas, 2009)	Results in analytical themes that contribute to a conceptual framework (Barnett-Page & Thomas, 2009) that does not align with this literature synthesis
Framework synthesis	Conducts qualitative data synthesis, generating theories relating to the effectiveness of an intervention that would be of relevance to policymakers (Carroll et al., 2013)	Appropriate for questions where pre-existing theories or frameworks exist (Carroll et al., 2013)
Meta-ethnography	Establish derived understanding, representation and understanding across studies in order to further meaning and create understanding (Soundy & Heneghan, 2022)	Findings in meta-ethnography are not expressed in the form of a synthesising argument but a search for new interpretations of the data (Aveyard et al., 2016)
Critical interpretive synthesis	It is both inductive and interpretive. It is an approach to the whole process of the review rather than just to the synthesis component (Barnett-Page & Thomas, 2009); Dixon-Woods et al., 2005)	It is based on subjective idealism, in which multiple realities are possible (Tong et al., 2007); it is similar to relativism and the interpretive philosophical underpinnings of this study

Interpretive review methods, as outlined in Table 4.1 above, are concerned with the development of concepts and theories as opposed to the mere aggregation of data (Schick-Makaroff et al., 2016). The essential tasks of interpretive reviews involve both induction and interpretation and an understanding of how things connect and interact (Dixon-Woods et al., 2004). Except for critical interpretive synthesis none of the

methods outlined in Table 4.1 synthesise the literature to generate a new theory, which is the aim of this synthesis, and hence they were eliminated as possible methodological choices for this systematic review. The generation of a completely new theory requires an exclusively inductive method such as critical interpretive synthesis.

The critical interpretive synthesis method aligns with constructivist grounded theory, in which the researcher subjectively plays a part in constructing the theory (Charmaz, 2014). Furthermore, critical interpretive synthesis supports this systematic review due to its overall aim to further develop the preliminary categories through initial data analysis (Tong et al., 2012).

The critical interpretive synthesis method was originally developed by (Dixon-Woods, Bonas, et al., 2006). This approach uses a broad sample of relevant research from various methodologies that will contribute to the construction of a theory and the development of new concepts (Aveyard et al., 2016). The methods used in this approach reflect those used in a grounded theory approach, which is in keeping with the overall methodological research design of this study. In critical interpretive synthesis, concepts and theories are developed using the body of literature as the object of enquiry (Evans et al., 2023) rather than just an exhaustive summary of the data (Dixon-Woods, Cavers, et al., 2006). It has been applied to many topics capturing experiences such as prognostic communication in cancer (Johnson et al., 2015), difficulties for university students with mental health problems (Markoulakis & Kirsh, 2013) and the experiences of healthcare delivery that matter to service users (Entwistle et al., 2012). Critical interpretive synthesis comprises six stages: formulating the review question, searching the literature, sampling, determining quality, extracting data and interpreting the synthesis (Talseth & Gilje, 2017). These will be discussed further throughout this chapter.

4.5.1 Literature inclusion and exclusion criteria

This review synthesises relevant data that captures how the everyday reality experienced by clinical nurse specialists compares with their prior conceptions of the

role. The criteria for including and excluding literature for this review are outlined in Table 4.2.

Table 4.2: Literature Inclusion Criteria

Inclusion Criteria	
Population	Participants' titles may include clinical nurse specialists, nurse practitioners, nurse specialists or advanced nurse practitioners. Registered nurses who are employed in a post that requires a higher level of decision making and expertise in palliative care therefore working as specialists within their chosen speciality are also included
Setting	Must be working in a specialist palliative care community setting. Specialist palliative care services are those services with palliative care as their core speciality and which are provided by an inter-disciplinary team (Crawford & Price, 2003)
Location	Refers to the location of the patient in which the specialist palliative care team is caring for them. That will include the community setting such as a community hospital (although not an acute hospital that deals with emergency care), nursing home, residential care setting, or their own, or a relative's, home
Research Design	Qualitative and mixed methods research
Article data to be included	How the everyday reality experienced by palliative care clinical nurse specialists compares with their prior conceptions of the role.
Language	English only

4.6 Literature search strategy and selection

4.6.1 Search strategy

The review question focused specifically on specialist palliative care community clinical nurse specialists. A search was carried out on Prospero to February 2024 to establish whether other, similar reviews had been registered regarding the chosen topic and no review registrations were found.

The initial search strategy structured around four key concepts; community setting, palliative care, clinical nurse specialist, and experiences but this did not successfully return relevant results or identify key papers pertaining to these areas (Husband, 2008); Leadbeater & Staton, 2014); Quinn & Bailey, 2011). One major challenge was that the term "community setting" was not consistently included in the key terms or keywords of abstracts or titles resulting in the exclusion of studies that would have been pertinent to the review (Quinn & Bailey, 2011); Seymour et al., 2002). Similarly, the concept of "experiences" proved too broad and variably defined across databases, contributing to a lack of precision in retrieved studies. These search terms were used for title and abstracts.

These challenges reflect broader difficulties in systematically searching the palliative care literature, which is still a relatively young and evolving field with inconsistent terminology and indexing practices (Rietjens et al., 2019).

Consequently, the search strategy was refined by reducing the number of concepts to two: *"clinical nurse specialist"'* and *"palliative care"*. This decision allowed for a broader and more inclusive search, avoiding overly restrictive combinations that had previously excluded relevant studies. Importantly, this streamlined approach was more effective in capturing a range of literature, which could later be screened and analysed in relation to the study's specific focus on community-based practice and professional experiences.

Boolean search techniques regarding these two remaining concepts used 'OR' to combine terms within the concept followed by 'AND' to combine the concepts. For databases that use controlled vocabulary, these concepts were applied to the search. An asterisk was used to broaden a search and find words that start with the same letters, such as 'hospice' or 'hospices,' which would become hospice* A search was carried out to ensure that known key papers were identified and included. A research librarian assisted with search terms and strategy at the start of the review. The search terms used are listed in Table 4.3, below.

Table 4.3: Database search terms

Concepts	Web of Science	CINAHL	APA PsychInfo	Pub Med
Concept One **Clinical nurse specialist**	"Clinical nurse specialists" OR "community health nurses" OR "advanced practice registered nursing" OR "palliative care nurses" OR "palliative care nursing"	"clinical nurse specialists" OR "community health nurses" OR "advanced practice registered nursing" OR "palliative care nurses" OR "palliative care nursing"	DE "clinical nurse specialists" OR DE "community health nurses" OR DE "advanced practice registered nursing" OR DE "palliative care nurses OR "palliative care nursing"	"Clinician, nurse OR "clinicians, nurse" OR "nurse clinician" OR "nurse specialist, clinical" OR "clinical nurse specialists" OR "specialist, clinical nurse" OR "specialists, clinical nurse" OR "Clinical Nurse Specialist" OR "Nurse Specialists, Clinical"
Concept Two Palliative Care	"Terminal care" OR "hospice" OR "end of life" OR "terminally ill" OR "palliative care"	terminal care* OR bereave* OR hospice* OR "advanced cancer" OR "end of life" OR "terminally ill" OR palliative* OR palliative care OR palliative therapy+)	DE "palliative care" OR DE "terminally ill patients" OR DE "Hospice"	"Palliative care"[Mesh] OR "Hospice and palliative care nursing" [Mesh] OR "palliative medicine"[Mesh]

4.6.2 Data sources

Several electronic online databases for health with multidisciplinary content were searched. Databases searched included PubMed, Web of Science, CINAHL and PsycINFO which, collectively, covered specialised subject databases (Haddaway et al., 2015); Rietjens et al., 2019). The search topic guided the databases that were chosen. No date limitations were applied to the search.

4.6.3 Screening Methods and Selection Results

Search results were uploaded onto Rayyan, where duplicates were removed. All papers were independently screened by two reviewers, initially by title and abstract only, using the inclusion and exclusion criteria (See Table 4.2) and review question as a guide. Both reviewers were blinded to the decisions of the other. This external reviewer was selected based on their expertise in specialist palliative care. After screening of titles and abstracts, the full text of the remaining papers was screened for inclusion. A selection of papers was reviewed by research supervisors in instances where the appropriateness for inclusion or exclusion was uncertain. The reporting of this systematic review was guided by the standards of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA, 2020).

The decision to use the PRISMA framework instead of ENTREQ (Enhancing Transparency in Reporting the Synthesis of Qualitative Research) was driven by the focus and nature of the systematic review itself. While ENTREQ is specifically designed for the transparent reporting of qualitative synthesis, PRISMA offered a more suitable structure for this review, as it focuses on clarity, reproducibility, and methodological rigor for all types of studies, including both qualitative and quantitative research. PRISMA is widely recognised for its comprehensive and structured approach to reporting systematic reviews and meta-analyses of quantitative studies, and it provides clear guidance on the systematic process of literature search, selection, and data extraction. Given that the review included both qualitative and mixed-methods studies, PRISMA's flexibility allowed it to accommodate the inclusion of various study designs, providing a more appropriate framework for reviewing the broader literature. The included articles were uploaded onto Clarivate Endnote.

4.7 Assessment of quality

Having identified the literature to be included, the research quality of the contributing studies was evaluated through a process of critical appraisal which involved carefully and systematically assessing the quality of the studies (Aveyard et al., 2016). The

appraisal aimed to determine the credibility, relevance and methodological rigor of studies (Tong et al., 2007) It was based on the content of papers, their likely relevance, and their theoretical contribution for critical interpretive synthesis. Studies deemed to be fatally flawed, for example, those lacking transparency in data collection or analysis, absence of ethical considerations, presenting incoherent findings, or failings to adequately address research questions were excluded for consideration (Depraetere et al., 2021). These issues are considered so critical that the study cannot be meaningfully included in a synthesis or systematic review (Depraetere et al., 2021) .

The appraisal was guided by predetermined criteria. In critical interpretive synthesis, five questions proposed by (Dixon-Woods, Cavers, et al., 2006) are commonly used to assess study quality. These focus on the study's aims, design, research process, amount of data and the method of analysis. The questions are as follows:

1. Are the aims and objectives of the research clearly stated?
2. Is the research design specified and appropriate for the aims and objectives of the study?
3. Do the researchers provide a clear account of the process by which their findings were produced?
4. Do the researchers display enough data to support their interpretations and conclusions?
5. Is the method of analysis appropriate and adequately explained?

(Dixon-Woods, Cavers, et al., 2006)

4.8 Data extraction

Details extracted included author(s), publication year, characteristics of study participants, methods of data collection and analysis, relevant categories or themes, and key findings relevant to this review (Dixon-Woods, Cavers, et al., 2006).

4.9 Data analysis

Each paper was individually appraised using established quality criteria as outlined in section 4.7, and its content was then compared with other included studies to identify patterns, theoretical insights, and variations in findings relevant to the synthesis. Synthesised interpretation emerged through extensive reading, reflexivity and dialogue with an external second reviewer and study supervisors. The data was consolidated into subthemes, themes, sub-concepts and synthesised concepts. Concepts and themes used by authors in the relevant studies were identified and translated to produce a summary of the content and context (Flemming, 2010). Each included paper was uploaded onto NVivo, and the data were coded line by line into nodes, concepts and themes. The initial coding of the fifteen articles produced 77 codes. They are described as actions within each line of the experiences of the clinical nurse specialists as outlined in the articles. Focused coding is the next level of analysis within constructivist grounded theory. Therefore, initial codes and fieldnotes were analysed using NVIVO. The analytical portion of the critical interpretive synthesis uses the constant comparative method drawn from grounded theory, whereby data points are analysed and compared with those previously analysed so that the sets of identified concepts shift as the study proceeds (Evans et al., 2023). This enabled a large set of codes and concepts to be refined into a set of two core categories.

4.10 Systematic review results

4.10.1 Overview of included studies

The total number of studies initially retrieved from the literature search was 1,043. Following an evaluation for relevance and suitability for inclusion the number of studies remaining for full-text assessment was 80. Thereafter, a more detailed analysis resulted in a final number of studies meeting all inclusion criteria of 15 for data extraction and analysis. The flow diagram in Figure 4.1 showing the number of papers identified, screened, included, excluded, and the rationale for exclusion (Sarkis-Onofre et al., 2021).

Summaries of the studies included are represented in Table 4.4. Four studies included perspectives from various members of the multidisciplinary specialist palliative care team, including nursing managers and doctors. Data about clinical nurse specialists was examined separately. Studies were conducted in the Republic of Ireland (3), United Kingdom (10), USA (1), and Canada (1).

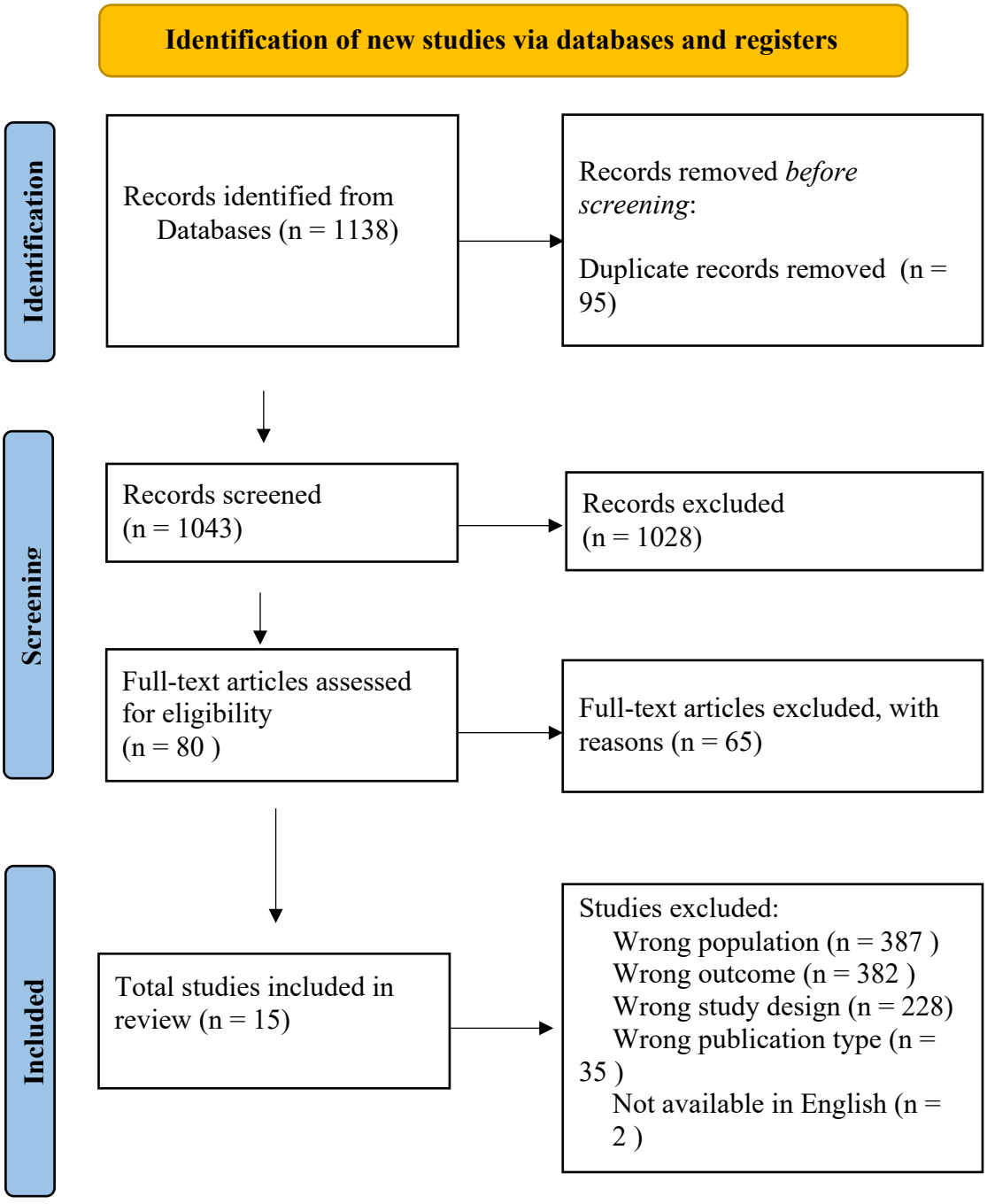


Figure 4.1 : PRISMA Flow Diagram

Table 4.4: Table of Included Studies

Author, Year & Country	Research Question or Aim	Research Design	Population and Setting	Data Collection	Study Findings	Summary of Data Relevant to Review Question
(Haskamp & Whitehead, 2024) USA	Reviewing the role of the clinical nurse specialist in palliative care providing care for a mother whose unborn baby is incompatible with life.	Case report outlining the importance of the clinical nurse specialist role	Involving a mother referred at 30 weeks' gestation and community palliative care clinical nurse specialists (n=1)	Narrative story of the palliative care clinical nurse specialist and review of the clinical notes	The palliative care clinical nurse specialist can support parents on their journey and decisions where a baby is incompatible with life.	The clinical nurse specialist role faces many challenges including the need to develop more consistent regulations from state to state in USA. The CNS role should be promoted within the nursing profession and professional organisations.
(Hough et al., 2024) Republic of Ireland	To evaluate the effectiveness of a clinical nurse specialist triage role in specialist palliative care	Mixed methods study involving Collation of referral log data and focus groups	Community palliative care clinical nurse specialists (n=23) Community palliative care	Two focus groups and quantitative data collected from iCare IT system and from daily	Five main themes emerged titled role definition, service benefits, perceived challenges,	The triage clinical nurse specialist role was pivotal as an initial point of referral contact. Increased compliance with

			healthcare professional managers (n=12) Community palliative care consultants (n=4) (nurses data can be independently identified)	written referral logs	necessary attributes and role development	national access standards occurred resulting in improvements in case and case-load management, information gathering, documentation, data collection and analysis.
(Currie et al., 2023) Republic of Ireland	Explored the perspectives of specialists palliative care teams in Ireland, in relations to personal learning needs and educations regarding dementia care	Mixed methods study involving a survey (quantitative and qualitative) and a focus group	Community palliative care clinical nurse specialists (n=44) Doctors (n=20) Health and social care professionals (n= 12), (nurses data can be	Online survey using qualitative data questions	Several dementia care challenges and learning needs are identified which should inform the design and delivery of tailored education programmes for specialist palliative care staff	Lack of knowledge, skills and difficulty assessing symptoms is a barrier to delivering effective palliative care for people with dementia. Palliative care clinical nurse specialists highlighted a gap

			independently identified)			in their learning needs regarding the non-pharmacological management of dementia symptoms.
(Mann et al., 2022) United Kingdom	To understand the experiences of the clinical nurse specialist team following implementation of new working practices during the pandemic	Phenomenology	Community palliative care clinical nurse specialists (n=11)	Semi-structured interviews	The use of IT including video consultations were embraced and positively adapted into working practices. The positive outcome of enhanced inter-professional working between the clinical nurse specialist and district nursing teams allowed the model to move away	Having efficient IT resources can enable clinical nurse specialists to improve collaboration and co-ordination of patient care. This enhances support for the team and helps to sustain resilience and wellbeing

					from working in 'silos'.	
(McCaughan et al., 2018) United Kingdom	To capture data that enhances understanding of factors that promote or prevent the integration of palliative care and haematology services	Incorporating interviews and content analysed using the framework method	Community palliative care clinical nurse specialists (n=14) Doctors (n=6) (nurses data can be independently identified)	Semi structured interviews	Numerous factors were found which influenced the likelihood of referral, related to organisation and delivery of specialist palliative care services. Others related to the pathway of haematological cancers	A range of barriers such as; lack of role clarity, late end of life discussions or organisational issues and facilitators such as; interdisciplinary working patterns, access to patient information or were identified which influence the referral pathway with haematological malignancies to specialist palliative care services.
(Howell et al., 2014)	To describe community palliative care	Ethnography involving observed and audio-	Community palliative care clinical nurse	Observed and audio-recorded 38	Community palliative care clinical nurse	The clinical nurse specialist role involves an

