

Transitions in palliative care provision across healthcare settings in the U.S.: a grounded theory of interdependence between specialist and generalist palliative care teams

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I declare that this thesis is my own work and has not been submitted for the award of a higher degree elsewhere.

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Abstract

Background: Individuals requiring palliative care near the end of life often receive that care in multiple healthcare settings, from both specialist and generalist palliative care teams. There is a need to better understand the processes that take place between the two teams that create or disrupt continuity of palliative care provision.

Aim: The aim of this study was to develop a substantive theory of the psychosocial processes that occur between inpatient specialist palliative care teams and generalist teams outside the hospital setting who care for palliative patients after discharge.

Methods: Semi-structured interviews were conducted with interdisciplinary clinicians from specialist palliative care teams and generalist healthcare teams in the U.S. Purposeful and theoretical sampling was used to recruit 21 clinicians. Data were analysed using constructivist grounded theory methods including constant comparative analysis of iterative levels of coding, memoing and diagramming, and abductive analysis of the literature.

Results: A grounded theory of interdependence identified the psychosocial processes that contribute to team perception and function, and the outcomes of those processes. Specialist and generalist palliative care teams function with different degrees of interdependence in relation to other teams caring for shared patients based on how they perceive themselves as a team. When teams function more interdependently across healthcare setting boundaries, clinicians perceive outcomes to be more positive for patients, families, and themselves. In contrast, when teams function more independently within boundaries, outcomes are perceived to be more negative. Additionally, a team's self-perception and way of functioning further perpetuate that self-perception and way of functioning over time.

Conclusion: This substantive theory contributes new insights into how palliative care specialists and generalists should work and communicate with each other across healthcare settings to provide continuous and collaborative care for patients and families experiencing advanced illness. It provides a theoretical starting point for additional research to explore interventions that impact teams' relationships and collaboration across healthcare settings.

Key words: Palliative care, interdisciplinary team, interprofessional collaboration in healthcare, continuity of care, self-construal, interdependence

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1 Introduction and Background

Millions of individuals worldwide need palliative care every year to ease the suffering of the person who is ill and their caregivers during the last phases of life. Palliative care can be provided within the walls of hospitals, care homes and facilities, primary care and speciality clinics, or patients' own homes by interdisciplinary healthcare professionals as well as by volunteers and laypersons trained in palliative care (World Health Organization & Worldwide Palliative Care Alliance, 2014). Seriously ill patients often receive healthcare in more than one setting over time, depending on the stage of their illness and their individual needs. Continuity of care between healthcare teams for individual patients as they move between settings is important in meeting the complex physical, psychosocial, and spiritual needs that often accompany serious illness (Meier & Beresford, 2008). Continuity of care across care settings depends, in large part, on collaborative actions and interactions of the healthcare teams who are working to meet patient and caregiver needs in each setting (Uijen, Schers, Schellevis, & van den Bosch, 2011). Understanding the interactions of professional teams from different healthcare settings in which palliative care is provided is necessary to promote continuity of palliative care, and thus better alleviate suffering at the end of life.

As a practicing registered nurse in the midwestern United States for the past 36 years, I have observed these realities in daily practice. My experiences in both the intensive care setting for over 20 years and on an inpatient specialist palliative care consultation service for the past 12 years have highlighted how interactions between healthcare teams can impact patients, families, and professionals. These experiences also contributed to a strong desire to better understand these interactions.

A constructivist grounded theory study designed to explore the interactions that occur between these teams was undertaken to develop a substantive theory of this process. The hope for this undertaking was that findings would help to guide future research, inform future palliative care delivery, and improve continuity of palliative care, impacting the experience of patients, families, and professionals. In this chapter, the scope of palliative care need and practice internationally is described, and the

importance of continuity of care across healthcare settings and the impact of continuity and team interaction (or lack thereof) on palliative care provision is presented. The specific focus of this study and an overview of the thesis concludes the chapter.

1.1 The scope of palliative care need

The World Health Organization and the Worldwide Palliative Care Alliance have identified an international need for and human right to palliative care for all patients with life-threatening illness to minimize suffering and promote quality of life at all stages of illness (World Health Organization & Worldwide Palliative Care Alliance, 2014). World Health Organization data from 2011 suggest that over 19 million adults worldwide and 63 children per every 100,000 population died that year from conditions requiring palliative care (World Health Organization & Worldwide Palliative Care Alliance, 2014). Other data from Europe, North America, Asia, Australia and New Zealand suggest that 38% to 74% of people who die may have palliative needs prior to death (McNamara, Rosenwax, & Holman, 2006; Morin et al., 2017; Murtagh et al., 2014). From 15% to 29% of hospitalised patients at any given time may be within their last year of life, suggesting a palliative care need for a large number of these individuals and their caregivers (Clark et al., 2014; Gott, Broad, Zhang, Jarlbaek, & Clark, 2017). Demographic shifts indicate an aging population and increased prevalence of chronic illness in many countries around the world (The Economist Intelligence Unit, 2015). As the overall population ages and lives longer with more chronic illnesses, the volume of individuals and caregivers with need for palliation of pain and other symptoms and support for the psychological and spiritual aspects of living with advanced illness will grow (Ankuda, Jetty, Bazemore, & Petterson, 2017). All these data demonstrate that the worldwide need for palliative care provision is great.

1.2 Specialist and generalist palliative care

The World Health Organization defines palliative care as an approach to care that strives to enhance quality of life by preventing and relieving physical, psychosocial, and spiritual suffering at all phases of a patient's illness (World Health Organization, 2018). Palliation has always been an element of

healthcare, as clinicians sought to ease suffering of those near the end of their lives when medical science could offer no further curative treatment. For example, prior to the advent of antibiotics, healthcare professionals could only offer patients symptom management and psycho-emotional and spiritual support in the event of a life-threatening infection. Primary care providers perceive that providing end of life care to patients and families with whom they have long-standing relationships is an essential responsibility of their role as primary managers of individuals' overall health needs (Nowels, Jones, Nowels, & Matlock, 2016; Senior et al., 2019). International efforts, with examples on all continents except Antarctica, have been underway in the last decade to establish resources to promote provision of palliative care across the spectrum of healthcare delivery from home health care to primary care practices to hospital intensive care settings (Advisory Board of IPAL-ICU, 2019; Murray et al., 2015; World Health Organization & Worldwide Palliative Care Alliance, 2014).

With the emergence of palliative care as a medical specialty, distinctions have arisen between what has been termed specialist and generalist palliative care (Murray et al., 2015; Pang et al., 2015; Quill & Abernethy, 2013; Schneider, Mitchell, & Murray, 2010; Shipman et al., 2008). The World Health Assembly, the World Health Organization and the Worldwide Palliative Care Alliance, and the European Alliance for Palliative Care have recognised this distinction as a way to describe varying levels of intensity and expertise in palliative care provision (Arias-Casais et al., 2019; Munday et al., 2019; World Health Organization & Worldwide Palliative Care Alliance, 2014). Some have used the term primary palliative care, which has been defined as "palliative care practised by primary health care workers, who are the principal providers of integrated health care for people in local communities throughout their life" (Munday et al., 2019, p. 621). Primary palliative care is considered a subset of generalist palliative care. Generalist palliative care includes non-primary care clinicians such as hospitalists or oncologists who meet patients' palliative care needs (Munday et al., 2019). The broader generalist term was used in this study to include non-primary care teams.

Specialist palliative care is provided by interdisciplinary healthcare professionals who have undertaken advanced palliative care training. In addition to advanced training, palliative care specialists are characterised by having a clinical practice dedicated to this type of care for patients with life-threatening illness (Arias-Casais et al., 2019). In contrast, primary care teams and teams working in other subspecialties, such as geriatrics or oncology, often provide palliative care, including symptom management and holistic psychosocial support, along with usual medical management for patients with life-threatening illness or who are approaching death. This approach of integrating palliative care into usual medical care is referred to as generalist palliative care (Quill & Abernethy, 2013; Shipman et al., 2008). Specialist and generalist palliative care approaches are seen as complementary methods to meet the needs of individuals and their caregivers during a life-threatening illness or at end of life.

Global healthcare leaders endorse this specialist/generalist distinction as one strategy to provide palliative care services to the most people possible who would benefit (Arias-Casais et al., 2019; World Health Organization & Worldwide Palliative Care Alliance, 2014). Models of palliative care delivery vary widely, impacted by healthcare systems' structures and financial resources as well as individual countries' income levels and public policies (Kumar, 2018). For example, specialist palliative care services around the world may be provided through inpatient specialist palliative care consultation services, residential or hospital-based palliative care units and hospices, community clinics, day centres, and home-based programs (World Health Organization & Worldwide Palliative Care Alliance, 2014). Generalist palliative care provision has been identified in a wide range of practice settings around the world, including but not limited to community-based general practice/family medicine (Ankuda et al., 2017; Schneider et al., 2010), geriatrics (Albers et al., 2016), cardiology (Gelfman, Kavalieratos, Teuteberg, Lala, & Goldstein, 2017), oncology (Gidwani et al., 2016) and rural or district nursing (Burt, Shipman, Addington-Hall, & White, 2008; Cumming, Boreland, & Perkins, 2012; Walshe & Luker, 2010). Generalist palliative care provision by interdisciplinary team members in the acute care hospital setting has been recognised as well (Anderson et al., 2017; Gardiner, Cobb, Gott, &

Ingleton, 2011). A combination of specialist and generalist efforts are perceived to be necessary to meet the growing need for quality care for people nearing the end of life.

1.3 Care transitions between settings

Care transitions occur when patients move to and from different physical settings, such as from home, where their healthcare is managed by a primary care team, to the hospital, where a hospital-based care team often assumes their care. Other examples of care transitions are from hospital to home or from a residential care facility to hospital (Abarshi et al., 2009). Older adults, those with complex conditions or lower socio-economic status, or who are minorities are at higher risk for difficult care transitions (Graham, Ivey, & Neuhauser, 2009; World Health Organization, 2016). Individuals with palliative care needs may experience multiple care transitions between healthcare settings during the course of their illness due to advancing disease, uncontrolled symptoms, or increasing physical care requirements at home.

Population health data from multiple countries has demonstrated that individuals nearing the end of life experience frequent transitions between healthcare settings. In Switzerland, 64.5% of patients in their last six months of life had one or more care transitions (Bähler, Signorell, & Reich, 2016); in the U.S., 80% had one or more, and 39% had four or more care transitions in the last six months (Wang et al., 2017). In Belgium, Italy, the Netherlands and Spain, 55-60% of individuals had one or more care transitions (including transitions to hospice units) in the last three months of life (Van den Block et al., 2015).

Care transitions between healthcare settings have been described as “chaotic” processes that put patients and caregivers at risk (Davis, Devoe, Kansagara, Nicolaidis, & Englander, 2012, p. 1652). Multiple negative clinical outcomes have been associated with these transitions, including increased mortality and morbidity, medication errors, delays in treatment, and unnecessary patient suffering (Davis et al., 2012; World Health Organization, 2016). Attention to the psychosocial needs of patients and caregivers is often neglected in the transition across settings and clinicians can experience

frustration secondary to the inability to resolve perceived gaps in care that occur at this time (Baillie et al., 2014). Care transitions, occurring frequently for patients with palliative care needs, introduce a potential occasion for failure of continuation of quality care.

1.4 Continuity of care

With an understanding that both specialist and generalist palliative care efforts may be necessary to adequately meet the needs of those requiring palliative care and that patients with palliative care needs frequently make transitions between healthcare settings, the concept of continuity of care gains importance. Continuity has been defined as “the degree to which a series of discrete healthcare events is experienced as coherent and connected and consistent with the patient’s medical needs and personal context” (Haggerty et al., 2003, p. 1221). With every patient care transition across healthcare setting boundaries or between different teams caring for the patient and their caregivers, opportunities arise to maintain or disrupt continuity of care for that individual.

1.4.1 Dimensions of continuity of care

Many dimensions of continuity of care have been identified that relate to different aspects of care, including the patient’s experience, time and geographic factors, interpersonal factors, transfer of information, clinical treatment of disease, and relationships between professionals (Alazri, Heywood, Neal, & Leese, 2007). Of the many types of continuity described, five dimensions of continuity of care seem to be most pertinent to care transitions of palliative care patients between settings. These are outlined in Table 1. For people with complex palliative needs and their healthcare teams, each of these dimensions is relevant in developing a meaningful, individualised, and effective plan of care that follows the patient across settings and can be followed by diverse healthcare teams.

Table 1: Dimensions of continuity of care

Dimension of continuity of care	Description
Informational continuity	Knowledge of an individual patient’s past and personal circumstances informs current treatment (Haggerty et al., 2003)
Management continuity	A consistent, coherent approach to treat health issues is used across various healthcare clinicians (Haggerty et al., 2003)
Relational continuity	An ongoing therapeutic connection between a patient and one or more healthcare clinicians is established (Haggerty et al., 2003)
Interdisciplinary continuity	Past knowledge of the patient is available across a span of medical specialties (Saultz, 2003)
Cross-boundary continuity	Care provided is consistent across boundaries of healthcare settings (Alazri et al., 2007)

1.4.2 Impact of continuity of care

Continuity of care between patients and their healthcare professionals can have both positive and negative effects on clinical outcomes. Increased continuity of care by a healthcare provider has been associated with increased preventive care, adherence to medical regimens, and decreased emergency department use, hospitalizations, and costs (Pereira Gray et al., 2003). However, when providers have followed a patient for a significant length of time, their ability to recognise slow development of disease or complications of disease is sometimes decreased (Alazri et al., 2007). Relational continuity has been associated with increased patient satisfaction, trust, and confidence in healthcare providers. Management continuity supports patient confidence in providers as well, when clinical advice given by different clinicians in different settings is consistent; when management continuity is absent, confidence is broken. Informational continuity, ensuring that knowledge of the patient’s past and present circumstances is communicated to all healthcare providers involved in the patient’s care,

contributes to cross-boundary continuity when patients move across healthcare setting boundaries (Alazri et al., 2007).

Patients value continuity of care with their health care providers more when dealing with serious conditions such as cancer or medical problems involving psychosocial as well as physical issues (Alazri et al., 2007; Delva, Kerr, & Schultz, 2011; Pereira Gray et al., 2003; Turner et al., 2007). Individuals with palliative care needs are experiencing serious illness and may be nearing death. These individuals often have complex physical needs, such as symptoms that are difficult to control or decreasing functional capability requiring specialised interventions to maintain or support physical independence. They and their caregivers may be suffering from social isolation or financial stressors, psychological issues such as depression, or existential distress related to facing the end of life. They may be facing emotionally difficult decisions related to medical treatment options or life-sustaining procedures. By nature, palliative care needs are complex, with strong psychosocial components along with advanced medical issues, so for this patient population, continuity of care may be particularly important.

Having multiple teams responsible for meeting patients' and families' needs in different settings creates complexity in carrying out a seriously ill patient's plan of care (Haggerty et al., 2003). The transition between healthcare settings and teams creates risk and uncertainty for patients, often characterised by poor communication and coordination of care, resulting in negative health outcomes (Cline, 2016). For individuals with palliative care needs, this may include communication and coordination between specialist palliative care teams in the hospital or specialty clinic and generalist teams in the hospital or in a person's home community. The potential divide between these teams that can impact continuity of care is twofold: the teams often reside and work within different physical boundaries, and they often come from different disciplinary or specialty perspectives.

1.5 Collaboration between specialist and generalist palliative care teams

Many aspects of collaboration between specialist and generalist palliative care teams have been studied, including interactional and psychosocial components related to how the teams perceive, understand, interact with, and communicate with each other. One of the motivators for generalists making consultation referrals to the specialist team is the generalist having an established interpersonal, cross-disciplinary relationship with the specialist team (Kirby, Broom, Good, Wootton, & Adams, 2014). Visibility of the specialist team in a shared work place, allowing frequent interaction, also contributes to this motivation (Ewing, Farquhar, & Booth, 2009; Kirby et al., 2014; McCaughan et al., 2018) as does an understanding of roles and boundaries of each team (Aitken, 2006; Wright & Forbes, 2014). Sometimes referrals are hindered by a sense of personal failure or patient abandonment on the part of generalists when they refer to the specialist palliative care team (Wright & Forbes, 2014) or negative perceptions of the other team (Walshe, Todd, Caress, & Chew-Graham, 2008). Factors that impact the ongoing working relationship between palliative care specialists and generalists include a sense of identity as a specialist or generalist (Albers et al., 2016; Firn, Preston, & Walshe, 2016; Keane, Bellamy, & Gott, 2017), the presence or absence of clear role and practice definitions (Dudley, Ritchie, Rehm, Chapman, & Wallhagen, 2019; Hanratty et al., 2002; Kamal, 2016; Kavalieratos, 2014) and the level of trust and respect between the two teams (Firn et al., 2016; Firn, Preston, & Walshe, 2017). Relationships between the two teams have been found to improve when generalist and specialist teams meet together by videoconference to confer regarding shared patients (Mitchell et al., 2014). Barriers to good collaboration between palliative care specialists and generalists include inadequate or infrequent communication (Albers et al., 2016; Dudley et al., 2019; Firn et al., 2017; Shipman et al., 2003; Woodhouse, 2009), power differentials and criticisms of the other team's practices (Walshe et al., 2008) and tensions related to professional territories (Gott, Seymour, Ingleton, Gardiner, & Bellamy, 2011; Street & Blackford, 2001). All of these factors that impact initial and ongoing collaboration have to do with thoughts, perceptions and understandings of, and relationships and communication with, the other team; that is, psychological and social factors.

1.6 Psychosocial processes in continuity of palliative care provision

In order for informational, management, relational, interdisciplinary, and cross-boundary continuity of care to be maintained through collaboration as patients move between palliative care settings and between specialist and generalist teams, the actions of multiple members of the two teams must interact in some way. How each clinician's or team's actions become connected with the actions of other clinicians or teams to create or disrupt continuity constitutes a process. Processes consist of a sequence of single events that become linked together as part of a larger entity and lead to an outcome (Charmaz, 2014a). Systematic processes for continuity of care between specialist and generalist palliative care providers are rare; instead continuity has been found to occur more randomly as a function of informal personal connections between healthcare providers (Gardiner, Gott, & Ingleton, 2012). The role of personal connections between professionals as one key to promoting continuity highlights the psychosocial nature of the process.

As demonstrated, many studies have explored the psychosocial factors that impact collaboration and teamworking between specialist and generalist palliative care teams in different settings. However, how those factors such as perceptions and understandings of the other team, or relationships and communication with the other team, influence the actions of teams and team members, and how those actions are then linked to become processes of collaboration, is yet unknown. No studies have looked specifically at the psychosocial processes related to continuity of care that occur between palliative care specialists in the hospital and generalists outside the hospital setting when patients with palliative care needs are discharged from the hospital and cross from one setting to the other.

1.7 Contextualisation for this study

Research examining collaboration and partnerships between specialist and generalist palliative care providers has been completed internationally (Firn et al., 2016; Gardiner et al., 2012). For example, in a 2012 systematic review of impacts on good partnership working between specialist and generalist palliative care providers, more than half of the 22 included studies were from the United Kingdom

(U.K.), about one third from Australia, and one study each from New Zealand and Canada (Gardiner et al., 2012). In a 2016 systematic review exploring facilitators and barriers to collaboration between specialist and generalist palliative care teams within the hospital setting, of 23 included studies, about half were from the U.K., one quarter from the United States (U.S.), and eight others from Australia, New Zealand, Japan, Europe, Africa, and Asia (Firn et al., 2016). A few studies from Australia include consideration of collaboration across hospital to community boundaries in palliative care provision (Mitchell, Del Mar, O'Rourke, & Clavarino, 2008; Street & Blackford, 2001).