United Kingdom	clinical nurse specialists activities during interactions with patients	recorded interactions with patients	specialists (n=4)	interactions with 34 patients	specialists provide multifaceted care, requiring a wide range of knowledge to enable them to act as liaison points in a complex health service.	enormous breath of activities within a framework of assessment, planning, intervention and evaluation
(Whittaker et al., 2014) United Kingdom	To explore what learning, development and support palliative care clinical nurse specialists need to enable them to fulfil the components of their role	Qualitative enquiry with a descriptive exploratory approach	Community palliative care clinical nurse specialists (n=33)	One to one semi-structured interviews	Three theme were identifies regarding participants learning needs and they are influence of the organisational culture, influence of the individual and learning solutions identified	Participants confirmed the stressful nature of the role and identified that the organisational culture and individual themselves influence the learning and development support available to fulfil the four components of the role.

(Leadbeater & Staton, 2014) United Kingdom	To investigate how specialist palliative care teams approached the delivery of rural specialist palliative care	Qualitative approach to gain insight into experiences and purposive sampling to interview people relevant to the research	Community palliative care clinical nurse specialists (n=6) from 6 different rural teams	Semi structured one to one telephone interviews	The majority of patients in rural areas were not accessing hospice services and there was a greater reliance on care in the home	Many of the common problems such a staffing, professional development, workload and patient expectations may apply to both urban and rural working. However there are variations to rural teams mainly relating to geographical visiting area, accessibility to hospice beds and the need for appropriate technology resources
(Quinn & Bailey, 2011) Republic of Ireland	To obtain a picture of the current nursing service that would help to determine	Qualitative descriptive design	Community palliative care clinical nurse specialists (n=7)	Semi-structured focus group	Provision of community children's palliative care is complex.	The participants demonstrated their commitment to consult, co-ordinate,

	whether the needs of these patients are being met					negotiate and ultimately deliver the care required by children and families but within complex background issues such as access to the patient and the family.
(Arnaert & Wainwright, 2009) Canada	Explore the experiences, perspectives and reflections of five nurse specialists in palliative care home care	Explorative research design	Community palliative care clinical nurse specialists (n=5)	Face to face semi structured interviews	Nurse specialists play a key role in palliative home care as resources of expert knowledge.	The nurse specialists can work collaboratively to improve patients quality of care and their quality of life. As the population ages, the healthcare system will be faced with increasing requests for high-quality palliative home care.

(Husband & Kennedy, 2006) United Kingdom	To explore the role of the community palliative care clinical nurse specialist as an educator	Heidegger's inductive phenomenological approach	Community palliative care clinical nurse specialists (n=8)	Semi structured interviews	Three main themes emerged including conflict of expectations, credibility as a teacher and making the education role work. A team approach may address conflict of expectations between the role and reality of practice.	Clinical nurse specialists have a role in education, providing informal education rather than formal education. If they provide formal education they require the knowledge and skills to deliver it effectively.
(Booth et al., 2003) United Kingdom	To determine what do specialist practitioners in palliative and cancer care perceive their practice development needs to be. To determine what factors affect	Mixed methods approach	1500 identified Macmillan postholders, the majority of whom, n=1048 (91.6%) were nurses (nurses data can be	Postal survey and focus groups	Substantial practice development needs are identified particularly in relation to organisational support and guidance, educational support,	Nurses felt unable to engage in improving care unless initiatives were supported in practical ways by their organisations.

	practice development activity.		independently identified)		resources and access to evidence.	
(Seymour et al., 2002) United Kingdom	To assess the adaption of Macmillan nurses to new working practices and procedures	Evaluation study of UK Macmillan nursing (Qualitative aspect of the evaluation)	Community palliative care Macmillan nurses (n=44)	Semi structured interviews	There is a need to clarify the nature and the scope of the Macmillan nurse role in order to ensure their expertise is used effectively and efficiently.	Macmillan nurses lack resources with which to develop an educative and consultative role and yet substitute for inadequacies in skills and knowledge of other healthcare staff.
(Skilbeck et al., 2002) United Kingdom	To gain insight into the way which Macmillan nurses manage their clinical caseload	Comparative case study	Community palliative care Macmillan nurses (n=37)	Caseload data and semi structured interviews	The main reasons for referral to the Macmillan service are emotional care of the patient and physical symptoms. Overall Macmillan nurses spent an average of	Activities associated with direct patient care account for the majority of nurses time, with little time spent in any other individual aspect of the clinical nurse specialist role. The delivery of

					56.6% of their time on activities relating to direct patient care	care to older patients at end of life is a major part of Macmillan nurses' clinical role
(Newton & Waters, 2001) United Kingdom	To analyse stories of community specialist palliative care clinical nurse specialists' stress in the course of their work and to discover the meaning of stress for them	Survey design and audiotaped interviews	Community palliative care clinical nurse specialists (n=21)	A questionnaire and a semi structured interview	Three major themes emerged ; pressure of workload, relationships with health professionals and the impact of sadness in the client group.	Relationships with some general practitioners seems to cause most difficulties. An overwork stress spiral is produced that can help to offer solutions

Findings led to the development of six concepts (See Figure 6, below). Following further analysis, codes and themes were compared, leading to the development of two final categories. These final two categories are: *Perceptions of the clinical nurse specialist's role* and *Reality of the clinical nurse specialist's role*.

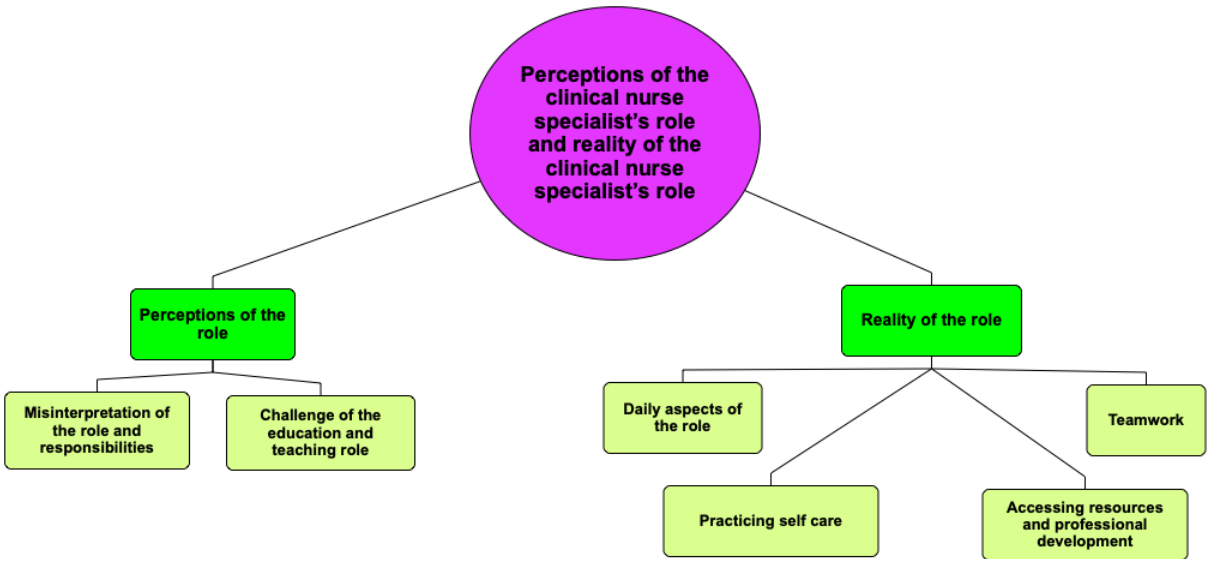


Figure 4.2: Concepts and categories developed

4.11 Core categories

4.11.1 Perceptions of the role

In this category the perceptions that clinical nurse specialists and other healthcare professionals have of their role are outlined. This category comprises two concepts: *Misinterpretation of the clinical nurse specialist's role* and *Challenges of the education and teaching role*.

Misinterpretation of the clinical nurse specialist's role

Some studies outlined a need for clarification of the scope of the clinical nurse specialist's role in palliative care, not only for the nurses themselves but also for patients, families, and other healthcare professionals (Leadbeater & Staton, 2014); Quinn & Bailey, 2011). Community specialist palliative care nursing has evolved in an uncoordinated manner, resulting in a variety of grades and expectations of the role (Leadbeater & Staton, 2014).

This evolution has been driven primarily by financial and organisational pressures, rather than a strategic workforce plan e.g. It is now common practice to have registered general nurses fulfilling the same role as a clinically nurse specialists (Cooper et al., 2019); Roche et al., 2005). This variation was mainly driven by financial constraints and has led to insufficient clarity about the role and responsibilities of the clinical nurse specialist.

Clinical nurse specialists highlighted paediatric specialist palliative as an area that requires greater role clarity. It is often misinterpreted by generalist healthcare professionals that clinical nurse specialists are experts in paediatric palliative care. While they demonstrated a strong commitment to co-ordinating care for children and their families, they acknowledged that their training, experience and comfort lie in adult palliative care (Quinn & Bailey, 2011). Their study identified a lack of knowledge, experience and confidence in children's nursing as key reasons for this discomfort. Although caring for children with life-limiting illnesses is seen as a required aspect of the role, many clinical nurse specialists expressed that this part of the job does not align with their skillset and is not a comfortable or confident area of practice. This lack of confidence within the role was a significant source of pressure for them. The referral of patients appeared to be further complicated by the well-meaning involvement of multiple agencies all actively contributing to the management of the child (Quinn & Bailey, 2011); clinical nurse specialists perceived that there were often too many people involved, with everyone trying to make a plan of care for the patient but not necessarily communicating with each other.

> Nurse*: "Oftentimes there are actually too many people involved. Far too many people all trying to make a plan"* (Quinn & Bailey, 2011)

Challenges of the education and teaching role.

There is an organisational expectation for clinical nurse specialists to provide formal and informal education in-house to their specialist palliative care colleagues and the wider generalist healthcare staff, balancing their clinical workload with informal education delivery to patients and families in their own homes or formally with other

healthcare professionals in a care or classroom-based setting (Arnaert & Wainwright, 2009); Booth et al., 2003); Leadbeater & Staton, 2014). Formal teaching commitments have ranged from communications skills training, symptom management and end-of-life sessions for a range of health professionals (Leadbeater & Staton, 2014). Although clinical nurse specialists recognise their responsibility to fulfil all aspects of their role, the clinical aspect is always given priority (Whittaker et al., 2014). The extent to which they fulfil other components depends both on their membership of various working groups, their levels of experience and time available.

> Nurse*: "I feel because we are so clinically focused at the minute that to try and fit in the other components of the role is a real challenge and as I chatted about doing that literature search, I ended up doing a lot of that in my own time" (Whittaker et al., 2014).*

Informal education is fundamental to the day-to-day role of the clinical nurse specialist and, although most of these specialists acknowledge their role in providing informal 'on the job' education, such informal education carried out in a GP practice or a patient's home is hard to evaluate (Husband & Kennedy, 2006). Their skilled knowledge is mainly gained from their day-to-day experiences and personal interactions with patients, families, their teams, and other healthcare providers (Arnaert & Wainwright, 2009). Informal education activities are so integral to their role that many clinical nurse specialists found it difficult to regard them as being separate from clinical care (Seymour et al., 2002). Some clinical nurse specialists considered educational components as interconnected, seeing the informal education of the patient, family, and multidisciplinary team as an essential part of the role (Whittaker et al., 2014). They viewed managing the clinical and education requirements of the workload as an unrealistic expectation and the informal education component as being easier to fulfil:

> Nurse*: "You cannot do all these roles properly. I think within teams all the roles are covered. However, I think individually as nurse specialists it is very difficult to encompass all these. Every day on the phone or during face-to-face visits we are providing informal education"* (Husband & Kennedy, 2006).

The literature indicates that clinical nurse specialists often experience conflict due to insufficient time to prepare for or engage in formal education. Ensuring adequate protected time could reduce the need for clinical nurse specialists to work beyond rostered hours or place unreasonable demands on themselves to complete educational presentations (Newton & Waters, 2001). On average, Macmillan nurses spent 10.9% of their time on formal or informal educational work of various kinds, including providing advice and guidance about medications and symptom control to patients, families, and to other healthcare professionals (Skilbeck et al., 2002). The authors noted that participants confirmed the stressful nature of the clinical nurse specialist's role and that the organisational culture and its individuals influence the learning and development support that is available to help them to fulfil the various components of their role (Whittaker et al., 2014).

> Nurse*: "You need to feel motivated so you need to get encouragement from management and feel you are doing a good job. If you enjoy it you want to learn more"* (Whittaker et al., 2014)

Clinical nurse specialists also identified personal characteristics such as fear, that hindered them to prioritise the delivery of education. Some of them were fearful of having to stand in front of other healthcare professionals to provide education (Whittaker et al., 2014). Although clinical nurse specialists are expected to contribute to the delivery of education, many receive no formal training to support them in this role (Husband & Kennedy, 2006). This study also found that lack of protected time for preparation decreased their motivation to become involved in formal education. Clinical nurse specialists raised questions about the appropriateness of their involvement in formal education. This is based on their knowledge that there are clinical staff who are trained as specialists in education and are perceived to be far more competent and expert in this area than staff who have not received specialist education training.

> Nurse*: "That was definitely daunting I have to say. The fact it was GPs and I had to keep telling myself that they don't know as much. I had to keep reminding myself about that"* (Husband & Kennedy, 2006)

Reality of the role

This category shows what occurs when clinical nurse specialists perform their role. This category comprises four concepts: *Daily aspects of the role, teamwork, practicing self-Care; and accessing resources and professional development*.

Daily aspects of the role

Throughout many studies, various aspects of clinical nurse specialists' daily role have been identified, including acting as a patient advocate, developing therapeutic relationships with families and patients, delivering bad news empathetically, providing emotional care, and carrying out clinical assessments (Currie et al., 2023); Howell et al., 2014); Leadbeater & Staton, 2014); Seymour et al., 2002); Skilbeck et al., 2002); Whittaker et al., 2014). They carried out these aspects of their role either face-to-face during visits or on the telephone. To manage caseloads, they would sometimes substitute telephone contact for a visit or might reduce the frequency of their visits (Newton & Waters, 2001). In a study by (Leadbeater & Staton, 2014), clinical nurse specialists from six rural teams found that the percentage of overall patient contact by telephone varied from 40% to 75%. This phone contact was with patients, families, primary care teams or a combination of these.

> Nurse*: "What I like most about this job, and I wouldn't work anywhere else in nursing, is the clinical work. I came into nursing to do clinical work, to work directly with people who were very ill. I'm not interested in administration, management or teaching"* (Seymour et al., 2002)

Clinical nurse specialists often work beyond their rostered hours, driven by heavy workloads, unpredictability, and the pressure to keep up with paperwork and digital records. A study by (Leadbeater & Staton, 2014) found this was a regular reality for nurses across six rural teams. Although time off in lieu is sometimes offered, taking it

can leave the team short, adding to the pressure. Despite the strain, many nurses described moments that made it feel worthwhile, like staying late with a patient and leaving only once they felt more at ease. These small but meaningful experiences offer emotional reward, even in the face of exhaustion.

Another important aspect of daily caseload management is the timely discharge of patients from the specialist palliative care service. Clinical nurse specialists viewed this aspect as challenging and noted that some staff are 'not very good at discharging people'. The clinical nurse specialists viewed closing cases as risky; services that close cases and then seek to re-open them may face criticism from other healthcare professionals or the general public that the service is non-essential or that management is ineffective (Hough et al., 2024) Timely patient discharge is a key yet emotionally and professionally challenging part of caseload management, with clinical nurse specialists expressing concern over the risks and perceptions tied to closing and reopening cases.

Another challenge is receiving appropriate referrals to the service that are too late as the patient is actively dying, particularly if the patient's preference was to die at home or if their symptoms were difficult to manage.