Because the U.S. model for providing specialist palliative care is different than models used in other countries, findings about interactions between palliative care specialists and generalists across settings in other countries do not necessarily translate to the U.S. setting. One key difference between the U.S. healthcare system and systems elsewhere in the world is a differentiation between specialist palliative care and hospice care. Hospice care in the U.S. is acknowledged as a subset of specialist palliative care, but there are specific rules about who can receive hospice care under U.S. government insurance and most commercial insurances. In order to receive hospice care in the U.S., an adult individual must have a life expectancy of six months or less and agree to forego life-prolonging treatments (Carlson, Morrison, & Bradley, 2008). In the U.S., specialist palliative care developed largely as a way to extend the supportive benefits of hospice care to those with life-threatening illness that do not yet meet hospice criteria. It is primarily provided in the inpatient setting and is yet uncommon in the community setting outside the hospital (Dumanovsky et al., 2015; G. Smith, Bernacki, & Block, 2015). Thus patients in the U.S. who consult with specialist palliative care teams whilst hospitalised often rely on their generalist teams to provide palliative care after discharge unless they qualify for hospice care and receive that specific subset type of palliative care from a specialised team in the community.

1.8 Key terms

Key terms used in this thesis are defined in Table 2.

Table 2: Key terms

Key term	Definition for this thesis
Specialist palliative care	Palliative care that is provided by interdisciplinary healthcare professionals who have undertaken advanced palliative care training and focus their practice solely on this type of care
Generalist palliative care	Palliative care that is provided along with usual medical management by interdisciplinary healthcare professionals who practice in a non-palliative care specialty, such as primary care, oncology, geriatrics, or others
Inpatient	Patients who are currently admitted to hospital for at least one overnight stay
Outpatient	Patients who are not currently admitted to hospital for at least one overnight stay
Inpatient/Hospital setting	Any location within the hospital where inpatients are treated
Outpatient/Community setting	Any location outside the hospital where outpatients are treated, or an area within the hospital where patients who are not currently inpatients are treated
Clinic setting	Any setting where outpatients are treated through periodic visits with a healthcare professional; this may be a free-standing building or may be attached to a hospital

1.9 Summary of the problem

The scope of need for quality palliative care for the world's population is great. Individuals needing palliative care often receive that care from a variety of healthcare teams across multiple settings. Continuity of care is important for people with life-threatening illness, given the complexity of needs. It is clear that psychosocial factors such as perceptions, understanding, communication and relationships between teams impact provision of that continuity of collaborative care, yet little is known about the processes related to those psychosocial factors that specialist palliative and generalist healthcare teams use to support continuity when patients transition across healthcare

setting boundaries. Understanding these processes from the perspectives of professionals as they exist today is a starting point for development of better processes in the future to enhance continuity of palliative care provision and improve the experiences of both palliative care recipients and providers.

1.10 The aim and research question

This study was undertaken to contribute to the understanding of this phenomenon by developing a substantive theory of the psychosocial processes that occur between inpatient specialist palliative care teams and generalist teams outside the hospital setting who care for palliative patients after discharge. The research question that was the impetus for this study was “What happens between specialist and generalist healthcare teams when patients transition from receiving palliative care from an inpatient palliative specialist team to receiving palliative care from a generalist team after hospital discharge?”

1.11 Overview of the thesis

In Chapter 1, the scope of palliative care need and the importance of understanding continuity of care between palliative care teams and healthcare settings was presented. In Chapter 2, the philosophical foundations of the study in relativist interpretivism are described and the related choice of constructivist grounded theory methodology is justified. Methods of study design, recruitment and sampling, data collection and analysis, and ethical considerations are presented. In Chapter 3, findings leading to constructed categories and a preliminary conceptual model of interdependence between inpatient specialist palliative care teams and generalist teams that provide palliative care for patients in the outpatient setting after discharge from hospital are reported. In Chapter 4, a review of the empirical literature, structured around the categories of the preliminary conceptual model constructed from the data analysis, is described. Further abstraction of two main categories from the data is offered. Integration of the literature review findings with the data, resulting in a final theory and illustrative model of interdependence between inpatient specialist and outpatient generalist

palliative care teams across hospital and community boundaries, is portrayed in Chapter 5. Finally, in Chapter 6, theoretical conceptualisation of interdependence between specialist and generalist palliative care teams across hospital and community boundaries is situated in the wider literature, including other current theories, and contributions made by this theory are discussed. Implications for practice, education, policy, and research are identified.

2 Methodology and research design

The research question guiding this study was

“What happens between specialist and generalist healthcare teams when patients transition from receiving palliative care from an inpatient palliative specialist team to receiving palliative care from a generalist team after hospital discharge?”

The aim was to develop a substantive theory of the psychosocial processes that occur between these teams in the specific context of patient transitions out of the hospital in the U.S. healthcare system. The philosophical foundations for the choice of methodology chosen to pursue this aim are laid out in this chapter, namely the epistemological and ontological positions that led to the selection of constructivist grounded theory as a research methodology. The research design and specific methods utilised to carry out the study are also described.

The nature of the research question and aim is a major driver of methodology in any research (Braun & Clarke, 2013). In this study, the question focuses on developing an understanding of a process of interactions between human beings – that is, team members on specialist and generalist palliative care teams – in the particular context of transition of responsibility for a patient’s palliative care provision across healthcare setting boundaries. The aim identifies development of a substantive theory as the goal. A theory articulates relationships between concepts in a way that explains or increases understanding of a phenomenon, and a substantive theory is an “interpretation or explanation of a delimited problem in a particular area” (Charmaz, 2014a, p. 344). How this question and aim informed the philosophical approach and choice of methodology will now be illuminated.

2.1 Philosophical foundations of this study

2.1.1 Ontological approach: relativism

Ontology is a philosophical belief about the nature of reality, and whether we can know something independent of our perspectives and consciousness of the subject (Poonamallee, 2009). The basic

ontological position of a researcher may influence the development of the research question itself and affects their approach to research design and conduct (Charmaz, 1990). The basic question underlying ontological positions is whether things and ideas are objectively “real” external to the one who is observing them and are discoverable, or if the reality of a thing depends on the subjective perspective of the one observing and may not be static (Bryman, 2008; Vasilachis de Gialdino, 2009).

Philosophical approaches to research are also impacted by the research question. In this study, the research question led me to seek perspectives on interactional processes between human beings who are social entities that live and work within a variety of disciplinary, organisational, personal, and cultural milieus in the U.S. One could approach this study as an exploration of the technical processes within organisations that operationalise the transfer of responsibility for provision of palliative care between the inpatient specialist and outpatient generalist teams. If this were the case, an ontological position such as realism, that looks for external facts in the form of rules or procedures could suffice. However, the research question emphasises seeking to understand psychosocial processes between teams, which may involve intangibles such as social hierarchies, feelings and attitudes toward colleagues, or past experiences that impact the present. Thus, this research question calls for an ontological stance that is open to unique perspectives of all participants.

The relativist ontological view holds that reality is only known within the context and frameworks of those experiencing it (Baghramian & Carter, 2017). Within a research context, this view acknowledges that a perspective about what is real is a social construction by both the participants in a study and the researcher (Markey, Tilki, & Taylor, 2014). Because this study was designed to capture social processes between groups of individuals within a specific context, that is, the U.S. healthcare system, a relativist view that regards the context of each participant and the researcher in these processes, was appropriate. Relativism assumes that people’s perspectives are “socio-culturally bound” and that what we know as reality is tentative and subject to change (Thornberg, 2012, p. 250). The relativist view acknowledges that what is perceived as true in one context may not be true in another

(Baghramian & Carter, 2017). Thus the findings of one study cannot be taken as infallible truth, as findings may be different than in similar study with a different researcher with different participants in a different culture.

I came to this study without preconceived notions or theories of what was happening in the psychosocial processes between U.S. hospital specialist palliative care teams and their community generalist counterparts, and desired to develop a thorough understanding through the perspectives of individuals across a spectrum of disciplines, geographies, and organisational cultures. An ontological approach was required that welcomed each unique perspective as valid and provided flexibility in adapting the approach to research as these perspectives were revealed throughout the study. Relativism met this need in a way that an objectivist approach could not.

2.1.2 Epistemological approach: interpretivism

Epistemology defines what one believes is “acceptable knowledge” (Bryman, 2008, p. 13). Basic questions related to epistemology have to do with how knowledge is acquired, and what is required for an idea to be accepted as knowledge (Steup, 2005). As is true with ontology, the epistemological foundation for a study is driven in part by the nature of the research question. If a study’s focus is a phenomenon that can be observed with one’s senses as an external observer, different epistemological principles serve as the foundation of the study than if the study is focused on the experience of human beings (Bryman, 2008). One’s epistemological position influences conduct of research by guiding the role of the researcher, how and what data is collected, what is done with the data, and how the data is presented as knowledge.

Because the research question in this study concerned exploring the perspectives of diverse human beings and their interactions with each other, an epistemological stance that emphasises the subjective nature of knowledge development was required. The interpretivist epistemological view emphasises the subjective nature of understanding the world and holds that new knowledge can only be generated through individuals’ interpretation of their experiences (Charmaz, 2014). Participants in

this study all come with experiences of interacting with professional colleagues when caring for palliative care patients who are transferring between healthcare settings that each may interpret differently based on their professional discipline, organisational culture, personal history, and individual biases. Each unique experience is vital to understanding the whole process thoroughly. This epistemology, which is open to all interpretations of reality that each participant brings, is well suited to capture the fullest understanding of the phenomenon.

An interpretivist stance also defines the role of the researcher. Rather than taking a neutral, distanced stance in regard to participants, the researcher seeks to engage with participants and respond to their interpretations of their experiences with an open mind. The researcher not only listens for the participants' interpretations of their experiences, but through engagement with the data and the wider literature, the researcher interprets the participants' interpretations to create meaning (Bryman, 2008). The social nature of the research question in this study, driving the choice of an interpretivist epistemological foundation, provided sound guidance for my function as a researcher in study design.

2.2 Choice of grounded theory research methodology

Given the nature of the research question, aim and philosophical underpinnings, a qualitative methodology was required. Qualitative methodologies apply to research that has the aim to understand and interpret meanings, perceptions, and experiences of participants, and looks for patterns in the data. In contrast, quantitative methodologies, coming from different philosophical foundations such as positivism and objectivism, are appropriate when the aim is to test a theory or hypothesis and there are already defined variables to be studied (Braun & Clarke, 2013). As there was no existing theory related to the process of interest for this study, and it was not yet known what variables might apply in this context, a quantitative approach would not have served the purpose of this research.

Numerous methodologies that stem from qualitative and interpretivist perspectives exist. Each has characteristics which commend it for different types of studies. Table 3 outlines the characteristics of alternative methodologies that were considered for this study.

Table 3: Qualitative methods considered

Methodology	Goal of research	Data collection and analysis methods	Role of the researcher	Research product
Ethnography	Description and interpretation of a cultural group’s behaviour (Creswell, 2013)	Interviews and observations, analysed through description and identification of themes about the cultural group (Creswell, 2013)	An active participant, striving to achieve intimacy with the cultural group (Polit & Hungler, 1999)	Rich description of a culture (Polit & Hungler, 1999)
Discourse analysis	Understanding of how language is used in social life to shape identities, relationships and activities (Shaw & Bailey, 2009; Starks & Brown Trinidad, 2007)	Interviews and observations, analysed through focus on words and how meanings are created through language (Starks & Brown Trinidad, 2007)	A participant in the discourse, aware of and candid about their own perspectives (Starks & Brown Trinidad, 2007)	Description of “language-in-use” and impact on production of social identities and relationships (Starks & Brown Trinidad, 2007)
Grounded theory	Exploration of how people make sense of social phenomenon and explanatory theory generation (Engward, 2013; Starks & Brown Trinidad, 2007)	Interviews and observations, analysed through constant comparison of coding leading to development of theoretical categories	In Glaserian grounded theory, an objective analyst of the data, without any interpretation; in Charmazian grounded theory, an engaged analyst of the data, with interpretation that includes	A theory generated from the data that provides a comprehensive explanation of social processes and patterns of behaviour (Engward, 2013; Polit & Hungler, 1999)

Methodology	Goal of research	Data collection and analysis methods	Role of the researcher	Research product
		(Creswell, 2013; Starks & Brown Trinidad, 2007)	the researcher's own views (Markey et al., 2014)	
Phenomenology	Description of the lived experience and basic essence of a phenomenon (Polit & Hungler, 1999; Starks & Brown Trinidad, 2007)	Interviews and observations, analysed through coding and categorisation for description of the essence of the experience (Creswell, 2013)	An active and engaged participant but with attention to "bracketing" any personal presuppositions (Polit & Hungler, 1999)	A thick description of the identified "essences" of the phenomenon (Starks & Brown Trinidad, 2007)

While each of these qualitative approaches can be useful to explore social phenomenon and can be congruent with an interpretive philosophical foundation, grounded theory methodologies aligned most thoroughly with the aim of this study. Ethnography could have been useful had the aim been to better understand the culture of the inpatient specialist or outpatient generalist palliative care teams as they do their work; as I have a clinical background in specialist palliative care, as a researcher I could have had opportunity to intimately observe that group culture. However, ethnography does not address the social processes addressed in the research question. Discourse analysis has some merit, as the processes of interest involve language, communication, and relationships between groups. However, I suspected that the interactions between specialist and generalist palliative care teams were multi-dimensional and wanted to capture both the language used and actions taken by team members. Phenomenology, like ethnography, does not focus on processes, but rather proposes to thoroughly describe the essence of an experience. While a thick description is useful, the goal of this study was to understand and explain the processes that occur between the teams in a specific context. Grounded theory as a methodology best matched the research question, as the focus is on understanding social processes and identifying patterns of behaviour that can help provide an explanation of the phenomenon under study.

2.2.1 Selection of the constructivist approach to grounded theory

Grounded theory as a research method has been operationalised in multiple ways, based on the researcher's philosophical positions about reality and knowledge generation. Based on the philosophical foundations of relativism and interpretivism that were drawn from the nature of the research question, constructivist grounded theory was selected as the particular methodology to guide this research. Charmaz developed the constructivist approach to grounded theory research as an evolution of the classic grounded theory approach proposed initially by Glaser and Strauss (Higginbottom & Lauridsen, 2014). Classic grounded theory developed as a method to apply systematic methods to qualitative research, thus increasing its acceptability in the research community. However, the classic grounded theory approach assumed that truth (theory) will

“emerge” from the data, reflecting a more positivistic belief in an observable and discoverable reality (Markey et al., 2014). Charmaz’s constructivist approach assumes that multiple social realities exist, that they are an interpretation by those who experience them, and that individuals construct realities out of their perceptions and interactions (Higginbottom & Lauridsen, 2014). The constructivist grounded theorist builds theory through active interaction with participants and interpretation of those interactions and anchors findings within a specific context, leaving the constructed theory open to re-examination in different contexts (Charmaz, 2014a; Kempster & Parry, 2011). Constructivist grounded theory methodology fit well with the relativist and interpretivist foundations of this study, drawn from the research question.

2.2.2 Alignment of key elements of constructivist grounded theory

Several key elements of constructivist grounded theory methodology recommend it for this study, including the acknowledgement of the complexity of human experience and social interactions. In palliative care practice, and particularly when multiple interdisciplinary healthcare professionals are involved in transfer of responsibility for palliative care provision for seriously ill patients and families, there are many dynamics at play. For example, there may be clinical factors related to medical treatment, relational issues between interdisciplinary professionals, or emotional aspects of caring for people who may be nearing death, among others. Healthcare professionals may or may not be consciously aware of the factors that contribute to their daily actions. A constructivist approach makes room for human complexity and provides the flexibility for uncovering more than is currently known or expected by either the participant or the researcher (Higginbottom & Lauridsen, 2014).

The second aspect of constructivist grounded theory that lends itself well to this study is the legitimacy provided the researcher’s background knowledge, perspectives and values. While Glaser’s classic grounded theory approach required the researcher to remain objective and try to set aside any previous knowledge of the topic in their analysis (Markey et al., 2014), the Charmazian constructivist approach acknowledges that researchers’ interactions with participants, the data, and their own

experiences play an important role, not only in interpreting, but co-constructing the data with participants (Harris, 2015; Higginbottom & Lauridsen, 2014; Markey et al., 2014). In grounded theory methods, researchers' knowledge and experience in an area of inquiry is referred to as theoretical sensitivity, which allows them to discern degrees of nuance in the data (Andersen, Inoue, & Walsh, 2012; Deacon, 2012; Higginbottom & Lauridsen, 2014). This sensitivity is imperative to developing a strong, well-integrated theory (Strauss & Corbin, 1990). I have been a nurse in the U.S. for 35 years, initially in the setting of the intensive care unit (ICU) followed by inpatient specialist palliative care. My clinical experience demonstrated that individual healthcare teams often do not communicate cohesively with each other, leading to stress and frustration for all and that care planning established in the hospital was often not followed through after discharge by their primary care teams. The constructivist grounded theory approach counts the researcher's previous knowledge and experience as an "inherent part of the research reality" (Charmaz, 2014b, p. 13).

The role of the researcher as co-constructor of theory with participants in constructivist grounded theory methodology impacts the conduct and reporting of research. The role dictates a requirement for researcher reflexivity. Researchers must remain aware of their own social and professional background and how that might influence their view of the data and the research process (McGhee, Marland, & Atkinson, 2007). This is operationalised through the use of reflective memoing throughout the research process. As this approach places value on the researcher's voice (McGhee et al., 2007), the first person voice will at times be used in this thesis to reflect the constructivist philosophy.

Another aspect of constructivist methodology is that any resultant theory is considered to be transitory (Higginbottom & Lauridsen, 2014). This view is valued when studying a topic about which little is yet known using a relativist, interpretivist perspective. This study examines psychosocial processes between specialist and generalist healthcare teams in specific contexts, from the perspectives of the unique individuals who participate in this study. Future researchers may construct different understandings of these psychosocial processes by accessing a different group of participants

in other organisations, disciplines, or countries. This attitude of humility about findings, acknowledging that the results of this study are only one building block in the ongoing construction of knowledge, leaves room for further development of theoretical concepts and relationships, as the phenomenon is studied in other settings and in other ways in the future (Thornberg, 2012).

Finally, the philosophical foundations and choice of constructivist grounded theory methodology impacts the timing of the literature review in grounded theory research. Classic grounded theorists call for postponing any literature review until after data analysis has begun, with the goal of keeping the researcher as free from preconceived ideas and assumptions as possible (Dunne, 2011; Harris, 2015; McGhee et al., 2007). Others believe that new theories generated by grounded theory methods are grounded in the data alone but are situated in the context of existing knowledge (Dunne, 2011). Charmaz does not dictate when a comprehensive review of the literature should be done in a constructivist grounded theory approach but acknowledges the strengths and weaknesses of both pre- and post-data analysis literature review. An awareness of the gaps in current knowledge as well as any sensitising concepts from the field that may inform the research question are important (Charmaz, 2014a). However, given the interpretivist approach, there is no way to know in advance of data analysis what the most relevant concepts will be, thus making a systematic literature review prior to commencement of data collection and analysis challenging.

For this study, a high-level literature review, presented in chapter one, was undertaken to determine what, if anything, was already known about the psychosocial processes that occur between inpatient specialist and generalist palliative care teams outside the hospital setting. The initial, high-level literature review also helped to increase my theoretical sensitivity and provide context for initial purposive sampling criteria and the initial interview guide (Harris, 2015). After core categories and the preliminary conceptual model had been constructed, the literature was then systematically reviewed for any publications that would clarify, deepen, or challenge the constructed categories. The resulting literature was treated as data and incorporated into the ongoing analysis and theory construction.