> Nurse*: "By the time of the referral, he was imminently dying…that is really, really difficult for us because you don't have time to build up a relationship, that trust… you often get involved in the very, very end stage. If we could get earlier referrals, build those relationships up so we can explain to patients and their families that we can support people at home, to put packages of care to support them, so that they build trust, so they know what contact numbers to ring it would be way better"* (McCaughan et al., 2018)

Clinical nurse specialists outlined many challenges when carrying out face-to-face visits. Teams covered large geographical areas where often 40% – 100% of patients were estimated to be living in rural areas (Leadbeater & Staton, 2014). The time required to travel such distances depends on the location of office bases and the vagaries of

weather (Skilbeck et al., 2002). While working as lone workers, clinical nurse specialists reported feelings of 'professional loneliness' and a heightened sense of responsibility (Whittaker et al., 2014): These challenges not only impacted their time and workload but also placed emotional and professional strain on their ability to deliver consistent, high-quality care.

Clinical nurse specialists saw triaging by a dedicated nurse co-ordinator as assisting caseload management due to its effective collection and communication of key information, resulting in advance planning for the first visit (Hough et al., 2024); Leadbeater & Staton, 2014). This ensures optimal use of the clinical nurse specialists' time in caseload management.

> Nurse*: "The categorisation of referrals helps manage our caseloads … who needs to be seen urgently. You are going into a situation with a holistic assessment already performed, and sometimes anticipatory medications and night nursing have been organised. Having worked pre-triage days, I would never go back"* (Hough et al., 2024).

Accessing resources and professional development

In the following studies, clinical nurse specialists identify the resources they require to be able to perform their role more effectively and efficiently. These resources vary from having access to designated palliative care beds where a community patient requires specialist admission to having administrative support that enables them to focus on their clinical duties rather than administrative paperwork (Leadbeater & Staton, 2014). Access to online patient records was a notable problem for many teams, resulting in working extra hours to keep up-to-date with records (Howell et al., 2014); Quinn & Bailey, 2011). Clinical nurse specialists viewed lack of access to patient information and over-reliance on the patient's providing details of his/her medical history as unsafe practice (Leadbeater & Staton, 2014). Accessibility, from remote access via laptops to only having access if they were in the office, varied across studies (Leadbeater & Staton, 2014); Mann et al., 2022); Newton & Waters, 2001). Clinical nurse specialists regarded access to online patient notes as time-saving and safer in delivering patient

care. While many broader healthcare systems have progressed significantly through the introduction of electronic health records and improved digital access to patient information, this advancement is still not been equally available to all professionals across all healthcare settings.

> Nurse: *"The main frustration of the job is the waste of time going back to base to input notes. You have to ensure you factor that travel time in at the end of the day when in reality you could have got another home visit done"* (Leadbeater & Staton, 2014)

An expectation among clinical nurse specialists is to fulfil their professional development (Arnaert & Wainwright, 2009); Booth et al., 2003); Leadbeater & Staton, 2014). If nurses are to be professionally accountable for the care they provide, they must keep up-to-date with the knowledge base of their profession (Arnaert & Wainwright, 2009). However, this can be challenging to achieve amid the clinical demands of the role. These pressures can leave clinical nurse specialists feeling frustrated, undervalued, and professionally compromised, expected to deliver expert, evidence-based care while lacking the time, resources, or support to stay current (Currie et al., 2023); Mann et al., 2022). This disconnect can create internal conflict, as they strive to uphold professional accountability yet feel they are falling behind in a rapidly evolving field.

Another challenge is sourcing funding to attend conferences or study days. Support from line managers is required in providing protected time and also in allowing time to put learning into practice in workplaces (Booth et al., 2003); Whittaker et al., 2014). Since many study days require attending a national event, a full day of travel and, often, an overnight stay are necessary, but they may be unable to secure funding to cover these expenses. Without protected time, adequate funding, and managerial support, maintaining professional development becomes a personal burden rather than a shared professional responsibility.

Clinical nurse specialists have identified many barriers that hinder educational opportunities for their professional development. These include lack of time and resources, workload pressure, organisational support, information technology and office facilities (Booth et al., 2003); Husband & Kennedy, 2006); Seymour et al., 2002). Macmillan nurses have highlighted the fact that lack of time, resources and organisational support affected the effectiveness of practitioners in fulfilling their specialist roles (Booth et al., 2003). In some instances, even when time and resources are allocated, it can be challenging to put the necessary learning into practice:

> Nurse*: "My employer will encourage and support anyone to undertake further education but I feel they don't allow you to build on the knowledge gained by putting it into practice. Therefore it becomes a paper exercise and is soon forgotten because there isn't the time to put learning into practice, e.g., change documentation or policies"* (Booth et al., 2003)

Practicing self-care

Clinical nurse specialists have identified that support is needed both within themselves and their service to sustain them in the role. Despite the challenges of the role, participants described how maintaining resilience was vital for them and how important it was for them to take care of themselves. They described how 'ensuring time taken to go for walks, enjoying hobbies and time away from work' helps to maintain their resilience (Mann et al., 2022). They reported self-awareness - including coping strategies developed with experience or individual personalities - as essential to their recognising and managing stress appropriately (Whittaker et al., 2014). They viewed support by management as essential to feeling valued, enabling them to develop to their full potential.

> Nurse*: "I don't feel that there is a lot of support, it's something that you need to self-manage and it can be difficult because it is busy and I don't feel that enough recognition is given for self-preservation in this job because it is very stressful; management doesn't see that"* (Whittaker et al., 2014).

Teamwork

Clinical nurse specialists viewed working effectively as a team as important, both within their specialist service and among generalist healthcare professionals. While working in emotionally charged situations daily can be overwhelming, it also can be very rewarding when a supportive team and appropriate expertise are in place (Arnaert & Wainwright, 2009). Clinical nurse specialists fulfil a central role in the leadership and coordination of patient care and are actively involved in case management through collaboration with other multidisciplinary team members (Howell et al., 2014). However, accessibility to primary care teams often proved challenging, which was frustrating for clinical nurse specialists particularly as they were the ones initiating the referral. This lack of communication undermined their ability to function as part of an effective, integrated team. Rather than feeling supported by a shared care approach, clinical nurse specialists were often left working in isolation, managing complex cases without the timely input or engagement of other professionals.

> Nurse*: "The GP kept me waiting an hour and he had no patients. He had paperwork he needed to do……I felt he wanted me to give up and go…..I would put that as more stressful than all the dealings I have had with patients"* (Newton & Waters, 2001)

Staff shortages placed huge demands on the clinical nurse specialist team, who felt pressurised to fulfil the role fully. Shortages occur when colleagues resign or are on sick leave, and it is often impossible to recruit additional resources permanently or short-term due to a lack of funds (Newton & Waters, 2001). Adequate staffing levels are, therefore, required to sustain clinical nurse specialists in their role and to help them to avoid stress and burnout.

Clinical nurse specialists considered support from colleagues within their team as invaluable, especially as a debrief at the start and end of the day. Working relationships and stability in teams had a significant impact on how clinical nurse specialists felt and should be considered by management when trying to meet the needs of individual staff while balancing the needs of the service (Newton & Waters, 2001); Whittaker et al.,

2014). (Newton & Waters, 2001) add that this influenced how nurses interacted with their colleagues in the primary healthcare team. Those who had a consistently supportive relationship with their doctor colleagues identified enhanced confidence in their knowledge and skills and better working relationships with GPs.

4.12 Discussion

This systematic review highlights the complexity and variability that clinical nurse specialists experience within their role on the specialist palliative care community team. It draws attention to the ongoing tension between clinical nurse specialists of their perceived and actual role expectations, with misinterpretations arising both within and outside the specialty. In answering the review question about how the everyday reality experienced by clinical nurse specialists compares with their prior conceptions of the role, the review highlights a clear disconnect.

Clinical nurse specialists appear deeply committed and passionate about delivering high-quality patient-centred care even within the challenges they face. They are frequently burdened by unrealistic role expectations, administrative overload, and inconsistent access to professional development and organisational support. The review shows that while clinical nurse specialists provide essential informal education and expertise in symptom management and end-of-life care, formal teaching duties and interdisciplinary coordination often stretch their capacity which leads to frustration. The role's emotional demands are compounded by geographic isolation in rural areas and the unpredictable nature of palliative care work, highlighting the importance of team cohesion, management support, and opportunities for self-care (Johnston et al., 2022); Walshe et al., 2008).

Clinical nurse specialists considered that non-clinical aspects of their role cannot be developed without protected time being made available and a reduction in clinical workload that might be facilitated through regular planned rotation of staff into working groups, e.g., audit committees (Whittaker et al., 2014). They deemed up-to-date, evidence-based specialist knowledge and skills as essential to working collaboratively,

confidently and competently. They considered that fulfilling the research component of the clinical nurse specialist role was more challenging than fulfilling the clinical workload, however, some place minimal value or interest in engaging with research add references (Furlong & Smith, 2005; Gerrish et al., 2011).

When contextualised within the wider literature, these findings are consistent with longstanding evidence that highlights persistent challenges associated with advanced and specialist nursing roles. Issues such as role ambiguity, lack of role clarity, and tension between clinical and non-clinical responsibilities have been widely reported across different healthcare settings and specialities (Bryant-Lukosius et al., 2017); Jones, 2015). Similarly, the difficulty in balancing direct patient care with leadership, education, and research responsibilities reflects broader discussions within the literature on role overload and competing priorities in clinical practice (Delamaire & Lafortune, 2015); Lowe et al., 2012)

Furthermore, the limited availability of protected time for professional development and research engagement is a recurring theme, often linked to organisational constraints and service demands (Gerrish et al., 2017). The emotional burden associated with palliative care work, particularly in community and rural settings, is also well documented, with studies emphasising the importance of peer support, reflective practice, and organisational recognition of emotional labour (Johnston et al., 2022); Walshe et al., 2008)

Overall, this review shows that the challenges identified such as role ambiguity, insufficient protected time, and the emotional burden of balancing clinical and educational responsibilities are not new, but rather reflect enduring issues highlighted in earlier studies. This suggests that despite increased recognition of the clinical nurse specialist role, there remains a gap between policy aspirations and the realities of practice, with many of these systemic and organisational challenges continuing to affect clinical nurse specialists today (Delamaire & Lafortune, 2015); Kilpatrick et al., 2016).

4.12.1 Strengths of the systematic review

This review provides a rich understanding of both the perceived and lived experiences of clinical nurse specialists in palliative care. The appraisal was guided by a critical interpretive synthesis approach. Across the included papers, there was variability in methodology, context, and focus. Some studies employed in-depth qualitative interviews while others included an ethnography approach examining perceived role experiences and workload. Geographic variation also contributed to differing health system influences, with studies conducted in the USA, Republic of Ireland, UK and Canada reflecting differencing operational and policy contexts. The review incorporates multiple studies across varying time periods strengthening the credibility of identified themes and also illustrates the continued challenges. The use of participant voices adds depth to the analysis, capturing the emotional and practical realities of the role.

4.12.2 Limitations of the systematic review

Most included studies are UK-based, which may limit generalisability to other international models of clinical nurse specialist practice. Some of the included studies are over two decades old, during which time the clinical nurse specialist role systems and practice have evolved, potentially limiting relevance to current practice. The review focuses primarily on nurse and healthcare professional viewpoints and did not focus on how patients and families perceive or experience the clinical nurse specialist role. This would be a recommendation for future research.

Many studies suffered from methodological variability, such as small sample sizes, and the use of convenience sampling, which limited generalizability.
Additionally, contextual differences such as geographic and operational variability alongside the lack of role clarity across studies made it difficult to compare findings. The emotional and psychological impact on clinical nurse specialists was often underexplored, and longitudinal data was scarce, limiting insights into the role's evolvement over time. These limitations suggest the need for more rigorous,

longitudinal studies to better understand the complexities of the clinical nurse specialist role in palliative care.

4.13 Conclusion

Clinical nurse specialists' perceptions and misunderstandings about their role and the subsequent reality of fulfilling it were explored in this systematic review. The literature presented several implications for specialist palliative care services. To meet the demands of the specialist palliative care population, clinical nurse specialists discussed new ways of practice that can enable better access to services for patients, thereby ensuring more efficient delivery of services such as ensuring adequate better access to services for patients, such as having adequate resources to fulfil the role (Hough et al., 2024). Clarity is required regarding the clinical nurse specialist's role and responsibilities to ensure that healthcare professionals who refer patients and families have a clear understanding of the service they will provide. The findings from the empirical research and systematic review will now be compared and contrasted in chapter 6.

5 Presentation of a grounded theory of the interdependence of personal, organisational and external factors on the clinical nurse specialist's experiences of fulfilling their role

5.1 Introduction

In this study the aim was to gain an understanding of the experiences of clinical nurse specialists in fulfilling their roles. The main findings and analysis of this study were presented in chapter 3. The themes were clinical nurse specialist's perception and reality of practice, the art of self-care, and professional development within the clinical nurse specialist role. The main findings from the systematic review were presented in chapter 4. The review question chosen was derived from the central theme from the participants' interviews, titled clinical nurse specialists' perception and reality of practice. The themes that emerged from the systematic review chapter were perceptions of the role and reality of the clinical nurse specialist role.

In Chapter 5, the final stage of analysis is presented, leading to the construction of a theory outlining the interdependence of personal, organisational and external factors on clinical nurse specialist's experiences. These factors must be aligned and mutually supportive to ensure the clinical nurse specialist can effectively contribute to patient care. Recognising and understanding the interdependence of these factors is essential for the clinical nurse specialist's functioning within their organisation and the wider specialist and generalist team members. In the following chapter I explore the relationship between these factors towards the creation of a substantive theory of their interdependence. Constructivist grounded theory methods were used to develop this substantive theory, which will provide a deeper understanding of the experiences of clinical nurse specialists.

5.2 Development of a Substantive Theory

After completing the systematic review, I compared the findings from the participants' interviews with those from the review to identify similarities and differences. Many commonalities occurred, reflecting the clinical nurse specialists' perceptions and realities of fulfilling their roles. Commonalities included misinterpretations of their role, the art of self-care, the importance of teamwork, access to resources, and professional development. The systematic review focused on the clinical nurse specialists' perception and reality of fulfilling their role. It also highlighted an additional concept that described the challenges clinical nurse specialists experience when fulfilling their education and teaching roles core competency.

The findings from the interviews with clinical nurse specialists and the data from the systematic review were incorporated into a grounded theory titled 'Interdependence of personal, organisational and external factors on clinical nurse specialist's experiences when fulfilling their role'. The findings suggest that there is a complex interdependence between three key factors: which affect the expectations and experiences of clinical nurse specialists when fulfilling their role. Their interdependence demonstrates that these three factors are not isolated but rather interact in shaping the role and experience for the clinical nurse specialist. Each factor can either support or hinder the clinical nurse specialist's experience of fulfilling their role and delivering effective care. Therefore, understanding the interconnectedness of these factors is crucial for improving job satisfaction, role clarity and overall effectiveness of clinical nurse specialists.

5.3 Personal, organisational and external factors to fulfil the clinical nurse specialist role

The summary of findings from the empirical research and the systematic review highlights that the role of the clinical nurse specialist is complex and multifaceted. The findings indicate that clinical nurse specialists navigate this balance of personal

dedication, organisational challenges, and broader system-level pressures while fulfilling their responsibilities. Clinical nurse specialists embark on this role with certain expectations and perceptions about what the job will entail. Both positive and negative experiences shape these expectations. Being a clinical nurse specialist necessitates the integration of personal, organisational, and external factors.

Empirical and systematic review findings showed the interdependence of personal, organisational, and external factors on clinical nurse specialists experiences of their roles. While these factors constantly interact with each other they equally need to be aligned and require a supportive heath care environment and health care system. The factors are not independent, they do not work in silo. There is constant movement of the clinical nurse specialists' experiences depending on whether the personal, organisational, and external factors are supportive or hindering to their role.

An example of this interdependency can be seen in the clinical nurse specialist's own personal education and training development. While the individual must demonstrate personal motivation and commitment to engage in continuous professional development, this is heavily influenced by organisational support, such as access to study leave, protected time, and encouragement from management. In turn, external factors, including the availability of funding, approval processes for travel, and access to relevant external courses or conferences, further shape these opportunities. Therefore, the clinical nurse specialist's ability to advance their knowledge and skills is not solely dependent on personal drive, but on the alignment and support of organisational structures and wider system-level provisions.

The development of the theory was informed by a continuous interplay between the empirical research and systematic review, where recurring patterns, shared concepts, and points of divergence were identified and critically examined. This iterative process enabled the refinement of key constructs and the clarification of relationships between personal, organisational, and external factors. Key themes identified across both data sources relating to personal, organisational, and external factors were compared, contrasted, and refined to identify areas of convergence and divergence. This process

enabled the identification of core constructs and the relationships between them. An example of this is the process of discharging patients from the specialist palliative care service.

The empirical findings provided rich, context-specific insights into the lived experiences of clinical nurse specialists, while the systematic review offered a broader evidence base, allowing these experiences to be situated within the wider literature. Through ongoing analysis, concepts that were consistently evident across both sources were prioritised and developed into central components of the emerging theory. Where discrepancies arose, these were critically examined, contributing to a more nuanced and comprehensive understanding of the role. Personal factors of the clinical nurse specialist include having the skills and confidence to be able to visit a patients home as a lone worker and discharge a patient from the service. The organisation has a responsibility to monitor caseloads and ensuring that referrals accepted to the service are for those patients who require specialist palliative care advice and support. External to the clinical nurse specialist and the organisation are external factors such as GPs and hospital consultants who are required to refer appropriately and timely to the service. These factors are all interconnected and dependant on each other. The final theory represents a synthesis of empirical evidence and existing knowledge, offering an explanatory framework that captures not only what influences the role, but how and why these influences operate in practice. Each of these factors will now be elaborated upon in detail. Figure 5.1 outlines the personal, organisational an external factors to fulfil the clinical nurse specialist role.

Undertaking this PhD and engaging deeply with both the empirical findings and the systematic review has significantly shaped my own perspective and thinking. Initially, I viewed the role of the clinical nurse specialist as largely centred on individual competence and professional responsibility. However, as the research progressed, my understanding evolved to recognise the interdependent nature of the personal, organisational, and external factors that influence practice. The findings challenged me to move beyond a simplistic, individual-focused lens and to appreciate the broader structural and systemic influences that enable or constrain the role. This process has

strengthened my critical thinking and reinforced the importance of considering context, collaboration, and system-level alignment in both research and practice. Ultimately, the journey of this PhD has deepened my appreciation of the complexity of the clinical nurse specialist role and has informed a more holistic and nuanced approach to understanding and supporting it.

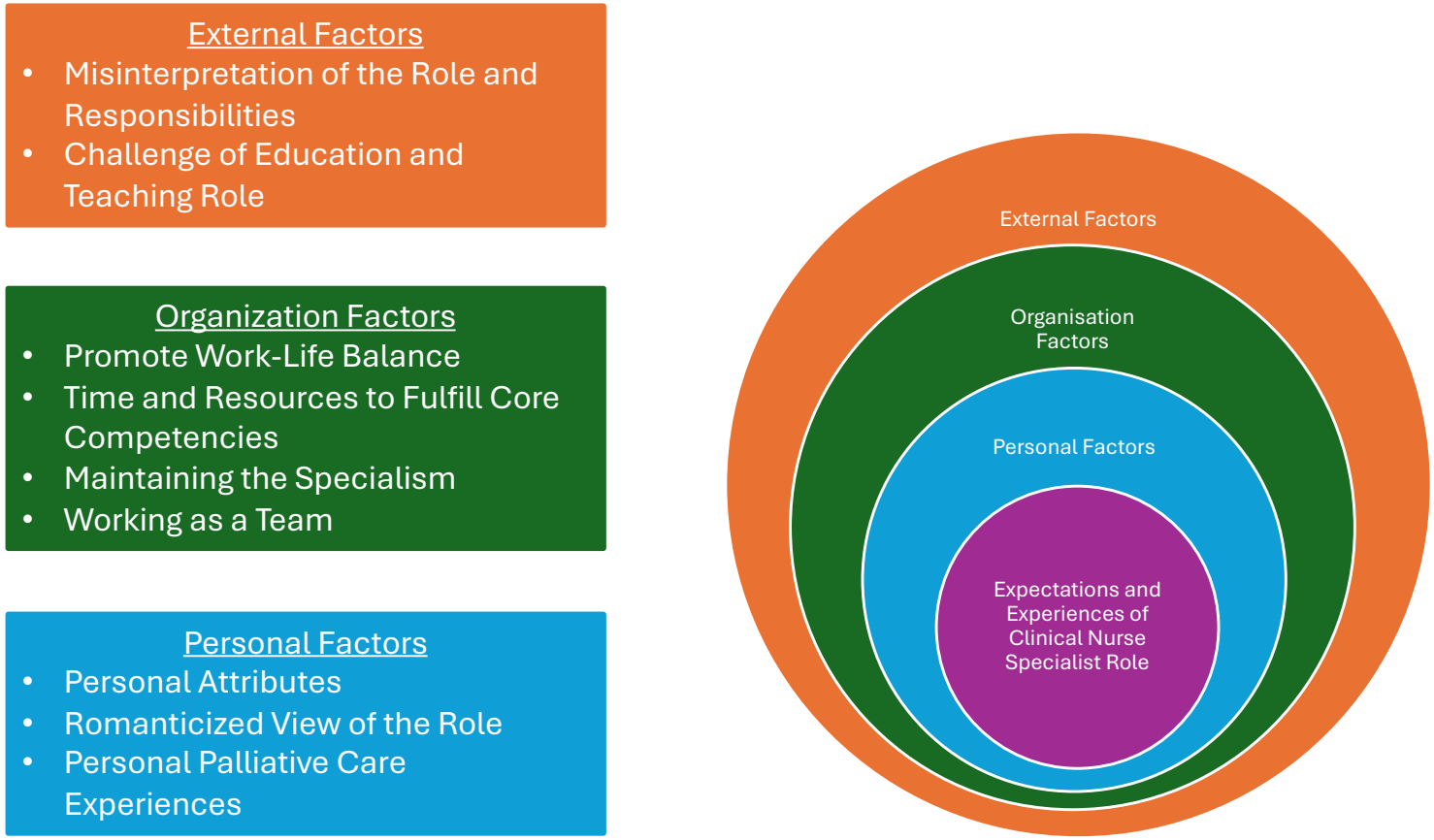


Figure 5.1: Interdependence of personal, organisational and external factors on the clinical nurse specialist's experiences when fulfilling their role

5.3.1 Personal factors

Personal factors are the skills and attributes the individual clinical nurse specialist requires to fulfil their role. These traits influence a clinical nurse specialist's experience when performing their job. Personal factors can shape how clinical nurse specialists approach their responsibilities and how they experience their work. From the empirical research and systematic review these personal factors are categorised as

- Personal attributes,
- Romanticised view of the role, and
- Personal palliative care experiences.

Personal Attributes

Clinical nurse specialists often find that their personal attributes can be both a strength and a struggle in the demanding experiences of their daily work. These qualities shape not only how they plan their workload but how they survive the emotional and physical intensity of the role. Every day can feel like firefighting: urgent decisions, competing priorities, and unexpected crises pull them in different directions, often without warning. Exhaustion is a familiar companion, yet they press on driven by commitment, compassion, and the immediate needs of their patients. Whether they're walking into a home where a patient may be in the final stages of life or answering a call from a colleague in crisis, they are constantly required to make fast, complex decisions:

Determining whether a patient requires hospital admission or can be safely managed at home, and assessing the capacity of families to provide ongoing or end-of-life care, are just some of the critical judgments made under pressure. These moments demand clarity, confidence, and emotional resilience, often in isolation and without the luxury of time. Clinical nurse specialists must lean heavily on advanced communication, problem-solving, leadership, and time-management skills, but these are more than just tools they are lifelines. Their day requires constant multitasking under pressure, prioritising workload and navigating emotionally charged conversations with empathy and clarity. Writing notes while supporting a grieving spouse, or listening attentively to a

colleague while mentally preparing for the next home visit are the realities they experience.

Self-awareness is critical; they must understand their own emotional states and limits to remain grounded. The isolation of lone working means they often rely solely on their own critical thinking in real time, often in unpredictable or even unsafe environments. They are problem solvers and innovators, sometimes crafting makeshift solutions on the spot when faced with limited resources or unique patient needs. Confidence in their clinical decisions is essential, not just to ensure patient safety, but to inspire trust in patients and families. Their presence in the home is more than professional; it becomes a source of reassurance, particularly when guiding families through complex symptom management or end-of-life care.

Time management isn't just about being efficient, it's about survival. It's about ensuring no one is left behind, no symptom unmanaged, no colleague unsupported. Their ability to plan and adapt rapidly can mean the difference between a crisis averted or one unfolding. Empirical research and systematic reviews highlight how these personal attributes can significantly influence a clinical nurse specialist's job performance, career progression, and collaboration with other healthcare professionals.

Prior specialist palliative care experience is a requirement to work as a clinical nurse specialist within the community team in the Republic of Ireland (Department of Health, 2024). This is preferably achieved by working in a specialist palliative care unit which is challenging given the small volume of in patient units in comparison to other countries. The required levels of expertise are gained through working as a clinical nurse specialist over several years. Participants developed more confidence and expertise the longer they worked in the role. Participants viewed this experience as more important than having the academic qualifications and theoretical knowledge to fulfil the role.

Romanticised view of the role

As illustrated in the participant interviews of this study, prior to becoming clinical nurse specialists, they romanticised about their current role when they were in a generalist setting. They viewed working within specialist palliative care as an area where all patients

died symptomatically controlled and that they would have time to be with them at the end of life.

Once in the role, the transition from the idealised vision of the experiences of being a clinical nurse specialist to the lived reality was often complex and emotionally charged. For some, the role met their expectations and reaffirmed their passion, but for others, it exposed the emotional weight of the work and the limitations of the system. While many patients did die peacefully, an outcome that brought a deep sense of fulfilment and purpose, there were also moments that left clinical nurse specialists feeling helpless, frustrated, and emotionally drained. The inability to provide optimal care, whether due to inadequate resources, lack of support, or the challenges of managing complex symptoms at home, created a profound sense of moral distress. These were the moments that lingered when they felt they were falling short, despite giving everything they had.

Being seen as role models by generalist nurses often brought a sense of pride, but also added pressure to consistently perform and embody expertise, even during times of personal or professional struggle. For many working within specialist palliative care, these experiences—both rewarding and painful—deeply influenced how they navigated their career paths. The emotional highs and lows became part of the fabric of their professional identity, shaping their resilience, their values, and their ongoing commitment to compassionate care.

Personal palliative care experiences

Clinical nurse specialists often encounter a range of emotions when caring for their own family or friends at some point in their nursing careers. They perceive these emotions as either positive or negative. Their personal experiences involve interactions with palliative and other healthcare teams. These interactions may have been positive, leading them to reflect their experiences when meeting patients and families in their own careers. However, these interactions could have been negative, encouraging them to actively ensure that patients and families do not experience inadequate palliative care in their own roles.

A clinical nurse specialist who develops their leadership skills through experience can advocate for better organisational support, while an organisation that values professional development can enhance that specialist's expertise. Equally, clinical nurse specialists have an influence regarding external factors as they are the healthcare professionals within the specialist palliative care team who have the most contact with primary care teams outside their own organisation. Hence, these factors are interdependent. We will now discuss organisational factors.

5.3.2 Organisational factors

Organisational factors encompass the policies, culture, resources and support structures within the workplace that influences clinical nurse specialists' performance, job satisfaction, and role fulfilment. They influence how clinical nurse specialists perform their roles and impact the fulfilment of the required job competencies. A clinical nurse specialist with strong leadership skills can advocate for better organisational support, while an organisation that values professional development can enhance the clinical nurse specialist's expertise. Some may be influenced by the clinical nurse specialist, e.g. working as a team; however, most are out of their control, such as having adequate staffing resources. From the empirical work and systematic review these organisational factors are categorised as

- Promoting work-life balance,
- Time and resources to fulfil core competencies,
- Maintaining specialism, and
- Working as a team

Evidence from both the systematic review and empirical research suggest that supporting staff creates a positive work environment, improves productivity, and fosters loyalty. This can help to promote a healthy work-life balance. A supportive environment for staff helps with retention, boosts morale, and makes the workplace more enjoyable. However, it can be difficult to balance developing a connection with patients while

showing professionalism and maintaining boundaries. Therefore, workplaces should encourage and provide self-care strategies and promote time management to foster a healthy work-life balance culture. This supports the clinical nurse specialist to balance developing a connection with patients while showing professionalism and maintaining boundaries.

To fulfil the clinical nurse specialist's core competencies, time and resources from the organisation were considered essential requirements. Time was needed to provide clinical care, complete audits, prepare content for education sessions. As early as 2001 research shows that having adequate protected time would enable clinical nurse specialists to avoid making unreasonable demands on themselves and working outside of rostered hours to complete educational presentations (Newton and Waters, 2001). This protected time is required by management as a culture. Required resources included having full staffing complement to ensure that clinical workloads are completed, while also facilitating other clinical nurse specialists to focus on professional development.

In recent years a specialist palliative care approach has been recommended early in a patient's illness and has a supportive and active care focus to optimise quality of life, enabling the patient to live as well as possible for as long as possible (WHO, 2020). Even within specialist palliative care, as previously outlined, there can be misunderstandings around the criteria for referral. So, these grey areas and misconceptions about specialist palliative care can lead to confusion among healthcare professionals and misinformation among the general public about when to make a referral.

Maintaining specialisation and identifying appropriate patients for discharge invariably involves the multidisciplinary team's clinical judgement and experience with the patient. Knowing the patient, recognising the presence or absence of specialist palliative care needs, and reviewing trends in patient outcomes over time all inform the multidisciplinary discussions that can lead to successful discharges. This requires ongoing monitoring of caseloads from an organisational level and confidence within the clinical nurse specialist's personal attributes to discharge a patient following review.

Working as a team is essential in professional workplaces as it promotes collaboration and enables the group's collective skills to be utilised. Teamwork is required within a specialist palliative care service with the multidisciplinary team and healthcare professionals outside the service. Teamwork in all areas was viewed as requiring effort to ensure that communication is open, roles are understood, and any conflicts are managed promptly.

An organisation that aligns its policies with national healthcare standards can better support clinical nurse specialists in fulfilling their roles. A clinical nurse specialist who is aware of external healthcare trends can help the organisation adapt to changes in the healthcare landscape.

5.3.3 External factors

External factors are broader influences outside the organisation and individual clinical nurse specialist that affect general operations and decision-making such as healthcare policies, regulatory frameworks, societal attitudes and external professional networks. These factors influence how clinical nurse specialists perform their role and impact their experience when fulfilling it. They also operationally impact an organisation’s internal structure, culture and practices. From the empirical research and systematic review these are categorised as

- Misinterpretation of the role and responsibilities, and
- Challenge of the education and teaching role

Clinical nurse specialists’ personal and organisational influences equally effect external factors. An organisation that aligns its policies with national healthcare standards can better support a clinical nurse specialist in fulfilling their role, while a clinical nurse specialist aware of external healthcare trends can help the organisation adapt to changes in the healthcare landscape.

While this study was based on clinical nurse specialists working in a community setting, its findings may be applicable to all settings as the core competencies are the same regardless of the specialty or the area they work within.

Misinterpretation of the role and responsibilities

Specialist palliative care, psychiatry of later life and gerontology have similar philosophies of care incorporating the physical, social, emotional and social needs of patients and their families (Visser et al., 2015). This person-centred care is essential when caring for those with life-limiting illnesses such as advanced dementia. However, clinical nurse specialists outlined that specialist palliative care healthcare professionals are not experts in dementia care and geriatricians/psychiatry of later life are not experts in palliative care. Therefore, when people living with dementia are referred to specialist palliative care, their care should be undertaken collaboratively. In addition, as multiple disparate specialities and services may be caring for these patients at any time, this care should be coordinated through effective interdisciplinary communication.

According to the participants their clinical nurse specialist role can be misinterpreted by both healthcare professionals and the public. They see a commonality among words to describe community care groups, such as home care teams, home help or home support teams. These are very different and specific roles and services; yet they differ very little in their title's description, especially for non-healthcare professionals. Misleading role titles can confuse patients and families when these healthcare professionals perform a home visit or contact them over the phone. This can lead to even greater misunderstanding if the patient and family are receiving visits from multiple agencies, such as home help and home care teams.

Clinical nurse specialists perceive that some generalist healthcare professionals think that once a patient is referred to specialist palliative care, they take over all care responsibility for that patient. In the community setting, where this study was conducted, a patient's GP remains the primary carer, and a specialist palliative care service is solely in an advisory capacity. In most instances, GPs have had a long-standing relationship and history with the patients referred and are most knowledgeable about their history.

Therefore, a collaborative approach is important for optimum patient outcomes. There is also a sense among clinical nurse specialists that patients want their GP to play a continued central role, as that relationship of trust and support has often developed over many years.

Challenge of the education and teaching role

Education, training and research are stated as core competencies of clinical nurse specialists (National Council for the Professional Development of Nursing and Midwifery, 2008) . They ensure that their specialist skills are maintained and up to date and their continued professional development. Clinical nurse specialists are also expected to provide education to generalist healthcare professionals and participate in research. To maintain and progress their professional development, clinical nurse specialists need both protected time and funding within an organisation, and also opportunities from the wider healthcare community to host up-to-date events and evidence based specialist training.

While clinical nurse specialists have advanced palliative care knowledge and specialised clinical expertise, as identified in the literature, they perceive that they do not have adequate skills to deliver education, especially to colleagues they perceive to have a more senior clinical role. Teaching and learning would not normally be a component of their specialist training. The organisation is responsible for providing access to resources, mentorship and continuing education opportunities. This support would enable the clinical nurse specialist to effectively perform education and training as per their core competencies.

5.4 A theory of interdependence of personal, organisational and external factors to fulfil the clinical nurse specialist role

The following theory outlines the final product of this research study. It offers a new way of illustrating the experiences and complexities of clinical nurse specialists when fulfilling their role. While this study was based on clinical nurse specialists working in a community setting, its findings may be applicable to all settings as the core competencies are the same regardless of the specialty or the area they work within. This theory offers a conceptual understanding of the reality of the clinical nurse specialist role, as interpreted by the researcher through interviews with participants and expanded by literature.

In this theory, interdependence refers to the connections of various factors. These factors are personal, organisational, and external, and they collectively form the theory's foundation. Their interdependence highlights that they are not isolated but rather influence and impact each other, which contributes to the overall theory's explanation. These factors have a mutual relationship, where one can influence and impact the other.

Attributes personal to a clinical nurse specialist significantly affect how they both perform in their role and how they collaborate with other members of the multidisciplinary team. In relation to each individual patient's needs, this team needs to work collaboratively to address care holistically. As such, both a patient's and their families experience of care is based on strong team ethic and effective team processes. An individual nurses ability to work within this team, as specified in many job descriptions, greatly effects both team and organisational culture. Conversely, a team and organisational culture greatly effects a nurse's ability to collaborate with the MDT and provide patient care. Often, the workplace environment and patient experience of care is the ultimate measure of these interdependent attributes working cohesively.

Participants highlighted a challenge for clinical nurse specialists: collaboration with and access to some patient's GP's, who remains their primary carer. Many GPs play a less active role in the patient journey once they are referred to specialist palliative care, an issue often due to increased workloads and inadequate resources within their own service. The relationship between the clinical nurse specialist, the specialist palliative care team and the GPs is key to ensuring that patients receive optimum coordinated care with the best outcome for them and their families. Regular communication is one of the functional attributes of an effective multidisciplinary team. Communication was seen to be key to working as a team, resolving issues or conflicts, and delivering palliative care overall. If the multidisciplinary team's focus was unclear, then professional boundaries were challenged, which could lead to staff not feeling safe within the team.