2.3 Research design

Design of this research study will now be outlined using the study design and data analysis domains of the Consolidated Criteria for Reporting Qualitative Research (COREQ) structure (Tong, Sainsbury, & Craig, 2007). Based on the philosophical and methodological choices described previously, the study was designed using the structure and methods of a constructivist grounded theory framework. Key elements of the design include:

- Purposeful and theoretical sampling
- Data collection through in-depth interviews
- Constant comparative data analysis utilising:
 - Initial, focused, and theoretical coding
 - Memo-writing and diagramming
- Incorporation of related literatures into data analysis through iterative engagement between the data and the literature
- Construction of the substantive grounded theory (Charmaz, 2014a; Thornberg, 2012)

Prior to initiation of the study, necessary ethical approvals were obtained. Details of ethical approvals and considerations underlying conduct of this study conclude this chapter in Section 2.5.

2.3.1 Participant selection

2.3.1.1 *Setting*

Because the foci of the research question in this study are the processes that occur between U.S. healthcare teams across transitions between the inpatient and outpatient setting, a setting was desired that allowed capture of perspectives of teams in both settings. A large healthcare institution encompassing integrated medical practices that span hospital and clinic settings and extend over three geographic areas of the U.S. (Midwest, southeast and southwest) and five states was chosen as the primary setting for selection of participants. However, because perspectives of healthcare professionals who work outside of this healthcare institution could enrich the depth of the data

collected, two U.S. professional organisations with members who work in both inpatient palliative specialist and community generalist settings were included in recruitment efforts. Participants were sought from large tertiary care hospitals, smaller local hospitals, and clinics in both urban and rural areas in the U.S.

2.3.1.2 Sampling

Purposive sampling was used to identify a group of participants who would have insights into the psychosocial processes that occur during the transfer of palliative care responsibility between inpatient specialist and outpatient generalist palliative care teams (Speziale & Carpenter, 2003). The following inclusion criteria were utilised to identify potential participants for this study (see Table 4).

Table 4: Participant inclusion and exclusion criteria

	Palliative care <i>specialists</i>	Palliative care <i>generalists</i>
Inclusion criteria	<ul style="list-style-type: none"> • Being a member of a specialist palliative care team in a hospital setting in the United States • Having provided specialist inpatient palliative care for at least one patient for whom a generalist team assumed responsibility for palliative care needs after hospital discharge • If a participant was a member of both a specialist inpatient team and a generalist outpatient team, they were considered eligible if they could recall at least one example in which they, as an inpatient specialist, 	<ul style="list-style-type: none"> • Being a member of a health care team providing primary care OR other subspecialty care (other than palliative care) outside the inpatient hospital setting in the United States • Having cared for at least one patient who previously received specialist inpatient palliative care consultation

	Palliative care <i>specialists</i>	Palliative care <i>generalists</i>
	transferred responsibility for palliative care provision to a different outpatient generalist team at time of a patient's hospital discharge	
Exclusion criteria	<ul style="list-style-type: none"> • Non-English speaker • Having a specialist palliative care practice in which responsibility for patients' post-hospital palliative care needs <u>always</u> continue to be met by a specialist palliative care team 	<ul style="list-style-type: none"> • Non-English speaker • Having extensive training or certification in palliative care

Analysis of initial data obtained through purposeful sampling produced preliminary categories that seemed to represent psychosocial processes occurring between inpatient palliative specialist and outpatient generalist teams. Theoretical sampling, in which additional participants are selected based on what is needed to complete the theoretical categories rather than on achieving a diverse or representative sample, was used to gain access to participants whose perspectives could help refine and strengthen the categories (Charmaz, 2014). Interviews with registered nurses on generalist teams provided key insights into one process identified as a core category. As only one specialist registered nurse had participated, I sought an additional nurse from an inpatient palliative specialist team to access the specialist nurse perspective to strengthen this category. Theoretical sampling also led to inclusion of a member of an oncology team as interviews with specialists showed that patients' generalist palliative care needs after discharge were often met by an oncology team. I sought oncology team members' perspectives to see if the emerging process categories held true with non-primary care teams, and if they added any confirmatory or contradictory data (Markey et al., 2014).

In addition to purposeful sampling based on characteristics of the target population, participants from a range of clinical and geographic settings were sought so that a range of perspectives would be represented in the data to allow for comparative analyses that would strengthen resulting theory (Bazeley, 2013). For example, if all participants worked in an urban setting with a more dense clinical work population with more opportunities to encounter members of the other team, psychosocial processes may differ than those of participants in a rural setting where teams are more isolated. In addition, patients who receive inpatient specialist palliative care at an urban tertiary care center may live in a distant rural community, with the team managing their palliative care needs after discharge from hospital working in a remote location. In order to have access the teams who are actually experiencing the processes under study, a variety of settings were pursued in sampling.

2.3.1.3 Recruitment and consent

Multiple efforts were taken to reach potential participants (see Table 5 for a timeline of recruitment activities). Interdisciplinary inpatient palliative care specialists and outpatient generalists were recruited from a large healthcare system covering five U.S. states via email distribution of a recruitment flyer (see Appendix A). Flyers were emailed to all members of inpatient palliative care teams at the six hospitals in the healthcare system that had active inpatient specialist palliative care consultation services. Flyers were emailed to all members of 27 primary care practice teams across the healthcare system. Practices were included if they had email distribution lists that included physicians, nurse practitioners, physicians' assistants, registered nurses, licensed practical nurses, and medical assistants. Some sites also included social workers or mental health practitioners.

Participants from outside the healthcare system noted above were sought through two professional organisations with permission from organisational leadership. Specialist palliative care clinicians were recruited through posting of the recruitment flyer on the online discussion forum of a palliative care organisation with members from over 90 institutions across the U.S. Additional generalist participants

were recruited through inclusion of the recruitment flyer in the electronic newsletter of a midwestern U.S. family medicine organisation with almost 2,000 family medicine physician members.

Midway through the study, in order to allow theoretical sampling as initial data analysis unfolded, two changes in recruitment were made after obtaining approval from the Institutional Review Board of the healthcare system and Research Ethics Committee at Lancaster University. First, because initial data from specialist palliative care participants revealed that sometimes the outpatient teams that the inpatient teams interacted with when a patient left the hospital were oncology, rather than primary care, teams, generalist recruitment was extended to interdisciplinary oncology teams within the healthcare system to seek perspectives of those outpatient oncology teams (considered palliative care “generalists”). Secondly, because the majority of respondents to initial recruitment efforts were from generalist teams, revisions were made to the recruitment flyer to try and encourage participation of more palliative specialists. Separate specialist and generalist participant flyers were created to allow a more focused approach to the palliative specialist teams in recruitment. A second round of emails were sent to the same group of inpatient palliative care specialists within the healthcare system with the revised palliative specialist-specific recruitment flyer attached (see Appendix B for revised palliative specialist-specific flyer). The revised palliative specialist-specific recruitment flyer was also posted on the palliative care organisation’s online discussion forum to seek more palliative specialist participants. In order to seek oncology team member participants, emails were sent to interdisciplinary oncology team members within the healthcare system with the revised generalist-specific recruitment flyer attached (see Appendix C for revised generalist-specific flyer).

Table 5: Timeline of recruitment efforts

Month	Recruitment activity
August 2016	Email with recruitment flyer sent to interdisciplinary inpatient specialist palliative care team members in one large U.S. healthcare system (see Appendix A for flyer).

Month	Recruitment activity
September 2016	Email with recruitment flyer sent to interdisciplinary primary care practice team members in one large U.S. healthcare system (see Appendix A)
October 2016	<ul style="list-style-type: none"> • Recruitment flyer posted on the online discussion forum of a U.S. based, interdisciplinary palliative care organisation (see Appendix A) • Recruitment flyer included in electronic newsletter of a Midwestern U.S. family medicine organisation (see Appendix A)
September 2017	Permission for use of revised recruitment flyers and to include non-primary care generalists (such as oncology) in recruitment efforts granted by healthcare system's Institutional Review Board
December 2017	Permission for use of revised recruitment flyers and to include non-primary care generalists (such as oncology) in recruitment efforts granted by Lancaster University's Research Ethics Committee
January 2018	<ul style="list-style-type: none"> • Second email with palliative care specialist-specific recruitment flyer sent to same interdisciplinary inpatient specialist palliative care team members in one large U.S. healthcare system (see Appendix B) • Palliative care specialist-specific recruitment flyer posted on the same online discussion forum of a U.S. based, interdisciplinary palliative care organisation (see Appendix B) • Email with generalist-specific recruitment flyer sent to interdisciplinary oncology team members in the large U.S. healthcare system (see Appendix C)

Interested clinicians contacted me via email. I responded to all via email with additional information and query about eligibility. Participants were evaluated for inclusion and exclusion criteria and six initial participants were chosen for the first round of interviews. A combination of inpatient palliative care specialists and outpatient generalists as well as a range of professional disciplines (nursing, medicine, and social work) were purposefully included initially to provide a variety of perspectives. Snowball sampling was utilised by asking participants to share study information with any colleagues

who may have insights into the interactions between inpatient specialist palliative care teams and generalist teams outside the hospital setting (Braun & Clarke, 2013).

Consent was obtained from each participant prior to undertaking the interview. Prior to the interview, each participant was provided with a Participant Information Sheet (PIS) explaining key elements of the study and participation (see Appendix D). After reviewing the PIS, participants signed a consent form, acknowledging that they understood the information provided (see Appendix E). For participants interviewing via videoconference, the signed consent was either scanned and emailed or mailed by postal service back to me.

2.3.2 Data collection through in-depth interviews

2.3.2.1 *Interview process*

Each participant was contacted via email and date, time and location for interviews were mutually established. Locations for interviews with participants who lived within driving distance of my home were set up based on the participant's preference. Interviews for those outside driving distance were arranged to be performed via Zoom, a secure videoconferencing platform ("Zoom meeting plans for your business," 2017). Participants self-selected a pseudonym by which to be identified in the data. Four participants were interviewed remotely with only audio; two instances due to technical issues with video capability and two at the request of the participants. Each participant was interviewed once.