Clinical nurse specialists manage their roles and responsibilities in the multidisciplinary team within a complex healthcare environment. This environment incorporates the patient, their carers, their specialist palliative care team members and the wider multidisciplinary team within the primary care setting. Navigating the patient journey in this setting requires skills such as strong leadership to guide clinical teams and influence practice changes. The healthcare environment is often high-pressure and dynamic one, so clinical nurse specialists require personal resilience and the ability to adapt to changing circumstances to manage stress and maintain high standards of patient care. While clinical nurse specialists require these skills, they also need an optimal organisational and external environment to support them in fulfilling all aspects of their role. This includes support for research, education and quality improvement. Clinical nurse specialists choose to expand into a speciality area such as palliative care. They require the skills and ability to manage their role and its expected competencies. A clinical nurse specialist committed to continuous learning can leverage external professional networks (where available) and so remain updated on evidence based practice. This will positively influence personal and organisational practice and ultimately improve patient care.

5.5 Conclusion

To optimally perform their role, clinical nurse specialists rely on a complex set of interdependent process working both cohesively and effectively. These involve a dynamic interplay between personal attributes, organisational processes, and external influences. Each of these in turn consist of other contributory factors, forming a complex interdependent matrix of patient care. An organisation that aligns its policies with national healthcare standards can better support a clinical nurse specialist in fulfilling their role, while a clinical nurse specialist aware of external healthcare trends can help an organisation adapt to changes in the healthcare landscape. The above has presented the major findings of this study. These formulate a deductive theory of interdependence relevant to the clinical nurse specialist role. Chapter 6 will now present the significance of this theory and its implications for future policy and practice.

6 Discussion

6.1 Introduction

The research question guiding this study is "What are the experiences of clinical nurse specialists in fulfilling their role?" In chapter 5 the study results leading to the construction of a grounded theory explaining the interdependence of personal, organisational, and external factors in fulfilling the clinical nurse specialist role were analysed. In chapter 6 the results of the developed theory with the existing literature will be compared and contrasted, also making recommendations for future policy, practice and research.

6.1.1 Summary of key findings

This study utilised constructivist grounded theory methods to develop a substantive theory that improves understanding of the roles and experiences of clinical nurse specialists. This includes evidence for the impact and interdependence of clinical nurse specialists' attributes on organisational or external factors, and vice versa.

Ultimately, it provides evidence for the existence of an interdependent, interrelating community healthcare system in which the clinical nurse specialist plays a pivotal role. This study demonstrates that these challenges existed 20 years ago.

6.2 Study strengths and limitations

6.2.1 Study strengths

Semi-structured interviews provided flexibility, enabling participants to share detailed narratives while allowing the researcher to probe and clarify, resulting in rich, nuanced data that captured the complexity of the clinical nurse specialist role. The study drew on the insights of experienced clinical nurse specialists, whose first hand perspectives provided authenticity and credibility to the findings.

Rich data from the participants made it possible to interpret and construct an original theory using a grounded theory methodology through data collection, interpretation, and analysis. This theory explained clinical nurse specialists' experiences when fulfilling their roles. The existing literature supported many of this study's findings, such as the challenge of fulfilling core competencies outside of their clinical role such as education, training and audit.

The use of grounded theory allowed for the generation of a theory rooted in the lived experiences of clinical nurse specialists. This methodology is particularly well-suited for exploring complex, under-researched phenomena such as role fulfilment in clinical nurse specialist practice. Supervisory discussions contributed to the credibility of the findings by helping to minimise researcher bias. The researcher maintained memos to support in-depth analysis. The participants' ages and years of experience spanned a diverse range, facilitating the achievement of theoretical saturation. Overall, this research builds on the limited existing evidence base, progressing the understanding of the complex interdependency of professional and personal attributes, community healthcare workers, organisational culture and the clinical nurse specialist role.

6.2.2 Study limitations

This study only used results from clinical nurse specialists within a single specialist palliative care service. Conducting the study at a single site may limit the transferability of findings. Organisational culture, staffing models, and local policies at the study site may have shaped participants' experiences in ways not representative of other settings. Additionally, the study's context is limited, as the participants were exclusively women from the Republic of Ireland. This limits the diversity of perspectives represented. Male clinical nurse specialists might experience unique challenges or role expectations that were not captured in this study. As a result, the findings may not fully reflect the experiences of clinical nurse specialist's across genders.

While the sample may have been appropriate for grounded theory, it may not fully represent the diversity of clinical specialist roles across specialties or geographic regions, or differencing organisations, potentially narrowing the scope of the emerging theory. The nurses' experiences were self-reported, and they were not observed in their roles. The data only reflected the perspectives and experiences of clinical nurse specialists, without incorporating the views of other healthcare professionals, patients or families. A single-phase data collection period and limited resources may have constrained the depth of theoretical sampling, potentially limiting the full development of conceptual categories or core theory saturation.

Every effort was made to minimise the risk of bias introduced by the researcher during data collection and analysis using steps such as memo writing and constant comparison to mitigate this. However, the participants were aware that the researcher held the position of Director of Nursing in another Irish service, which may have limited their ability to provide an accurate and honest account of their experiences.

6.3 Discussion including relationship to the systematic review and empirical research

This section outlines the findings in the context of other studies, particularly highlighting any notable differences in results. Five core competencies for the clinical nurse specialist role were developed in 2008 (National Council for the Professional Development of Nursing and Midwifery, 2008). These include:

1. Clinical focus
2. Patient/client advocate
3. Education and training
4. Audit and research
5. Consultancy role

Competencies for specialist practice are categorised into core competencies, which are those shared by all who practice at the specialist level, and specific competencies that are identified as particular to the practice role and setting, as outlined in (National Council for the Professional Development of Nursing and Midwifery, 2008). These competencies vary internationally; however, they encapsulate the key expectations for the clinical nurse specialist's role. These five core competencies for clinical nurse specialists provided a valuable foundation for defining the role and promoting professional identity. They reflect the multifaceted nature of clinical nurse specialist practice. They acknowledge that clinical nurse specialist's contribute not only to direct care but also to leadership, service improvement, and evidence based practice. The inclusion of audit and research promotes evidence-based practice and continuous quality improvement, both of which are essential for advancing healthcare outcomes and accountability.

Despite the recognised importance of core competencies for clinical nurse specialists, their effective implementation and monitoring remain fraught with difficulties as evidenced in this systematic review and empirical evidence. The core competencies

have several limitations. They were developed through a top-down approach with limited input from frontline clinical nurse specialists or service users, and they have not been meaningfully updated to reflect changes in healthcare practice, such as digital transformation and integrated care. There has been little revision or refinement of these competencies. As a result the competency has become outdated and less applicable to current clinical service demands.

Given the ongoing challenges in fulfilling current core competencies, are clinical nurse specialists are being set up to fail? These professionals are expected to demonstrate expertise across multiple domains, including clinical practice, patient advocacy, education and training, audit, research, and consultancy. However, this empirical and systematic review data suggests that these competencies are often not being met, either due to the overwhelming demands of clinical workloads or a lack of individual engagement. This raises important concerns about whether the expectations placed on clinical nurse specialists are realistic within the current healthcare environment. In practice, additionally there is often role misunderstanding between clinical nurse specialists, advanced nurse practitioners and senior staff nurses. The competencies do not always help clearly delineate clinical nurse specialist roles from these positions, potentially leading to confusion or duplication of roles within teams.

From the findings presented the main focus of clinical nurse specialists each day is to provide complex clinical expertise and holistic patient care. In their daily practice clinical nurse specialists prioritise clinical focus, patient autonomy and consultancy. Other competencies include audit and research, yet this study illustrates that there is limited support for clinical nurse specialists to effectively measure and demonstrate the impact of their role on patient outcomes, service delivery or system efficiency. Despite the establishment of five core competencies for clinical nurse specialists in the Republic of Ireland, there is no formal or standardised system in place to measure whether these competencies are consistently fulfilled in practice, including time for fulfilment. This lack of structured evaluation means that role implementation and performance are often shaped by individual motivation, local organisational priorities, and managerial interpretation of the clinical nurse specialists role.

Self-care must be woven into all domains of the clinical nurse specialist reflecting dual responsibilities at both the individual and organizational levels for staff well-being. Individually, clinical nurse specialists must actively cultivate self-awareness, emotional resilience, and personal well-being through practices like self-compassion, boundary setting, seeking support, and reflecting on stressors and coping strategies (Barraclough et al., 2024). Concurrently, organisations share responsibility for fostering a supportive culture where self-care is normalised and enabled, not stigmatised. Enablers include the provision of information on burnout, relaxation strategies, peer-to-peer mentoring, motivational messages, online support programmes and policies that integrate staff well-being into workforce strategy (Hardy et al., 2025). In summary, embedding self-care into the role of the clinical nurse specialist requires a dual commitment, where individuals intentionally prioritise their own well-being, and organisations create an environment that normalises and supports these efforts as essential to sustainable, compassionate care.

The study findings are explored and elaborated in this discussion in relation to relevant research and the clinical nurse specialists core competencies, focusing on how the participants experiences align with their core competencies. These five core competencies will be used to frame this discussion.

6.3.1 Clinical Focus

Practical experience is recognized as a significant influence on how nurses deliver patient care, allowing them to develop expertise in their specialty and recognise subtle changes in a patient's condition through what is often described as intuitive judgement (Benner, 1984). Despite having substantial experience and training in other areas of nursing, many nurses report feeling like novices when transitioning into specialist palliative care clinical nurse specialist roles (Bergdahl et al., 2007). Nevertheless, clinical nurse specialists are recognised worldwide for their advanced knowledge and skills in a specific field, which they apply not only to enhance patient care but also to support the practice of their colleagues (Austin et al., 2006); Currie et al., 2023). This highlights the importance of both practical experience and continued professional

development in supporting nurses as they transition into and excel within specialized roles.

Emotional support and expertise in managing symptoms are the most important elements of specialist palliative care, as perceived by patients and their carers (Mitchell, 2010). Generalists who refer to the specialist palliative care team see clinical nurse specialists as a source of expert knowledge. Although some of this knowledge or intuition is learnt through practice, the challenge lies in passing these skills and training on to newer clinical nurse specialists. Expertise resides not only within the individual but also in the knowledge and practices specific to a particular context and organisation (Benner, 1984). Ongoing training for new and existing clinical nurse specialists should be continuously supported by the organisation.

Evidence from the available literature would suggest that clinical nurse specialists are often more comfortable than GPs or physicians at delivering end of life care (Latham et al., 2023). This is because end-of-life care is considered one of the most difficult aspects of healthcare practice (Brown, 2019). This is due to the complex physical, emotional, psychological, spiritual, and ethical needs of patients and their families during the final stages of life. Healthcare professionals must navigate difficult conversations about death and dying, manage distressing symptoms, provide emotional support, and help families cope with loss—all while respecting the patient's wishes and maintaining dignity (Gamondi et al., 2013) As clinical nurse specialists have more experience of delivering this care, they have more confidence in this role. A recent study of clinical nurse specialists (n=101) and physicians (n=104) supports this, finding there is less of a risk of the ever-present fear of failure impacting their confidence, communication, decision making or team working (Latham et al., 2023). This experience and resulting confidence may help understand the interactions between clinical nurse specialists and GPs,where the clinical nurse specialists is seen as the authority and lead in a patients care at this phase of their illness.

Clinical nurse specialists are often drawn to specialist palliative care based on their perceptions of what the role involves, particularly the opportunity to provide

compassionate, end-of-life care. However, a significant challenge for many clinical nurse specialist's has been the ongoing evolution of their role in response to shifting patient populations, changing healthcare policies, and broader definitions of palliative care (McCallin, 2001); Rabbetts et al., 2020). Those who entered the field ten to fifteen years ago often cared primarily for cancer patients with short prognoses, typically measured in days or weeks. In contrast, today's palliative care landscape includes a broader range of chronic, complex conditions and patients with longer, more unpredictable illness trajectories. This shift has led many clinical nurse specialist's feeling overwhelmed and uncertain as they are continually required to adapt their practice and expectations in an ever-evolving and emotionally demanding environment.

However, this role has recently changed with an equal number of patients now referred with non-malignant conditions. These patients are often diagnosed with a life limiting illness and are referred early in their disease. Consequently, specialist palliative care services are becoming involved for a period in these patient's care and then discharging patients when the no longer have specialist needs (Murray, 2013). This represents a significant change from the traditional palliative care practice, which focussed solely on end-of-life care, and may challenge nurse specialists' previous perceptions of their role. Moreover, clinical nurse specialists now require a broad range of specialist clinical skills to ensure they can care for patients regardless of their diagnosis.

6.3.2 Patient/client advocate

Clinical nurse specialists take pride in their ability to be present with patients, especially during emotional and vulnerable times in their journey. Being present for a patient refers to providing more than just medical care, it involves offering emotional support, listening attentively, and creating a compassionate environment where the patient feels understood and valued. Studies have shown that when healthcare providers are fully engaged with patients, it can improve their overall well-being, reduce anxiety, and contribute to better clinical outcomes (Gable & Haidt, 2005); Kozłowska & Doboszyńska, 2012). Being with someone or spending time with someone enables the clinical nurse specialist to act as an advocate for patients and their families, as

challenging or end-of-life care conversations may often arise in these moments. However, role overload can lead to feelings of frustration and moral distress, as the clinical nurse specialist's ability to focus on advocacy is often diluted by insufficient time and competing clinical demands.

One clinical nurse specialist viewed her advocacy role as an anchoring one. Often primary care teams or other specialist palliative care healthcare professionals contact them as they are seen as a central communication coordinator for holistic care in the community. The clinical nurse specialist's role was described by one clinical nurse specialist as an anchoring one, yet an anchor is a stationary object. This contrasts significantly with the real-world experience of the role, which is to be dynamic and flexible. The role assimilates the wholeness of the patient's story and journey while ensuring appropriate interdisciplinary connections and communications. They view their role as having the most patient contact among all the specialist multidisciplinary team members such as occupational therapists, physiotherapists or medical colleagues. This deep level of involvement can be both profoundly meaningful and emotionally taxing, as they carry the weight of patient's stories while striving to maintain coordination and compassion amid constant change.

Many studies have outlined the valuable role of clinical nurse specialists in palliative care (Chapple et al., 2006); Mulvihill et al., 2010); Rabbetts et al., 2020). They are generally considered lone workers, as they primarily visit the patients' place of care on their own. Clinical nurse specialists are a vital resource not only to patients but also to families and healthcare professionals to enable patients to die at home (Tunnah et al., 2012). Early initiation of specialist palliative care is associated with lower costs over the last months of life, and ensuring the availability of specialist palliative care services enables patients to spend more time in their usual residence (Kenny et al., 2024). Clinical nurse specialists' are a key part of this care, and ensuring these positions are adequately resourced in the community reduces pressure on inpatient services and facilitates death at home when preferred (Bergqvist & Ljunggren, 2020). The emphasis on holistic, patient-centred care aligns with Slaintecare reform, and clinical nurse specialists can enhance this approach through their advocacy role by ensuring patients preferences are central to all care decisions (Department of Health, 2017). Collectively,

these findings highlight the pivotal role of clinical nurse specialists in delivering effective, patient-centred palliative care in the community, underscoring the need for sustained investment in these positions to support quality end-of-life care and patient choice. Without this support, there is a growing sense of concern and frustration among clinical nurse specialists, who are deeply committed to their patients but increasingly stretched by the demands of a system that does not always match their dedication.

6.3.3 Education and training

While clinical nurse specialists perceive they are experts in palliative care and exhibit confidence in communicating with families and patients, many lack the confidence to communicate and educate GPs or other healthcare professionals. They feel inadequately trained in delivering and preparing effective education sessions. Clinical nurse specialists are concerned about their credibility as teachers and their ability to communicate clinical information (Currie et al., 2023); Husband & Kennedy, 2006). This uncertainty can lead to feelings of self-doubt and diminished confidence, highlighting a need for further development in this area. Providing formal training could help clinical nurse specialists feel more empowered and supported in their educational role.

Although the formal education and teaching role of clinical nurse specialists has traditionally been viewed as an essential component of the position, this aspect could be made optional offered only to those with a genuine interest and the time to engage effectively. Nevertheless, rather than removing it entirely from the clinical nurse specialist role, an alternative perspective could be that structured training in education and facilitation skills should be integrated into clinical nurse specialist education (Jokiniemi et al., 2018) Competency-based frameworks and validated core competencies highlight the importance of preparing clinical nurse specialists to function not only as clinicians but also as leaders and educators who can improve care quality across care settings such as nursing homes, primary care and community hospitals.

Since the introduction of clinical nurse specialist roles there are now also advanced nurse and midwifery practitioner roles. Advanced nurse practitioner role competencies in the Republic of Ireland include;

1. Professional values and conduct of the registered advanced nurse
2. Clinical decision making,
3. Knowledge and cognitive competences,
4. Management and team competences
5. Leadership and professional scholarship competences
6. Communication and interpersonal competencies

(Nursing and Midwifery Board of Ireland, 2017)

Policy makers identified challenges in the introduction of clinical nurse specialist and advanced practitioner roles. Clinical nurse specialists work at a similar level to advanced nurse practitioners, however, advanced practice roles have the advantages of improving service delivery, greater leadership, increased research opportunities, and an accreditation structure (Begley et al., 2013). While criteria are clearly outlined for becoming a clinical nurse specialist, there is no requirement to fulfil certain criteria to maintain certification each year (NMBI, 2015). These differences in role structure and accreditation highlight the need for clearer policy direction and ongoing professional development frameworks to support the sustainability and impact of both clinical nurse specialist and advanced nurse practitioner roles within the healthcare system.

International, national and local healthcare policies and standards of practice support and shape the practice and development of clinical nurse specialist roles (Mlambo et al., 2021). These policies influence the scope of practice, certification requirements, and competency framework the clinical nurse specialist works within. In contrast, several countries have implemented mandatory CPD requirements for nurses and midwives. For instance, in the United Kingdom, the Nursing and Midwifery Council (NMC) mandates that nurses and midwives complete 35 hours of CPD every three years as part of their revalidation process (NMC, 2024) . Similarly, in Australia, the Nursing and Midwifery Board of Australia (NMBA) requires nurses and midwives to undertake

CPD activities annually to maintain their registration (NMBA, 2016).In the Republic of Ireland, continuous professional development points are not mandatory to maintain nursing registration but have been on the agenda with the Nursing and Midwifery Board of Ireland for some time. However, as of now these requirements have not been implemented. Together, these varying international approaches highlight the evolving global emphasis on professional development and regulatory standards in shaping and sustaining the clinical nurse specialist role.

Within some speciality fields clinical nurse specialists specialize in disease-specific areas. For example, clinical nurse specialists specialising in oncology can offer more tailored cancer care improving quality of life and outcomes for patients (Jansen & Blair, 2015). Clinical nurse specialists in oncology often then sub specialise in specific types of cancer, such as breast cancer clinical nurse specialists (Kerr et al., 2021). Similarly clinical nurse specialists in palliative care are experts in managing complex symptoms through pharmacological and non-pharmacological interventions leading to enhanced patient comfort (Matzo & Sherman, 2009). Subspecialising in specific disease areas is not standard practice in most community palliative care services either nationally or internationally. As such, current models of specialist palliative care may not be the most appropriate for addressing complex and specialist problems (Skilbeck & Payne, 2005). An alternative model could be to structure care around patients' disease specific problems, such as having clinical nurse specialists within specialist palliative care specialise in specific sub specialties. This could enable them to provide expertise tailored to the unique needs of patients with certain conditions such as clinical nurse specialist in non-malignant conditions. There is the risk, however, that specialisation could lead to limitations in broader professional practice and adaptability making it harder for clinical nurse specialists to address situations that fall outside of their usual area of expertise (Tingle, 2014). One resolution to this challenge could be to develop a hybrid model where the clinical nurse specialists would receive advanced training in clinical skills for specific conditions, while also maintaining a broad foundation of their specialist palliative care base (McCallin, 2001). The decision regarding specialising in disease specific areas should be dependent on patient outcomes, patient needs, individual career goals and organisational or healthcare needs.

6.3.4 Audit and research

Professionals working within palliative care often lack the required time, skills and support needed to fulfil this function. This indicates that a shift in organisational culture is required to optimise research opportunities and capacity (Walshe et al., 2024). Allocated protected time should be made available to clinical nurse specialists, training provided and associated funding made available in relation to carrying out audit and research. Within the clinical nurse specialist role as currently structured, there is insufficient time complete all that this role requires, which often leads to frustration and diminished job satisfaction. As such, a compromise is necessary within each organisation so completion of the multiple demands of the job can be achieved along with clinical nurse specialists having fulfilment within their role (Kilpatrick et al., 2016). This requires managerial and organisational support.

While organisations and management hold a responsibility to ensure that clinical nurse specialists are provided with the necessary time, resources, and training to carry out audit activities effectively, there is also a clear professional obligation on the part of clinical nurse specialists themselves. Clinical nurse specialists are expected to meet their core competencies (Bryant-Lukosius et al., 2017). Fulfilling these competencies not only supports accountability and service improvement but also reinforces the leadership and evaluative functions central to the clinical nurse specialist role.

Equally, in practice, audit participation is not guaranteed. Audit is a core competency of the role. Some clinical nurse specialists may not have the personal motivation or interest to engage in audit work as it may be perceived as burdensome, time-consuming, or disconnected from direct patient care (Alexander et al., 2022); Michl et al., 2024). Research indicates that nurses' willingness to participate hinges on how audit and feedback are presented, with demotivating effects like stress or burnout noted when the process resonates poorly with them. Participants in the study expressed reduced motivation when insufficient time prevented them from completing

audits or acting on their findings. This lack of intrinsic motivation can act as a barrier to consistent audit engagement, highlighting the need for both organisational support and the cultivation of a workplace culture that values clinical audit as an integral part of improving patient outcomes and professional practice.

6.3.5 Consultancy role

There are many challenges facing healthcare professionals when providing specialist palliative care, including ethnicity, geographical location, diagnosis, cultural beliefs, and attitudes toward death and dying (Hindmarch, 2012). Organisational theorists contend that the success of any organisation is largely influenced by its culture, values, communication pattern and willingness to communicate (Parker, 1999). Improved coordination and collaboration are needed within and across services to ensure patients receive the most appropriate and specialised care when required. This necessitates an upgrade in information technology so that patient records can be accessed across all care settings. For instance, when a patient is admitted to the hospital, the clinical nurse specialist in the community can review notes outlining events and decisions during the admission. Some families are involved with several services and agencies, there is a clear need to improve their connectivity and coordination.

The interdependence of personal, organisational, and external factors impacts the current interpretation and ongoing clarification of the clinical nurse specialist role. The organisation is responsible for ensuring that patients referred meet defined referral criteria. Over time, varying models of specialist palliative care have evolved throughout the Republic of Ireland depending primarily on the availability of resources. This impacts on referrals to the specialist palliative care service and the role of the clinical nurse specialist (Fisher et al., 2017). In addition to resourcing other organisational and team culture-based factors are of influence. These disparate models of care across services within the country have created an imperative to develop a more unified model of community specialist palliative care. For example, in some more well-funded and

developed services, there is a perception that a only social worker can provide psychological care to patients and families. In contrast, as described by one of the participants in this study, many services have no social worker. In these services the broader multidisciplinary team address these psychological and supportive needs, and this is seen as the responsibility of all team members.

Where roles within a team overlap there needs to be clear communication between the professionals. This is to ensure that important patient needs are not omitted, duplicated or forgotten. The National Adult Palliative Care Policy in the Republic of Ireland supports this approach, which states that the extension of the workforce must ensure that staff providing a palliative care are adequately resourced and trained to deliver a palliative care approach corresponding to their role (Department of Health, 2024). In a literature review of community nurses caring for patients in their own homes, it is highlighted that community palliative care requires a different approach to nursing care, which can be challenging due to shortfalls in service and clinical expertise in regional and rural areas in many countries (Rabbetts et al., 2020). This review concludes that there is insufficient evidence available about the challenges of providing palliative care in patients' homes in rural settings. They recommend that future qualitative research is undertaken to explore the challenges faced by nurses when providing care in this settings.

In community specialist palliative care, care is delivered by a team of specialists alongside the patient's primary care team. In this consultative model, the specialist palliative care team does not assume overall responsibility for the patient and their family. This approach requires that in addition to ongoing disease-specific treatments, provided by a hospital or GP, further support is required to address the holistic needs of the patient and family. Integrating expertise from different individuals into the patient's palliative care journey can lead to care being managed holistically (Fernando & Hughes, 2019). The National Adult Palliative Care Policy outlines that the GP has overall responsibility for the medical care of patients in the community. International research suggests that although GP practices serve as the initial point of contact for patients, a crisis in primary care persists due to increasing GP workloads and insufficient

resources (Croxson et al., 2017); Svedahl et al., 2019); Van den Hombergh et al., 2009). One potential approach is to transition specialist palliative care from an advisory-only in the community to one where full responsibility is taken by the team where the patient is receiving end-of-life care at home. While the GP remains a crucial part of the patient's journey, allowing specialist palliative care teams to manage the care of dying patients can ease the GP's workload.

Within primary care in the UK GP's are incentivised to maintain a palliative care register of patients in the last 12 months of life however (Mitchell et al., 2015) interviewed eight GPs who collectively provided care to over seventy-three thousand patients to explore how they identify patients who require entry into the palliative care register. They explained that there is a risk that some patients will not receive the necessary support as no definition of a palliative care patient exists. In addition, (Ding et al., 2018) carried out a systematic review of forty-three studies and one of its aims was to describe how end-of-life care is provided in general practice. Many GPs did not consider that they were the primary coordinators of palliative care even though they were highly involved in all aspects of palliative care for their patients. This misconception could mean that some GPs could assume that the specialist palliative care team will take overall responsibility for the patient once a referral is made to their service.

In healthcare, multidisciplinary, multi-professional, and interdisciplinary terms are used interchangeably. Regardless of whether a palliative care team operates as a multidisciplinary or interdisciplinary team, the composition of the team is very important (Speck, 2006).Communication within a team determines how effective the multidisciplinary team will be (Fernando & Hughes, 2019). Multidisciplinary teams should ensure optimal communication due to the wide range of disciplines and healthcare professionals involved. There is significant potential for miscommunication and poor coordination of patient care (Fleissig et al., 2006). Communication is a challenge and a core requirement to establish roles and responsibilities within a team (Crawford et al., 2021). Many studies acknowledge the failings that poor communication can produce in a multidisciplinary team (Klarare et al., 2013), (Fleissig et al., 2006) and (Spruyt, 2011). (NICE, 2004) guidance in the United Kingdom for cancer

services defines a multidisciplinary team as a group of health and social care professionals from a range of disciplines who meet regularly to discuss and agree on a plan of treatment and care for people with a particular type of cancer or problem, or in a particular location. This includes primary care teams, disease-specific teams and specialist palliative care teams (p.200). The effectiveness of the multidisciplinary team relies heavily on its composition and, critically, on clear, consistent communication to ensure coordinated, high-quality patient care.

In the above described research, clinical nurse specialists discussed frustrations when key information regarding patients is not available or accessible. Ineffective communication and inadequate sharing of information about the dying person is a recurrent finding where inadequate care has been reported (NHS Improving Quality, 2013).

The challenge can be in determining what members constitute a multi-disciplinary team and how information should be shared. A way to address this is to have structured, regular communication among team members and all other external healthcare professionals involved to prevent crises and ensure consistent goal-coordinated care (Warner & Gualtiere-Reed, 2014) . Whether the clinical nurse specialist is liaising with the multidisciplinary team within their speciality or externally, the common denominator is that all these healthcare professionals are part of a multidisciplinary team providing care for the patient and their family.

Often, multidisciplinary teams are not connected electronically across care settings, which added to the communication difficulties of the participants in this study. Care records must encompass patient's needs and preferences even as they approach the end of life. With the patient's permission, and in compliance with GDPR standards, these records should be shared with all those involved in patient care (Ambitions for Palliative and End of Life Care, 2015-2020). This is supported by the NICE (2019) guidance for service delivery in end-of-life care for adults. This states that electronic information-sharing systems that are accessible between different organisations should be used to enable information to be reviewed, updated and shared efficiently

between teams (p.12). However, these quality improvement initiatives have often not achieved their aims, and the rate of failure has been high because of poorly designed interventions and difficulty targeting those most likely to benefit from care coordination (Thiel et al., 2013). Updating electronic patient management systems also requires significant funding and time.

6.4 Meaning of the study for policy and practice

The findings from this study have implications for future policy, practice and research.

6.4.1 Implications for policy

Review of clinical nurse specialist's competencies

A review and revision of the clinical nurse specialist competencies, involving stakeholders and reflecting current healthcare challenges, is needed to ensure their continued relevance. As a result of no formal system in place to measure the fulfilment of these competencies in practice, the extent to which clinical nurse specialists engage in areas such as audit and research, consultancy, or education varies significantly across settings. In some environments, clinical nurse specialists are empowered and supported to fully enact the competencies, while in others, they may be constrained by service demands, unclear role expectations, or limited leadership and managerial support. This variability undermines the potential impact of the role and highlights the need for more consistency among all clinical nurse specialists.

These core competencies must be re-evaluated in the context of how dramatically the healthcare landscape and clinical pressures have evolved since 2008, when this framework was initially developed. To ensure clinical nurse specialists can operate at the full scope of their roles, realistic expectations must be set, supported by clear oversight, accountability structures, and robust mechanisms for professional development and organisational support.

The competencies identified from the data include

1. Clinical focus,

2. Advocacy,
3. Consultancy,
4. Self-care, and the
5. Maintenance of education and clinical expertise. Clinical expertise refers to having theoretical and practical proficiency in an area through extensive experience, specialised training and continuous learning.

These competencies are likely applicable not only within specialist palliative care and an Irish context but across all clinical nurse specialist roles internationally, regardless of care setting or specialty. Emphasis should be placed on enabling clinical nurse specialists to become true clinical experts, with a strong focus on sustaining and advancing their specialist knowledge through continuous education. In addition to their clinical responsibilities, clinical nurse specialists must also prioritise self-care as an essential component of sustaining their role long-term.

Participants widely acknowledged the demands of the role, yet consistently reported that what sustains them is the job satisfaction derived from managing complex patient care. Interestingly, caring for dying patients was not described as a challenge, but rather as a meaningful aspect of the role that contributes to this satisfaction. Given the increasing complexity of clinical work, clinical nurse specialists require realistic, focused core competencies that truly support their specialist function. Doing so would not only enhance job satisfaction but also help ensure they are not constantly 'chasing their tails' trying to fulfil what is now evidenced as an overly broad or unrealistic scope.

Continuous professional development

Changes to the national Nursing and Midwifery Board of Ireland's guidance on mandatory continuous professional development for nursing in the Republic of Ireland necessitate that organisations review and revise their local education, development, and support policies for staff. This presents an opportunity for collaborative planning between nursing staff and management to implement a local continuous professional development policy aligned with national standards. Such a policy would support the introduction of continuous professional development points as an annual requirement to maintain professional registration. To achieve this effectively, organisations must commit sufficient funding and allocate protected time for staff to engage in continuous

professional development activities. However, it should be noted that any local policy would ultimately be superseded by national Nursing and Midwifery Board of Ireland mandated continuous professional development frameworks, once formally introduced.

Clinical nurse specialists encounter communication challenges frequently and often daily with patients, families and their colleagues. The study findings highlight that clinical nurse specialists engage in daily, often difficult conversations with patients and their families, requiring considerable patience, emotional intelligence, and negotiation skills. These encounters can be challenging and require patience and skill. Therefore, yearly communication training should be considered mandatory as part of maintenance of education and clinical expertise for all clinical nurse specialists to help manage these encounters and improve patient and family care.

Review structuring of clinical nurse specialist pay scales

In the Republic of Ireland, clinical nurse specialists currently operate under a single pay grading system that includes annual increments over a 10-year period, along with an additional long-service increment. However, this structure offers limited opportunities for career progression unless clinical nurse specialists transition into advanced nurse practitioner or managerial roles. In contrast, general nursing roles benefit from a more diverse grading structure, ranging from staff nurse to senior enhanced nurse, each with corresponding pay scales and clearer pathways for advancement.

There is a pressing need to develop a distinct grading and increment system tailored specifically to the role of clinical nurse specialists. Such a framework could better reflect the complexity and value of the clinical nurse specialists role by linking progression and financial incentives to the attainment of defined professional competencies and ongoing education. Importantly, while increased pay would not provide a solution to time constraints, it may serve to support and reinforce the personal motivation many clinical nurse specialists have toward professional development and excellence in practice.

In addition to recognising the advanced skills and responsibilities associated with the clinical nurse specialist role, this type of career structure could play a critical role in addressing ongoing resource and recruitment challenges. This research has highlighted the difficulties in recruitment of specialist nursing staff. A more structured, competency linked pathway with clear opportunities for advancement may help entice more nurses into the clinical nurse specialist profession by offering a more appealing and sustainable long-term career trajectory.

6.4.2 Implications for current practice

Education requirements

Under the current model of specialist palliative care in the Republic of Ireland, eligibility criteria for appointment to the clinical nurse specialist role include completion of a higher diploma, post registration qualification in palliative care or an equivalent in another specialty. However, direct experience within an inpatient specialist palliative care unit is not a mandatory requirement. A nurse becomes eligible to apply for the clinical nurse specialist role after just one year of post-registration experience. Given the complexity of the role including high-level decision-making, lone working practice, and the emotional and clinical challenges of working in isolation, one year of experience is insufficient preparation and warrants revision. Currently, the interview process plays a critical role, ensuring managers assess whether candidates possess the necessary knowledge depth of specialist palliative care and are equipped to meet the expectations of the clinical nurse specialist role.

Insufficient time to fulfil the education, training, and audit requirements of the clinical nurse specialist role emerged as a recurrent issue, with clinical workload consistently taking precedence. This imbalance often resulted in essential non-clinical responsibilities being deprioritised, despite their importance in maintaining professional competence and service quality. To address this, services should review how time is allocated and protected for clinical nurse specialists to engage in non-patient facing activites such as education. One potential solution is to assign dedicated

non-clinical time for example, one protected week every four months, specifically for self-care and maintenance of clinical expertise through education ensures these responsibilities are systematically integrated into the role rather than treated as optional or secondary. This should be factored into workforce planning. Taking protected time away from direct patient care to focus on this enables clinical nurse specialists to return to practice equipped with updated, evidence-based knowledge and enhanced skills, ultimately improving the quality and effectiveness of patient care.

Mentorship and organisational knowledge retention

The sharing of expert advice and support from experienced practitioners to novices is invaluable. Healthcare organisations need to review how they capture this expertise from retirees, many of whom have worked in the specialty for 10–20 years and are ideally positioned to teach, mentor, and share their knowledge with the new generation of clinical nurse specialists. Creating opportunities for overlap between outgoing retirees and incoming recruits could help bridge this gap, ensuring the transfer of critical experiential knowledge and promoting continuity in clinical expertise.

6.4.3 Implications for future research

A limitation of this study is that it only captures the experiences of clinical nurse specialists within one service in the Republic of Ireland. While this provides valuable contextual insight, the findings may not be transferrable to other healthcare settings with different organisational structures, governance models, population needs or resource allocations. Further research could therefore explore the experiences of clinical nurse specialists across multiple services, including acute hospitals and community settings. Comparative studies across different regions in the Republic of Ireland, as well as cross-jurisdictional research involving services in United Kingdom, Australia, Canada or other European healthcare systems, would enable how policy frameworks and service configurations influence the experiences and impact of the clinical nurse specialist role.

This study captured solely the experiences and perspectives of nurses, excluding input from other healthcare professionals, patients, or family members, which would provide a more comprehensive understanding of care experiences, outcomes and the impact of the clinical nurse specialist role from those directly receiving or affected by care. Future studies could also adopt a mixed-method or longitudinal design to evaluate measurable outcomes associated with clinical nurse specialist interventions, including patient safety indicators, service efficiency, cost-effectiveness and quality of care metrics.

Patient roles in palliative care decision-making are often not explicitly addressed and tend to be indirect or limited, even though person-centred care indicates that care should be delivered around the needs and wishes of the patient (Corner, 2003). Most research discusses the palliative care multidisciplinary team from the healthcare professional's perspective. However, there is very little evidence on the effectiveness of the multidisciplinary team from the patient's and carer's perspective.