In line with the constructivist grounded theory approach, interviews were conducted using a general topic guide instead of a rigid schedule of questions (Speziale & Carpenter, 2003). Basic demographic data was collected with which to be able to describe the participant group (see Appendix F). Interview guides were developed for specialist and generalist participant groups (see Appendix G and H for initial interview guides), though the questions asked of each group initially were similar but not identical. Development of questions on the initial interview guide was informed by both the overview of the literature and theoretical sensitivity (Charmaz, 2014). Throughout the study, the interview guide

evolved iteratively to reflect developing categories from the data and to enable theoretical data collection (Charmaz, 2014). See Appendices I and J for the revised interview guides.

2.3.2.2 *Data management*

Interviews were audio recorded using an Olympus WS-853 device which provides encrypted digital files. The interview audio files were transferred onto a password protected laptop. I transcribed the recordings verbatim as they were completed, using NCH Express Scribe Professional software ("Express Scribe Transcription Software," 2017) , omitting any participant identifiers or identifying details to ensure anonymity. The transcribed files were saved on an encrypted, password protected flash drive and in the secure online Lancaster University data repository. As the transcripts were completed, the files were imported into NVivo's qualitative data analysis software program (QSR International, 2019). Each post-interview reflexive memo was also imported into NVivo. The audio file of each interview was reviewed a second time (separate from the transcription) to attend to meanings that may have missed during the interview itself. This provided three opportunities to be immersed in the data and to reflect on other ways that the participants' perspectives could have been explored (McGhee et al., 2007; Speziale & Carpenter, 2003).

2.4 Data analysis

A hallmark of grounded theory research is the use of constant comparative analysis in which all new data is compared with previously analysed data (Speziale & Carpenter, 2003). While the methods used are described here in a linear fashion, the nature of constant comparative analysis created a cyclical, not linear, process; thus, some of the steps described occurred concurrently or cyclically.

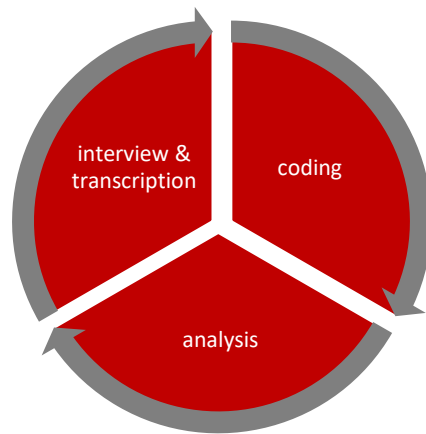


Figure 1: Iterative process of constant comparative analysis

2.4.1 Initial coding

Initial coding is the first step in constructivist grounded theory data analysis that serves to “fracture data” (Charmaz, 2014, p. 147) to provide the building blocks that will eventually be constructed into theory. Each transcript was initially coded for any content that could have relevance to the psychosocial processes that occur between inpatient specialist palliative care and generalist healthcare teams outside the hospital setting. Initial coding produced a large number of codes, which helps to ensure thorough exploration of the data (Speziale & Carpenter, 2003).

2.4.2 Focused coding

The next step in constructivist grounded theory analysis is focused coding, which serves to raise the level of data analysis to a more abstract level. Asking questions of the data like “What’s happening here?” and “What are the circumstances that lead to this action?” served to guide this process and helped capture the actions and conditions within the processes between the teams (Charmaz, 2014a). These measures helped to keep analysis of the data focused on psychosocial processes occurring between the specialist and generalist teams.

Working with the initial code labels assigned to segments of text while simultaneously reviewing the transcript data, codes were categorised within NVivo according to similarity of meaning. In addition,

a manual sorting exercise with sticky notes helped to clarify categorisation of initial codes. To reflect the focus of inquiry on social actions, most categories were constructed using active words in the form of gerunds (Charmaz, 2014). Codes that did not lend themselves to categorisation at this stage or were deemed to be outside the scope of this study were reserved in a separate file for further consideration later in the study as needed.

2.4.3 Theoretical coding

The final stage of coding in constructivist grounded theory methods focuses on developing the identified categories rather than trying to capture every possible idea in the data, narrowing the scope of analysis to the evolving theoretical categories (Charmaz, 2014). At this stage of analysis, six main categories had been developed. All subsequent interview transcripts were coded using these categories as a coding framework and all earlier transcripts were reviewed and recoded using this framework. Theoretical sampling continued until no further insights into the theoretical categories were uncovered. This is theoretical saturation, as defined by Glaser (2001) and endorsed by Charmaz (2014): “It is the conceptualization of comparisons of these incidents which yield different properties of the pattern, until no new properties of the pattern emerge” (Glaser, 2001, p. 191).

Additional theoretical coding was completed with the literature selected through the systematic literature review described in Chapter 4 and iteratively with the previous interview transcript data after theoretical coding of the literature, described in Chapter 5. Literatures included in the review were uploaded into NVivo and coded using the theoretical categories from the data as a coding framework. A sticky note sorting exercise was completed with the codes identified in the literature to compare to coding findings in the data. After literature analysis was complete, all interview transcripts were once again analysed using expanded conceptual categories gained from the literature. Findings from the literature were only incorporated into the final construction of the grounded theory if the literature data was congruent with participants’ and researcher’s perspectives and interpretations (Thornberg, 2012).

2.4.4 Memo-writing and diagramming

Memos are a fundamental part of the grounded theory research process that help the researcher to remain engaged with the data, to recognise their own biases and assumptions, to explore relationships between codes and categories as they develop into concepts, and to document the process of theory construction (Charmaz, 2014a). Memos were written after each interview to reflect on the interaction with the participant and to capture any immediate thoughts about ideas expressed. Memos were also created during the coding process to capture a conceptual idea or to note how this transcript might relate to a previously coded transcript. Memos were considered part of the data, in line with the constructivist belief that theory is constructed as a result of the interactions of researchers with participants, their own experiences, and the literature (Charmaz, 2014b). An example of a post-interview memo is shown in Table 6 (see Appendix K for additional examples of reflective and analytic memos).

Table 6: Example of post-interview reflection memo

Post interview reflection memo	<p>Hill (SPC MD) is well known to me, as she works within the same health system, about 2 hours away from where I work. We are frequently in meetings together. I have a nursing leadership role in the Center for Palliative Medicine in which she works, but no authoritative role in regard to her.</p> <p>Despite not having video connection, we had a lively conversation; I think already knowing her was a help, as I could imagine her face and connect it with her voice inflections, etc. Interestingly, in the situation example that she gave when there WAS a strong connection with the GPC team, she attributed a lot of that connection to the RN complex care coordinator. The RN reached out to her – took the initiative (like “Lou”?) and it sounds like the CCC was the key to drawing Hill and the PCP into a shared conversation after discharge for continued collaboration.</p>
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She also gave an example of shared visits with the PCP (like Lou and Crash).
 Of note, this MD only does inpatient SPC, so going to a clinic visit in primary care with a patient was out of the ordinary – maybe I should ask her how often this happens.

Diagrams and conceptual maps illustrating the development of relationships between categories and concepts are valuable analytic tools in theoretical construction and are another form of memoing in grounded theory research (Andersen et al., 2012; Charmaz, 2014a). Throughout the data and literature analysis and eventual theory construction, exploratory diagrams were drawn on a whiteboard and on paper, all dated and captured through photography so they could be reviewed sequentially to see analytical progress. One example is displayed below in Figure 2; for the complete series of drawings and diagrams, see Appendix L.



Figure 2: Early diagramming of code relationships

2.4.5 Construction of the substantive grounded theory

“Constructivist grounded theory” is both a methodology and a product. The process of “theorising” occurs while carrying out the prescribed methods designed to apply rigour to data analysis, while allowing for creative abduction by the researcher, that results in construction of a theory. The

outcome of theorising, a constructed grounded theory, serves to illustrate one interpreted understanding of the relationships, patterns, and meanings in a social process (Charmaz, 2014a). In this study, theory construction developed in stages. After the initial analysis of the interview data, utilising three stages of coding and memos and diagramming, a preliminary conceptual model was developed to illustrate my interpretation of the categories and relationships between categories at that stage. Adaptations were made to that conceptual model after analysis of the literature which furthered theoretical development by raising two of the main categories to a more abstract level. Finally, after returning to the interview data for further analysis using expanded conceptual categories from the literature, final propositions of the grounded theory were articulated, and the conceptual model was amended to reflect those propositions and became a graphic representation of the final theory. The final theory offers a socio-culturally bound understanding of the psychosocial processes that occur between inpatient specialist and outpatient generalist palliative care teams at time of hospital discharge, which was the aim of this study.

2.5 Ethical considerations

The Institutional Review Board (IRB) of the large healthcare system deemed this study to be minimal risk and exempt from requirement for IRB approval in June 2016. Approval was obtained from the Lancaster University Faculty of Health and Medicine Research Ethics Committee in July 2016 (see Appendix M for IRB submission and Appendix N for approval notification from each organisation). Permission for revisions to the recruitment process and a change in secure videoconferencing software was requested and granted by the healthcare system's IRB in September 2017 and the Lancaster University Research Ethics Committee in December 2017. Requests made were to include non-primary care generalist teams, such as oncology, in recruitment emails and to use revised team-specific recruitment flyers, one for specialists and one for generalists (see Appendices B and C for revised flyers). Permission was obtained from the research department of the healthcare system to utilise internal email distribution lists for participant recruitment and from the palliative care and

family medicine professional organisations to contact their membership with study information and the recruitment flyer.

I did not approach potential participants directly so as to avoid any sense of coercion. While some of the participants were professionally known to me, there were no participants with whom I had a reporting or authoritative relationship, which may have influenced their responses during the interview. Participants were provided with printed information about the study and had opportunity to ask questions prior to consenting to participate. All participants signed informed consent forms prior to participation. They were made aware of their freedom to stop the interview or withdraw from the study at any time. There were no direct benefits to participants for participating in the study, other than the potential to contribute to knowledge that may improve the care of patients and families requiring palliative care in the U.S. A small potential risk of emotional distress was present, depending on a participant's experiences that the interview evoked; in this event, participants had the right to stop the interview and a referral would be made to their employer's Employee Assistance Program for support, if desired.

All paper interview materials were stored in a locked cabinet until shredded after electronically stored. Audio recordings were immediately downloaded from the recording device to a password protected computer. I transcribed the interviews myself, minimising risk of loss of confidentiality. Electronic files of interview transcripts were encrypted and stored on the password protected computer and also saved to a secure online Lancaster University repository. All interview data was anonymised by using participant-selected pseudonyms. Any potentially identifying details were edited out of the transcripts without changing the meaning of the content. Participants were offered the opportunity to receive a report of the findings after conclusion of the study.

2.6 Summary

This study of psychosocial processes that occur between specialist and generalist palliative care teams across healthcare setting boundaries was undertaken using a constructivist grounded theory

approach, based in the philosophical foundations of relativism and interpretivism. With this methodology, a substantive grounded theory was constructed utilising iterative, constant comparative analysis of data from participant interviews, my interpretations of the data and related extant literature.

3 Findings from the initial analysis of interview data

The methodology and design described in Chapter 2 provided the direction for analysing the interview data collected through in-depth interaction with participants in this study. In this chapter, participants are described, and the construction of core categories and in-depth explanation of each category are presented. A summary and depiction of a preliminary conceptual model concludes the chapter. Findings from analysis of data from the literature and iterative analysis of interview data will be presented in Chapters 4 and 5, with the final theory described in Chapter 5.

3.1 Composition of the participant group

A total of 35 potential participants responded to recruitment efforts. These 35 were made up of 12 registered nurses, 10 physicians, six advanced practice nurses (nurse practitioners or clinical nurse specialists), four social workers, and three chaplains. Of these 35 potential participants, 16 (46%) were from generalist healthcare teams and 19 (54%) were from specialist palliative care teams. Seven respondents did not meet eligibility criteria and seven failed to respond to email requests to set up a time for interview. Of note, while three chaplains did initially respond to recruitment efforts, none participated. Two had left the palliative care field and did not wish to proceed to an interview, and one did not respond to requests to set up an interview. As a result of purposeful and theoretical sampling, the participant sample included specialists and generalists from urban clinic or tertiary hospital settings and rural clinic or smaller, local hospital settings. One oncology clinician and a second palliative specialist registered nurse participated as a result of theoretical sampling. The characteristics of the 21 participants are described in Table 7. Interview length ranged from 22 to 62 minutes with a mean of 33 minutes.

Table 7: Characteristics of participants

Characteristic	Inpatient specialists N = 10	Outpatient generalists N = 11
Gender		
Female	8 (80%)	10 (91%)
Male	2 (20%)	1 (9%)
Age		
31-40	4 (40%)	5 (45.5%)
41-50	2 (20%)	2 (18.2%)
51-60	2 (20%)	3 (27.3%)
61-70	2 (20%)	1 (9%)
Ethnicity identified		
White	10 (100%)	11 (100%)
Professional discipline		
Medicine	4 (40%)	2 (18.2%)
Nursing – Registered nurse	2 (20%)	6 (54.5%)
Nursing – Advanced practice	2 (20%)	3 (27.3%)
Social work	2 (20%)	1 (9%)
Professional subspecialty		
Family medicine	0	6 (54.5%)
Internal medicine	0	4 (36.4%)
Oncology	0	1 (9%)
Palliative medicine	10 (100%)	0
Years of experience in subspecialty		
< 5 years	1 (10%)	4 (36.4%)
5-15 years	8 (80%)	4 (36.4%)
16-25 years	0	1 (9%)
26-35 years	0	1 (9%)
>35 years	1 (10%)	1 (9%)
Holds certification in Palliative Care	7 (70%)	0
Practice setting		
Tertiary care hospital	6 (60%)	n/a
Community hospital	4 (40%)	n/a

Characteristic	Inpatient specialists N = 10	Outpatient generalists N = 11
Urban/suburban clinic	n/a	6 (55%)
Rural clinic	n/a	5 (45%)
Geographic region of U.S.		
Midwest	9 (90%)	9 (82%)
Southwest	0	2 (18%)
Southeast	1 (10%)	0

3.2 Construction of the categories of the preliminary conceptual model

Constructivist grounded theory methods of constant comparative analysis through initial, focused, and theoretical coding, memoing, and diagramming were used to progressively refine a large number of initial codes to a final set of five core categories. Figure 3 depicts this progression.

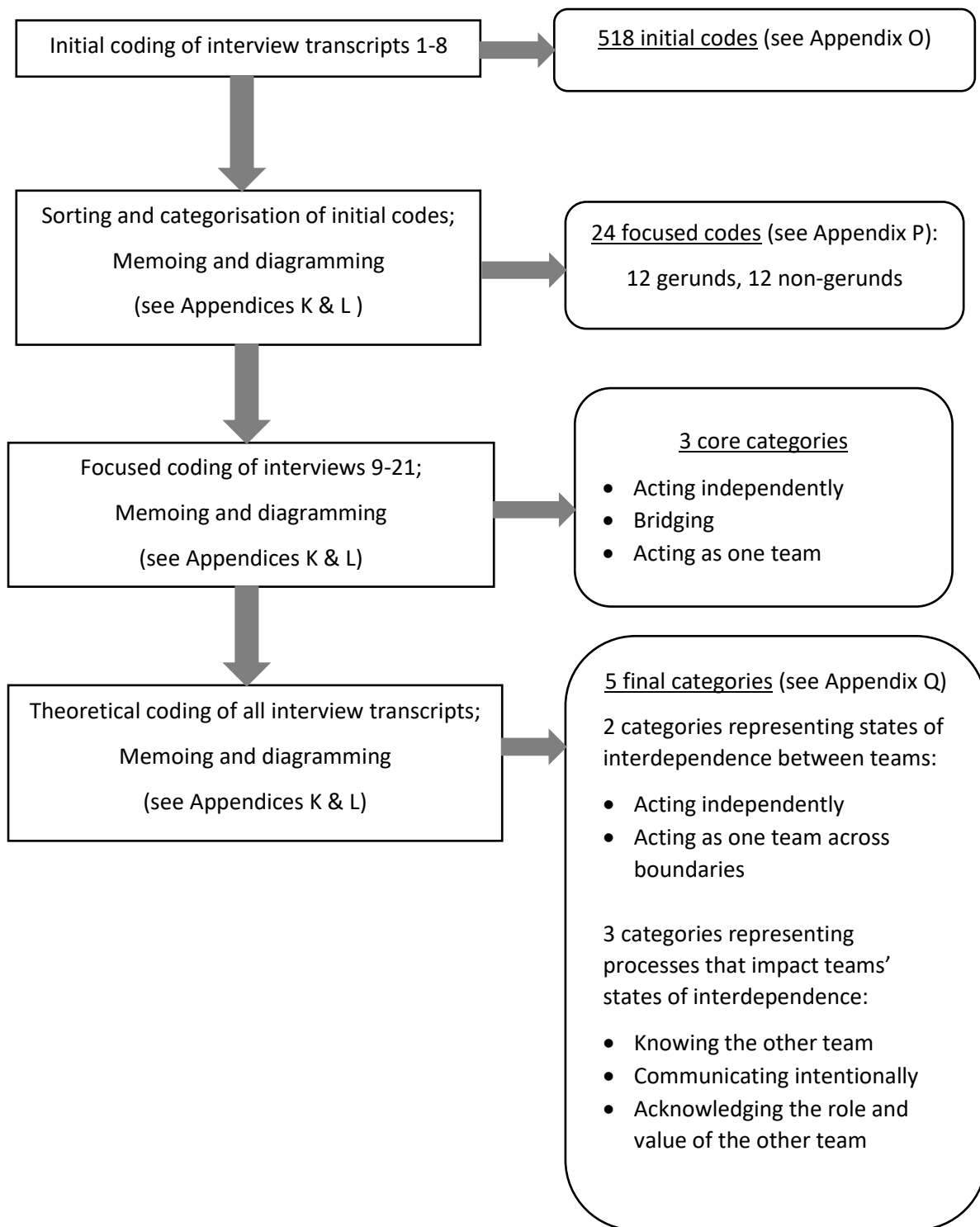


Figure 3: Progression of coding throughout transcript analysis

The remainder of this chapter will present the findings from the iterative analysis of the interview transcripts and the preliminary conceptual model constructed from the findings. Representative text

from interview transcripts that contributed to construction of the categories and model will be provided. Quotes will be in italics and identified by the self-assigned, sometimes humorous, pseudonyms chosen by each participant and by their professional role, abbreviated as noted in Table 8.

Table 8: Participant role abbreviations used to identify quotes

Role or specialty	Abbreviation
Inpatient specialist palliative care	ISPC
Outpatient generalist care	OGC
Registered nurse	RN
Nurse practitioner	NP
Social worker	SW
Physician	n/a

3.3 States of interdependence between inpatient palliative specialist and outpatient generalist care teams across boundaries

Analysis of participants' reports of experiences as a member of a palliative specialist or generalist team resulted in the construction of two categories depicting "states of functioning" which explain the way teams carry out their clinical practices in relation to the other team. These two states have been conceptualised in this study as states representing degrees of interdependence. In a social context, interdependence has been described as that which "occurs when two or more persons interact and the outcomes of those interactions depend in part on the action of each person" (Balliet & Van Lange, 2013, p. 1091). Participants described two main states: one in which inpatient specialist palliative care teams had little or no interaction or collaboration with the generalist teams caring for the same patients in the community after discharge from the hospital, and one in which the two teams had a stronger connection with more interaction which facilitated collaboration and a level of reliance on the other to provide coordinated care for patients. The first state was labelled "acting independently"

and the second, “acting as one team across boundaries.” Differing perceived outcomes were identified associated with the degree of interdependent functioning of the teams.