The clinical nurse specialists welcomed the opportunity to be shadowed as part of an ethnographic study to determine if there are more efficient ways of fulfilling their role. The overall theory could have varied had nurses from other countries and cultures been included.

6.5 Conclusion

Most people only encounter death a few times in their lives with the death of their close friends and relatives. Clinical nurse specialists are unique in that they are faced with death and dying daily. They have the opportunity to shape the patient's experience of death and dying. It can be challenging to comprehend why clinical nurse specialists choose to work in specialty areas characterised by symptomatic patients, complex family dynamics, intense emotions, and the reality of death. This study illustrates that many are drawn to these roles because they are motivated by a desire to make a meaningful difference during some of the most critical moments in people's lives.

Comprehensive care provided by the clinical nurse specialists can stabilise a patient and family at home and combines addressing complex and individual care needs with effective psychosocial and communication skills. This holistic approach to care requires a comprehensive skillset which augments their physical, psychological, social and spiritual care to improve overall wellbeing (Seipp et al., 2021). Specialist palliative care is an acknowledged speciality for nurses, requiring specific education, development and maintenance of these skills.

The fulfilment of the clinical nurse specialist role is a complex process that relies on the interdependence of personal capabilities, organisational structures and external factors. This dynamic interplay can result in an effective clinical nurse specialist role. The multidimensional nature of holistic palliative care prides itself on caring for the 'whole' person. That encompasses the physical, psychological, social, occupational and spiritual domains of a patient and their family. The team approach is required to provide effective and efficient care in all of these domains.

The Republic of Ireland's clinical nurse specialist core competencies align with international standards. However, challenges remain in their implementation, support, and evaluation. To fully realize the potential of the clinical nurse specialist role, the Irish health system needs to address:

- Core competencies for clinical nurse specialists
- Resource and time constraints
- Standardisation across regions
- Role clarity vs advanced nurse practitioners

Understanding the specific and complex requirements and core competencies of the community specialist palliative care clinical nurse specialist role is essential for those applying to work in this field. Once in the role personal development plans should be carried out on an ongoing basis. This will ensure that the clinical nurse specialists and their line manager can progress towards maintaining specialist skills and identify any challenges in practice. Continuous learning opportunities, including training, mentorship, and promotion, should be created and encouraged. Given the

evolving nature of specialist palliative care both nationally and internationally, services must adapt their care and service delivery. This imperative is reflected in the experiences described by the clinical nurse specialists in this study.

7 References

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Appendix 1: Core competencies of a clinical nurse specialist

Core Concept	Associated Competencies
Clinical Focus	• Articulates and demonstrates the concept of nursing and midwifery specialist practice within the framework of relevant legislation, the *Scope of Nursing and Midwifery Practice Framework* (An Bord Altranais 2000a), *The Code of Professional Conduct* (An Bord Altranais 2000c) and *Guidelines for Midwives* (An Bord Altranais 2001). • Possesses specially focused knowledge and skills in a defined area of nursing or midwifery practice at a higher level than that of a staff nurse/midwife. • Performs a nursing/midwifery assessment, plans and initiates care and treatment modalities within agreed interdisciplinary protocols to achieve patient/client-centred outcomes and evaluates their effectiveness. • Identifies health promotion priorities in the area of specialist practice. • Implements health promotion strategies for patient/client groups in accordance with public health agenda.
Patient/Client advocacy	• Enables patients/clients, families and communities to participate in decisions about their health needs. • Articulates and represents patient/client interests in collaboration with the interdisciplinary team. • Implements changes in healthcare service in response to patient/client need and service demand.
Education and Training	• Provides mentorship, preceptorship, teaching, facilitation and professional supervisory skills for nurses and midwives and other healthcare workers. • Educates patients/clients, families and communities in relation to their healthcare needs in the specialist area of practice. • Identifies own Continuing Professional Development (CPD) needs and engages accordingly.
Audit and Research	• Identifies, critically analyses, disseminates and integrates nursing/midwifery and other evidence into the area of specialist practice. • Initiates, participates in and evaluates audit. • Uses the outcomes of audit to improve service provision. • Contributes to service planning and budgetary processes through use of audit data and specialist knowledge.

Consultancy	• Provides leadership in clinical practice and acts as a resource and role model for specialist practice. • Generates and contributes to the development of clinical standards and guidelines. • Uses specialist knowledge to support and enhance generalist nursing/midwifery practice

(National Council for the Professional Development of Nursing and Midwifery, 2008)

Appendix 2:Lancaster university ethical approval

Name: Jacinta Kelly

Supervisor: Sarah Grace Brearley

Department: Health Research

FHM **REC Reference:** FHM-2022-0843-ExRev-1

Title: Clinical Nurse Specialists' (CNSp's) experiences of fulfilling their role in a community palliative care service in Ireland using a grounded theory approach

Dear Ms Jacinta Kelly,

Thank you for submitting your ethics application in REAMS, Lancaster University's online ethics review system for research. The application was recommended for approval by the FHM Research Ethics Committee, and on behalf of the Committee, I can confirm that approval has been granted for this application.

As Principal Investigator/Co-Investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licences and approvals have been obtained.

- reporting any ethics-related issues that occur during the course of the research or arising from the research to the Research Ethics Officer at the email address below (e.g. unforeseen ethical issues, complaints about the conduct of the research, adverse reactions such as extreme distress).

- submitting any changes to your application, including in your participant facing materials (see attached amendment guidance).

Please keep a copy of this email for your records. Please contact me if you have any queries or require further information.

Yours sincerely,

Dr Laura Machin
Chair of the Faculty of Health and Medicine Research Ethics Committee
fhmresearchsupport@lancaster.ac.uk

Lancaster University

Appendix 3: Requisition of access letter

Re: Participant Access

23/06/2022

Dear XX

As you are aware I am completing a PhD in Palliative Care at Lancaster University since 2019. With the support of my academic supervisors Dr Sarah Brearley & Dr Amy Gadoud at Lancaster University we are completing a study titled Clinical Nurse Specialists' (CNSp's) experiences of fulfilling their role in a community palliative care service in Ireland using a grounded theory approach.

A grounded theory approach will be used involving qualitative methods in this study. This will be done by utilising a semi-structured interview. Participants will be selected through purposive sampling. The consented commitment of participants would involve a recorded interview via Microsoft teams. It is envisaged that this would take approximately 30-40 minutes. The interview would take place at a time, date, and location convenient to the Milford service and the participant.

Thank you with your assistance with recruitment for the study. My inclusion criteria are as follows.

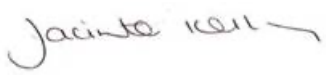
- Community palliative care team Clinical Nurse Specialists' with a minimum of 12 /months experience working within the community palliative care team

- Clinical Nurse Specialists' who carry a clinical caseload and visit patients within their place of care in the community setting providing symptom control and advice
- Clinical Nurse Specialists' who have completed a Higher Diploma in Palliative care or equivalent

I have enclosed a letter of invitation, an information sheet, a consent form, a demographic questionnaire for each participant. In this initial interview phase I am seeking 5-6 participants and following analysis of these transcripts I may seek further participants. Return of a completed demographic questionnaire and consent form will imply consent. I would be grateful if they could be returned to me by July 5th 2022 as I plan to schedule the interviews end of July 2022.

If you require any further explanation or clarification of the project, please do not hesitate to contact me.

Yours sincerely,



Jacinta Kelly, DON

North West Hospice,

Sligo.

And

PhD Student in Palliative Care

Lancaster University

Phone: 0877509588

Email: jinciekelly@gmail.com

Appendix 4: Participant invitation letter

Dear

I am completing a PhD in Palliative Care at Lancaster University since 2019. With the support of my academic supervisors Dr Sarah Brearley & Dr Amy Gadoud at Lancaster University we are completing a study titled Clinical Nurse Specialists' (CNSp's) experiences of fulfilling their role in a community palliative care service in Ireland using a grounded theory approach.

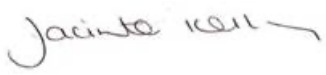
A grounded theory approach will be used involving qualitative methods in this study. This will be done by utilising a semi-structured interview. Participants will be selected through purposive sampling. The consented commitment of participants would involve a recorded interview via Microsoft teams. It is envisaged that this would take approximately 30-40 minutes. The interview would take place at a time, date, and location convenient to the service and the participant.

The information you provide will be used only in structured formats i.e., PhD thesis, production of evaluation report or articles for publication. Your name will not be used at any stage. It may be necessary with your permission for me to clarify certain points after the interview (should you choose to take part) with you. While I would greatly value your involvement in this project, your participation is entirely voluntary. You are advised that you can withdraw at any time during or up to two weeks after the study without having any fear or compromising any working relationships. Participation does not commit you to any further research or project connected with North West Hospice.

I have enclosed an information sheet which should answer any questions you may have, however if you require any further explanation or clarification of the project, please do not hesitate to contact me. If you are willing to take part, I would be grateful if you would

complete the enclosed demographics and consent form and return it to me in the envelope provided by 30th May 2022.

Yours sincerely,



Jacinta Kelly Acting ADON

North West Hospice,

Sligo.

And

PhD Student in Palliative Care

Lancaster University

Phone: 0877509588

Email: jinciekelly@gmail.com

Appendix 5: Consent form

We are asking if you would like to take part in a research project titled Clinical Nurse Specialists' (CNSp's) experiences of fulfilling their role in a community palliative care service in Ireland using a grounded theory approach. Before you consent to participating in the study we ask that you read the participant information sheet and mark each box below with your initials if you agree. If you have any questions or queries before signing the consent form please speak to the principal investigator, [Jacinta Kelly].

1. I confirm that I have read the information sheet and fully understand what is expected of me within this study
2. I confirm that I have had the opportunity to ask any questions and to have them answered.
3. I understand that my interview will be audio recorded and then made into an anonymised written transcript.
4. I understand that audio recordings will be kept until the research project has been examined.
5. I understand that my participation is voluntary and that I am free to withdraw at any time during or up to two weeks after the study without giving any reason, without my medical care or legal rights being affected.
6. I understand that once my data have been anonymised and incorporated into themes it might not be possible for it to be withdrawn, though every attempt will be made to extract my data, up to the point of publication.
7. I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published; all reasonable steps will be taken to protect the anonymity of the participants involved in this project.
8. I consent to information and quotations from my interview being used in reports, conferences and training events.
9. I understand that the researcher will discuss data with their supervisor as needed.
10. I understand that any information I give will remain confidential and anonymous unless it is thought that there is a risk of harm to myself or others, in which case the principal investigator may need to share this information with their research supervisor.
11. I consent to Lancaster University keeping written transcriptions of the interview for 10 years after the study has finished.
12. I consent to take part in the above study.

Name of Participant_____ **Signature**_____

Date _____ **Phone Num:**_____

Email: _____

Name of Researcher _____**Signature** _____

Date _____

By proceeding to the survey you confirm that:

- • You have read the participant information sheet and understand what is expected of you within this study
- • You understand that any responses/information you give will remain anonymous
- • Your participation is voluntary
- • You consent for the information you provide to be discussed with my supervisor at Lancaster University
- • You consent that the data will be pooled and published and that if quotes are provided they could be published
- • You consent to Lancaster University keeping the anonymised data for a period of 10 years after the study has finished

Appendix 6: Participant information leaflet

Title of the study:
Clinical Nurse Specialists' (CNSp's) experiences of fulfilling their role in a community palliative care service in Ireland using a grounded theory approach

What is the study about?

The aim of this study is to interview community palliative care team CNSp's to determine their experiences when carrying out their role.

What will your participation involve?

If you agree to be involved, you will be asked to participate in an interview via Microsoft teams.

How often and how long will you be interviewed for?

The semi-structured interview may last approximately 30-40 minutes and will be held at a time and location convenient to the participants. The interview will be tape recorded, as it would not be possible for me to remember or write all your contribution during the interviews. It is my intention to perform an interview once, but I would be grateful if you would give me permission to return for a second discussion should I deem it necessary for additional clarification.

What will happen to the information once collected?

If you participate in the interview the data will be analysed using the NVIVO which is a qualitative data analysis computer software package.

If you participate in the interview, the information on the tape will be transcribed onto paper so I can read it and begin the process of looking at the information for common meanings between participants.

Where will the information be stored and for how long?

The tape-recording transcriptions will be stored in a locked filing cabinet my home. The tape recording will then be transferred to an encrypted computer. Any subsequent printed transcripts of the interview will also be stored in a locked filing cabinet. At no

stage will your name appear on the transcript. The recording and written transcript will be given a number for identification purposes and pseudonyms will be utilised. I will be the only person who will know who the transcript corresponds to, and I will not divulge this to anyone. My supervisors for this study is Dr Sarah Brearley, Senior Lecturer in Health Research at Lancaster University and Dr Amy Gadoud Senior Lecturer in Palliative Medicine, Lancaster Medical School.

Who will have access to the information?

The only people who will have access to the digital audio recording is myself. At no stage will your name appear on the tape or in transcripts.

Are there any consequences if I choose not to be part of the study or if I want to opt out halfway through?

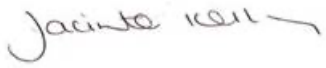
There is no obligation on you to participate in the study. If you choose to participate you are free to withdraw your consent at any time without obligation to anyone. This means you can opt before or during or after the interview. Participation does not commit you to any further research or project.

Will people know I took part in the study?

I will not be informing anyone that you participated in the study. Your name will not appear on the tape or transcript. Information that might identify you will not be used in any publications resulting from the study. If you wish to talk to people about the study, you are free to do so.

You are under no obligation to participate in this study and deciding not to participate will make no difference to your employment.

Thank you for taking time to read this leaflet and for considering taking part in this study. Should you require any further information please feel free to contact me.



Jacinta Kelly Acting ADON,

North West Hospice,

Sligo and

PhD Student in Palliative Care

Lancaster University

Ph: 0877509588

Email: jinciekelly@gmail.com

Appendix 7 : Demographic questionnaire

The details below will be treated with the same degree of confidentiality as the verbal information given in the interview. The researcher may draw on this information when analysing the data from the interviews. Please circle corresponding answer below

Gender: Male Female Prefer not to say

Number of Years Qualified: 1-5 6-10 11-15 16 or greater

Number of Years as CNSp in SPC 1-5 6-10 11-15 16 or greater

Number of Years in Current Position 1-5 6-10 11-15 16 or greater

Where does your CPCT cover Rural Area Urban Area Urban & Rural Area

Have you completed the Higher Diploma in Palliative Care (or equivalent) Yes No

Have you completed the Masters in Palliative Care (or equivalent) Yes No

Have you completed PhD in Palliative Care (or equivalent) Yes No

Have you completed Nurse Prescribing Yes No

Any other comments re: Educational achievements?

Appendix 8: Interview guide

Icebreaker questions

1. How long are you working in specialist palliative care?
2. Tell me about how you came to work in specialist palliative care? How did your journey take you to where you are today?

Explain that the next questions will be based on the 5 core competencies of a CNS

1. *Describe your understanding of your role as a Clinical Nurse Specialist on the Community Palliative Care Team?*
2. *Can you think of a time when things went well in your role? If so what happened to enable it to go well? (Clinical Focus)*
3. *Is there anything that could have been done differently in that scenario? (Enabling and disabling factors to clinical focus)*
4. *Can you think of a time when things didn't go well in your role? If so what happened? (Clinical Focus)*
5. *Is there anything that could have been done differently in that scenario? (Enabling and disabling factors to clinical focus)*
6. *Tell me about working with other teams in your role? (Consultancy)*
7. *What are the challenges when you are working on a team? (Consultancy)*
8. *Discuss a time when the team worked well together? (Consultancy)*
9. *Tell me about a time you had to act as an advocate for a patient? (Patient advocate)*
10. *Tell me about what you see as important training to carry out your job? (Education and Training)*
11. *Have you had an opportunity to carry out audit or research? (Audit and research)*
12. *How do you switch off from work? Lunchbreak? Switch work phone off?*

Closing question

13. Can you name anything that would enhance your clinical nurse specialist role in the future or do you feel you have sufficient means?
14. Have you any other comments or thoughts?

Appendix 9: Codes and themes of interviews 1-9

Name	Description	References
Fulfilling core competencies and professional development within the clinical nurse specialist role	**Discusses the challenges of fulfilling the core competencies of clinical focus, advocacy, consultancy, audit, training, education, and research. Identifies skills and training required to continue to fulfil and develop their role.**	
act other roles		1
advocating for patient		1
autonomy of job		2
being novice to expert		5
being objective		1
clinical focus		3
Clinical nurse specialist trusting own judgements		10
collation of work		1
consultancy of role		2
continually educating		1
coordinator of roles		2
core competencies		5
different practices		1
doing mandatory training		2
drowning in clinical work		1
educating the generalist		4
education re the role		3
education second place		2
focus on mandatory training		2
frustrations of advocating		2

Name	Description	References
grandfather clause		1
have specialist knowledge		1
having academia versus experience		5
having education opportunities		12
increase knowledge base		1
interest in education updates		4
job satisfaction		6
just knowing		1
learning in action		1
limited career path		1
maintaining clinical nurse specialist role		1
more autonomy		1
more education opportunities		1
need for ANP		3
need for education		17
no audit or research		12
not meeting core competencies		1
nurse prescribing		7
outside our skillset		1
participation in research		2
progressing clinical nurse specialist role		1
support for education		11
time for service improvement		1

Name	Description	References
Informational Technology and Infrastructure	**Outlines the information technology skills now required as clinical nurse specialists including the burdens and benefits of same. Discusses some of the challenges regarding facilities and infrastructure**	
accessing patient information		3
admin of role		2
bogged down in paperwork		2
challenge of online meetings		5
challenging office space		5
changes in pandemic		1
clinging to paper		1
insufficient admin support		4
ISBAR reduces time		1
IT challenges		1
IT system upgrade		1
Learning new IT		9
more administrative support		1
poor internet reception		2

Name	Description	References
Maintaining the specialism and teamwork	**Discusses areas for improvement in ensuring that specialist palliative care is available to those who need it. Identifies areas for improvement to support clinical nurse specialists in their role and in maintaining their specialism. Discusses healthcare professionals' perception and expectations of the clinical nurse specialist's role and the specialist palliative care service**	
'cleaning up' caseloads		5
'linking in' with services		2
'roping' in everyone		6
access to iv's at home		2
accessing GP's		12
advisory capacity of role		1
anchor of the team		1
being competent		1
being part of a hub		1
blurring of roles		1
buddy of people		1
case reviews needed		4
centre of continuity		1
changing communication style		7
clinical nurse specialists experiences		0
collaborative working		3
connecting with people		3
crossover of roles		1
daunting for students		1

Name	Description	References
death after PRN med		3
differing medical practices		2
difficulty discharging patients		5
dilution of service		4
discharging following triage		3
discharging patients		2
discrepancy of roles		2
doing case reviews		3
draw into palliative care		1
drawn to palliative care		1
expectations of role		10
expectations of role		2
failing to link with HCP's		1
feel the team support		2
filter new referrals		9
frustration contacting GP		1
gaps out of hours		9
get student nurses		1
good hospital relationships		4
good leadership		1
good working relationships		2
GP and PHN unseemless		1
GP not supportive		3
GP supporting decisions		4
GP takes backseat		2

Name	Description	References
have most patient contact		1
having confidence in role		1
higher expectations of knowledge		1
home help v's home care		2
honesty about the service		6
ICS nurse is gold		3
identifying when to discharge		3
impact of admissions		1
importance of triage		3
Inadequate in paediatric cases		10
inappropriate referring		11
inconsistency in staff		1
intense care investment		1
interdisciplinary role		4
joining the dots		1
joint visits		1
keep people at home		2
knitting the services together		1
knowing the patient		4
lack of bereavement care		4
learn from each other		1
learning in role		1
less respect for the role		1
lines are blurred		3

Name	Description	References
link between services		1
MDTs are beneficial		1
meaning of hospice		1
Medicalization of service		4
more involvement if more symptoms		1
networking of role		5
no home GP reviews		1
organizing ambulatory clinics		1
paediatrics - outside scope		7
PCOC to prioritize care		1
PHN not doing review		7
PHN relationship		1
poor GP assessment		1
poor knowledge base		1
poor palliative care		1
primary care centre reviews		1
primary care team working		12
prioritizing workload		1
psychosocial needs		2
public awareness		3
public awareness of SPC		1
public dissatisfaction		6
reliant on NH staff		1
remembering specialist role		9
retirement of experience		3

Name	Description	References
rewarding job		6
slow GP responsiveness		1
specialist role		3
staffing shortages		3
step down beds		1
support of HCP's		1
talking with GP's		1
team effort		6
therapeutic relationship		2
two-way communication		1
two-way relationship		1
using correct terminology		3
value of night nursing		8
variety of role		1
working hours		1
working together		1
Planning the working day within available resources	**Outlines the importance of planning and prioritizing the working day for the clinical nurse specialist. Preempting what could happen and always trying to stay ahead. This is done within the given resources**	
'keeping an eye' on patients		1
admit to hospice		1
a lot of phone support		2
anticipating ahead		1
anticipating events		6
back up of IPU		1
being a guest		1
being present		1

Name	Description	References
bread and butter of EOLC		1
care at home not working		1
challenging symptom management		1
clinical nurse Specialists experiences		0
connecting with patients		3
difficult conversations		1
documenting everything		7
documenting visits		3
doing basic nursing care		1
doing what's achievable		1
doing your best		1
drawn to SPC		4
efficiency of working		2
enormity of work		1
escalating care		1
facilitating discharges		1
filling a gap		1
firefighting in role		6
firefighting in work		6
focus on living		1
following their journey		8
functioning when stressed		2
hard to get it right		1
heartbreak when insufficient services		1

Name	Description	References
holistic care		1
honest discussions		1
honesty with patients		1
identifying safety issues		1
Importance of first visit		4
insufficient time		5
Interpersonal connection		8
journey about living		1
keep patient central		1
knowing home limitations		2
knowing the conversation		1
managing symptoms		2
more time for patients		6
need to get it right		1
no access to what's needed		1
not ideal to die at home		1
not letting them down		1
not manageable at home		3
not managing symptoms		1
not send patients to acute service		3
nothing to offer		1
opportunity to tell story		1
our duty of care		1
out of your control		1
patient at the core		1

Name	Description	References
pre-empting events		1
pressure on families		4
preventing a death		1
pride of the role		1
providing Comfort		1
providing psychological care		1
recognizing deterioration		1
recognizing symptoms		1
regrets regarding scenarios		1
responding to gut feeling		8
reversing out the door		1
rewards of job		1
ring for support		1
services overlap		1
services step back		6
setting things up		1
share caseloads		1
someone to observe role		2
subtle ques		4
support at end of phone		1
system access challenges		1
tailoring the visit		2
time for new referral		1
trust the process		1
unexpressed contract		1
value of phone support		4

Name	Description	References
working outside specialist role		1
The art of self-care	**Outlines the difficulties in trying to plan self-care into a working day. Includes ways clinical nurse specialists have integrated self-care for themselves both in and out of work.**	
analysing your care		1
burnout		1
can’t say no		1
dashboard dining		8
debriefing with each other		4
dwell on challenges		1
energy for own family		5
fear of doing wrong thing		1
fearing covid		6
finishing on time		2
hard to walk away		1
having 'a heart' in the role		1
having bad habits		1
having black humour		1
having dark humour		1
lunch break in car		5
lunch on the go		2
missing information		2
no time for staff support		1
not getting it right		1
pressure of role		5
pressure to get on road		6
shedding a tear		1

Name	Description	References
switching off		38
unable to work late		1
usefulness of toll tag		1
you cannot walk away		1

Appendix 10 : Distress protocol

Distress Protocol for qualitative data collection

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&

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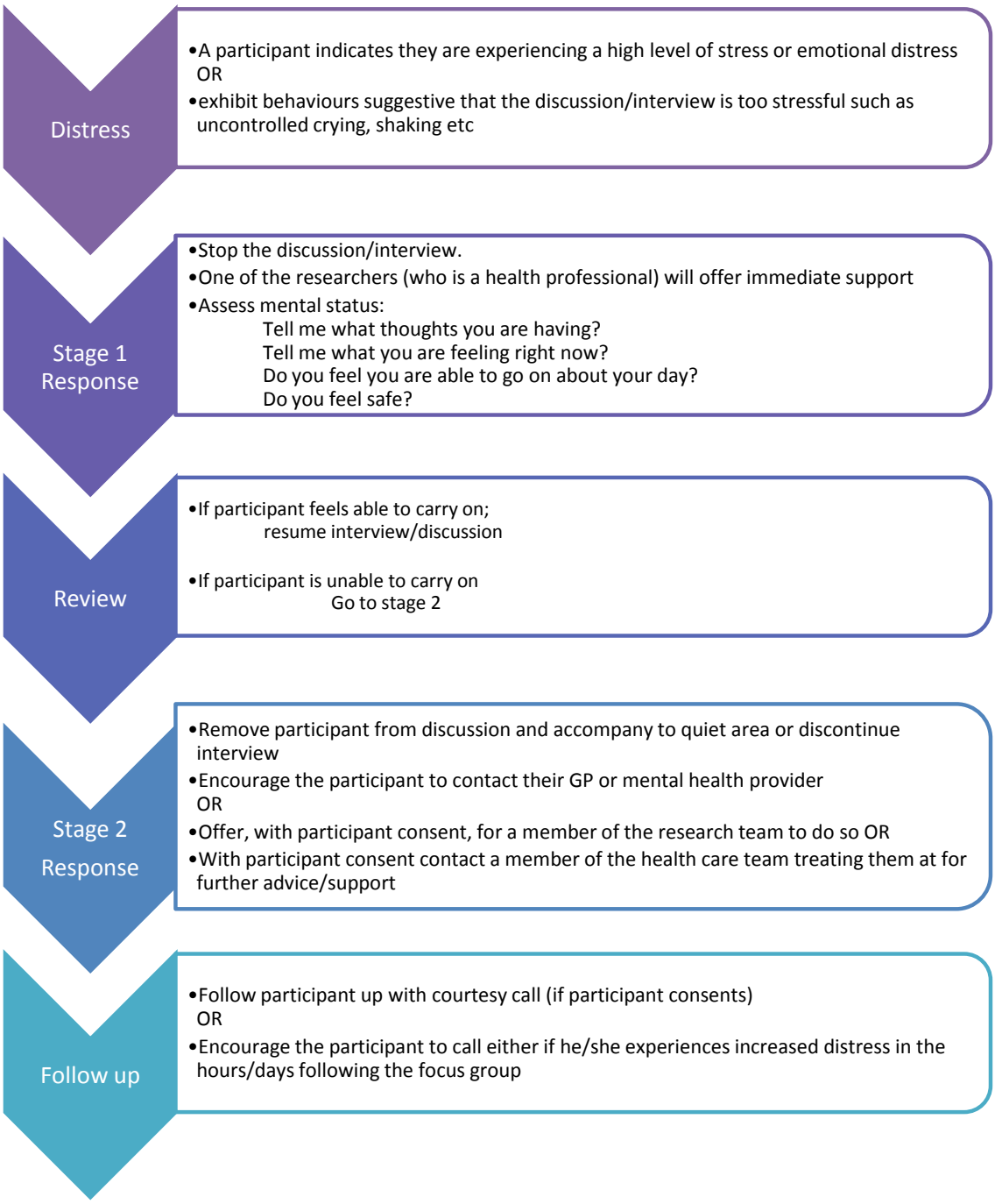
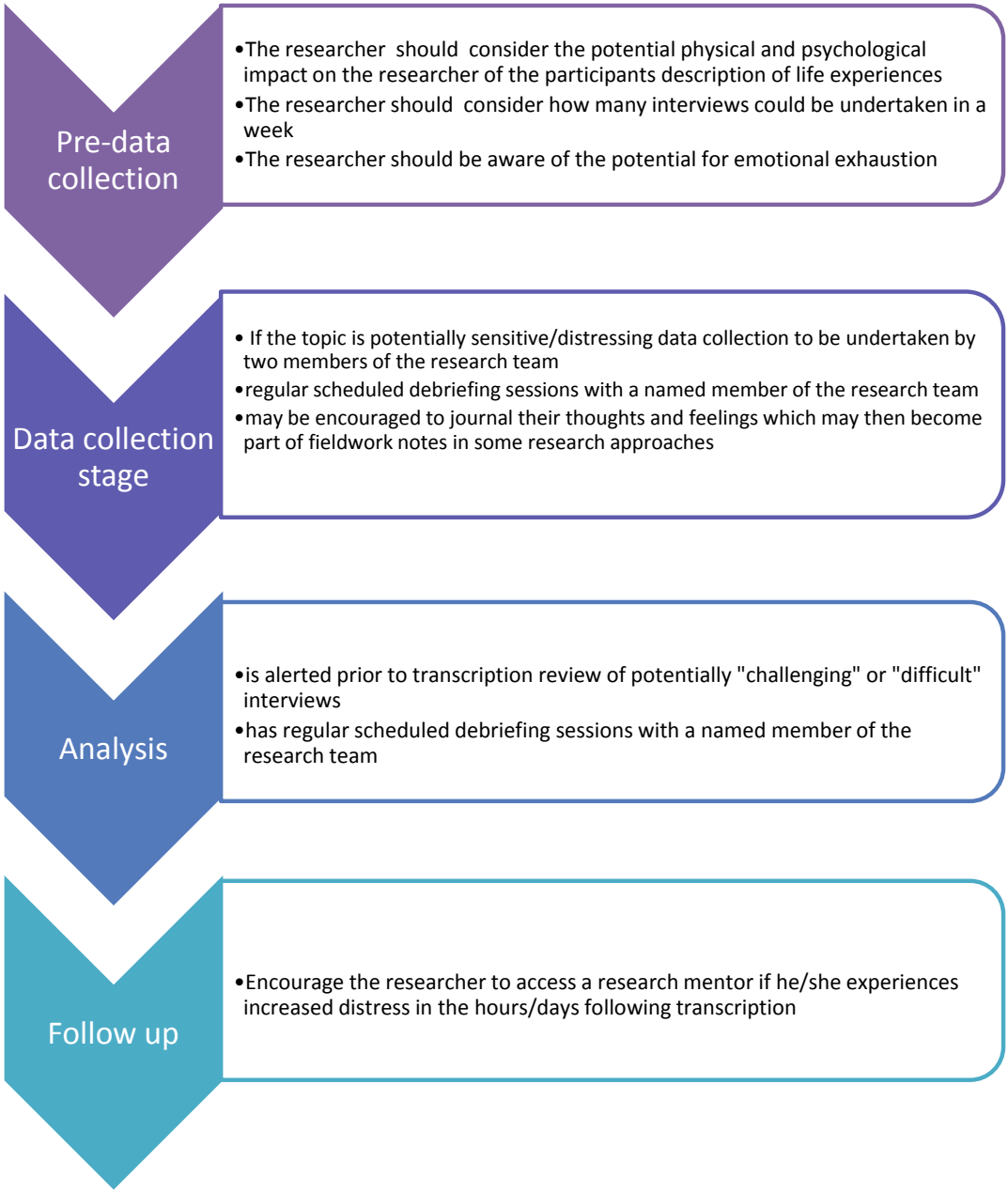
Distress Protocol 1: The protocol for managing distress in the context of a research focus group /interview

(Modified from : Draucker C B, Martsolf D S and Poole C (2009) Developing Distress Protocols for research on Sensitive Topics. *Archives of Psychiatric Nursing* 23 (5) pp 343-350)

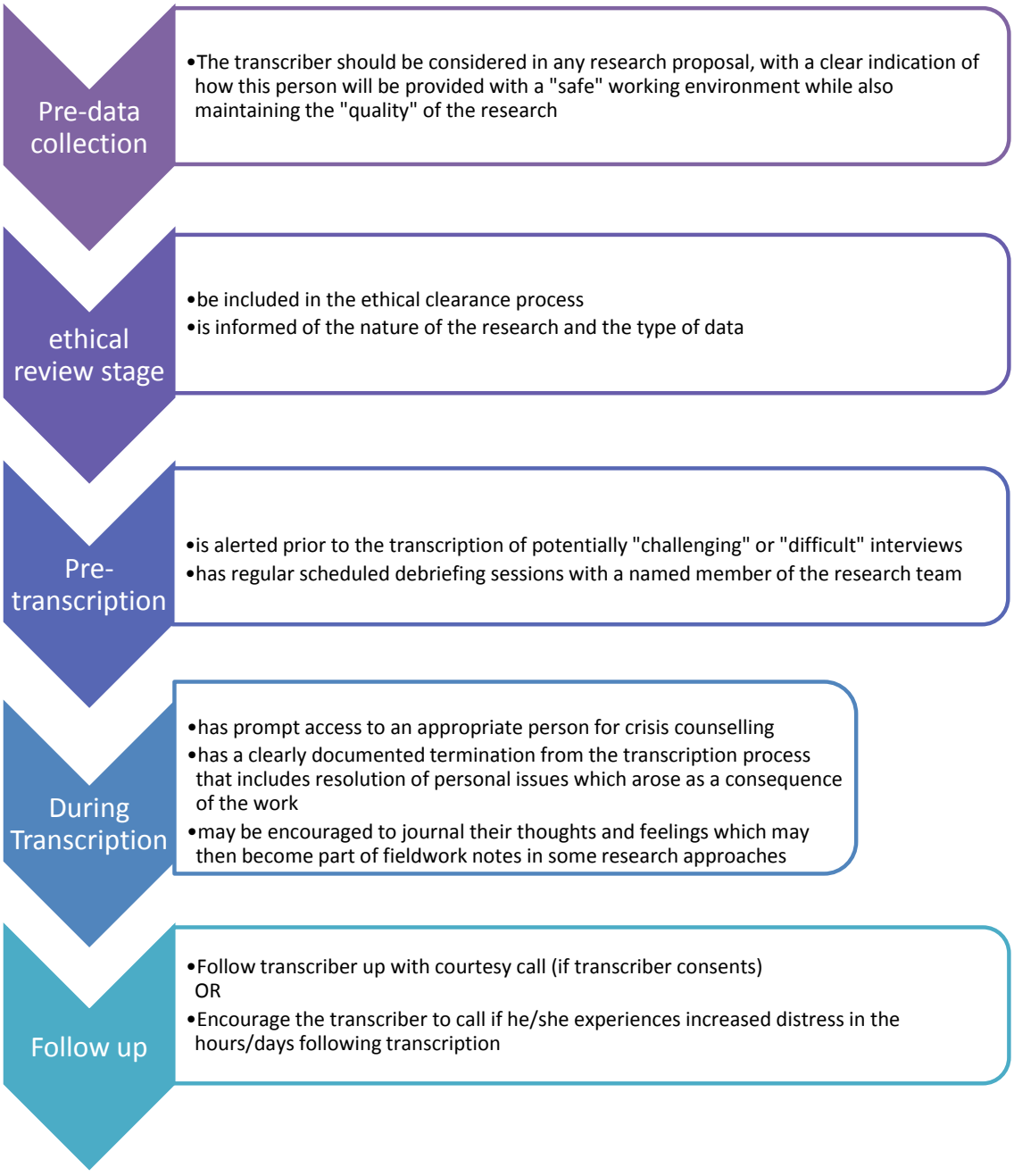


Distress Protocol 2: The protocol for managing distress in the context of a research focus group /interview management
McCosker,H Barnard, A Gerber, R (2001). Undertaking Sensitive Research: Issues and Strategies for Meeting the Safety Needs of All. Forum: Qualitative Social Research, 2(1)



Distress Protocol 3: The protocol for managing distress in the context of a research focus group /interview transcription

(Gregory, D Russell, C Phillips, L (1997). Beyond textual perfection: transcribers as vulnerable persons. Qualitative Health Research, 7(2), 294-300.)



Appendix 11: Focused codes and themes