The timing of opportunities for the inpatient palliative specialist teams and the outpatient generalist teams to act independently or as one team was not limited to the actual time of the patient’s discharge from the hospital and transition back to a community setting. Opportunities were evident during the hospital stay, in which the inpatient specialist teams did or did not interact or engage with the patient’s outpatient generalist team and vice versa, and after the patient’s transition back to the community, throughout their ongoing course of treatment. Even though one team was not actively managing the patient’s care in one or the other setting (for example, the generalist primary care team was not the managing medical team while the patient was hospitalised, and the inpatient palliative specialist team was not actively involved in managing the patient’s care in the community), both teams had opportunities to be engaged with the other team in both settings.

3.3.1 “Acting independently”

“Acting independently” was the default state and the most common occurrence for inpatient palliative specialist and outpatient generalist teams working across hospital/community boundaries. Without any deliberate action taken by either team, inpatient specialist teams provided their palliative care consultation in the hospital and the outpatient generalist teams provided the patient’s care after the hospitalisation, separately from the other team’s engagement with a patient and their caregivers. Each team carried out their part of the treatment plan of care as they perceived it without the insights into the patient’s situation that would be gained through interaction with the other team.

Oftentimes the smaller primary care clinics or the home primary care providers are limited to their access... oftentimes, there’s this gap of knowledge of what’s transpired during the hospitalisation and maybe what has taken place in terms of conversations and symptom management... (Crash, ISPC RN)

It felt like the knowledge of the person in the outpatient setting wasn't really applied to her in the acute care setting. (JGG, OGC physician)

The state of acting independently was demonstrated in multiple ways. Both inpatient specialist palliative care teams and outpatient generalist teams sometimes relied solely on documented notes in the electronic health record to communicate their findings from working with the patient and any resultant care plans to the other team, hoping or trusting that the other team will read their notes. Sometimes, the inpatient palliative specialist teams by default depended on patients or patients' families to inform the generalist team about the content of the inpatient palliative consultation, or to provide post-discharge feedback on patient outcomes to the inpatient team as needed. Teams in both the hospital and community settings had difficulty reaching a member of the other team by phone, when attempted. Teams made assumptions about accountability for certain aspects of care, such as symptom management, without verifying with each other who would take responsibility after the patient left the hospital setting. At times there was overt resistance by one or the other team to efforts to interact or engage regarding a patient's care. Participants from both inpatient specialist palliative teams and outpatient generalist teams voiced that a relationship or connection with the other team was non-existent.

I've never had any, I didn't have any contact with them at all. I just know they exist. (Jane, OGC RN)

3.3.1.1 Contributors to acting independently

Several factors contributed to teams acting independently, related to procedure, attitudes and perceptions, awareness, and time and space. Procedurally, team members noted that there was no standard process for ensuring that inpatient palliative specialist teams made connection with outpatient generalist teams and vice versa. This resulted in the default dependence on clinicians in the other setting seeking out, or finding by chance, any clinical documentation of interactions with the patient or established care plans by the other team. It also resulted in inconsistency from patient case

to patient case; sometimes there would be a more intentional connection, but often there was not. Individual clinician characteristics often drove whether or not a connection was made, rather than a policy or procedure that helped to ensure this was done consistently.

We don't have a process in place for that. (Rose, ISPC NP)

I think there's people that are better, just easier to connect with, or more receptive, and it's more how they are personally or professionally. (Susan, ISPC RN)

Attitudes and perceptions of members of both teams contributed to teams acting independently. Some outpatient generalist teams did not see a need for the inpatient specialist palliative care team's involvement, believing that they were able to provide all the palliative care a patient required. Other teams, both inpatient palliative specialists and outpatient generalists, felt a strong sense of ownership of the patient which sometimes led to a reluctance, or even fear, of sharing the responsibility for the patient with the other team. These perceptions increased the likelihood that the teams would work independently.

There's some providers that very strongly feel that they can manage all of the symptom management, palliative care type needs on their own... (Lacy, OGC SW)

I felt very protective in wanting to control what I could.... I didn't want to totally let them know my own apprehensions, that "Oh, I don't know if they know what they're doing" ... But at the same time, you know, I wanted to protect him, and make sure he was gonna be okay. (Dr. Zhivago, ISPC physician)

Certain perceptions unique to the outpatient generalist teams also contributed to teams acting independently. Generalist team members' perceptions that professionals on the other team saw them as incompetent in the ongoing care of patients with palliative needs hindered interdependence by raising a level of defensiveness on the part of generalists. This perception on the part of the generalist teams was noted by both generalists and palliative specialists. Some generalists felt a lack of respect for their historical relationships with patients from the inpatient specialist palliative teams. Inpatient

palliative specialist team members also noted that some generalists had ethical concerns related to their perception that specialist palliative care clinicians' practice tended toward euthanasia, and this hindered interdependent practice by impacting trust.

I think there was some component of just maybe some animosity or distrust, or that maybe there was some judgment happening, even though I didn't think there was, but I can imagine that there, they may have felt that way. (Dr. Zhivago, ISPC physician)

His belief of both palliative medicine and hospice is that our goal is to give people a bunch of morphine and hasten their death. (Hill, ISPC physician)

A general lack of awareness also contributed to teams acting independently. Generalist teams were often unaware that a consultation with specialist palliative care had happened while a patient was hospitalised. In some cases, the patient was the one who communicated to the generalist team that they had been hospitalised and that they had consulted with the inpatient specialist palliative care team. The hospitalist model of care, in which the patient's medical care in the hospital is provided by hospital medicine specialists rather than the patient's primary care providers, was perceived to add to this lack of awareness. There was also a bilateral lack of awareness and understanding of the other team's practice, the team's disciplinary makeup, and the role of various clinicians on the other team. This led to role ambiguity and confusion about responsibilities during and after the transition from hospital to community settings.

I don't know if there is a lot of communication between the teams. I do know that they'll place a note in the chart, and then the primary care provider would go in and read that. I think from that point... they kind of just go, "well now what?" (Jo, OGC RN)

I've had some conversations with the palliative care people, and I – people that I thought were appropriate for palliative care, and I was told that they weren't ... So I had a hard time trying to figure out what is the criteria to qualify for what they see as palliative care? I guess that

was my previous experience was one thing that kept me from trying to actively contact them.

(Kay, OGC RN)

Time and space factors were the final contributor to teams acting independently. Busy clinical schedules in daily workflow both in hospital for palliative specialists and in community practices for generalists promoted teams working separately when caring for shared patients. Finding enough time to identify the appropriate person on the other team was difficult. Once that contact was known, there was little time to make direct connections with the other team, either by phone or in person. Schedules for the two teams and the inpatient and outpatient practices differed, making it challenging to establish a time to connect. Time delays in completion of hospital discharge documentation contributed to generalist teams practicing independently, without the benefit of the specialists' consultation. Finally, geographic separation was a contributing factor. This separation could be local, with the two teams working in separate buildings, rarely interacting face to face, or it could be that specialist inpatient care was provided in a tertiary hospital and the patient's generalist team was located in a smaller town hundreds of miles away.

Just the amount of time that goes into trying to track down the right person to talk to. (Susan, ISPC RN)

You know, you can't have, you don't have time to have those conversations. Or you don't take the time to have those conversations. (JGG, OGC physician)

You'd have to walk across the parking lot – we are not connected to the hospital. So none of them come over here. There is no, we don't go into the hospital, so it's kind of those silos. (Andrea, OGC NP)

3.3.1.2 Perceived outcomes of acting independently

When inpatient palliative specialist teams and outpatient generalist teams acted independently across hospital/community boundaries, clinicians perceived that patients and caregivers receive fragmented

care. In this case, fragmented care was characterised by lack of a clear treatment plan, lack of appropriate follow up, and lack of defined roles and accountability for care after discharge. Treatment plans established in hospital by palliative care specialists, such as plans for symptom management or a patient's preference for aggressive versus non-aggressive interventions, were not readily accessible to the generalist team after discharge. Some generalists were not comfortable with particular medications or doses started by the inpatient palliative team and were unwilling to manage those medication regimens in the community setting, meaning patients were unable to get prescription refills. Palliative specialists worried that patients did not get appropriate follow up assessment for symptoms or complications from the generalist team. Sometimes the generalist team, unbeknownst to the inpatient palliative team, did not have the physical resources to carry out a plan established in the hospital with the palliative specialist team. Lack of clarity about accountability for aspects of care, like symptom management, also contributed to fragmented care. Fragmented care across the hospital/community boundaries could render plans of care for patients' palliative needs ineffectual.

The biggest challenge is making sure that what we start here in the hospital can actually happen outside of the hospital... We know that they need close follow up, but we can't guarantee any of that – that's out of our control. So we can start things here and, you know, make recommendations, and we try to connect them back with their home providers, but things can fall through – and then patients go without, or they are calling us in a panic... (Sally ISPC SW)

Fragmented care as a result of teams acting independently led to worse clinical outcomes, according to participants' perceptions. Perceived negative clinical outcomes on the part of both inpatient palliative specialists and outpatient generalists included patient suffering and unwanted medical visits and interventions. When care was fragmented and care plans established in the hospital fell apart after discharge from the hospital, participants perceived that patients experienced loss of symptom control, which led to emergency room visits or unwanted hospitalisations. Fragmented care

sometimes led to a reversal of decisions that were made in the hospital to limit further aggressive medical interventions and patients received treatments that they previously expressed a desire to avoid.

I worry about whether their symptoms are being managed, you know, whether they're suffering. What kind of distress they're having as a result of maybe a plan not being followed?

(Jean, ISPC SW)

I don't think we're giving the patient the best care possible... I think that patient didn't need to have those final hospitalizations that he had. We could have prevented those – they were not necessary. (Jane, OGC RN)

Patient and caregiver emotional and mental distress was also perceived by both specialist and generalist clinicians as an outcome of teams acting independently. When patients heard discordance between the care plan presented by the inpatient palliative specialist team and the generalist team providing care after discharge, participants perceived that patients experienced a sense of abandonment, fear, and confusion. They perceived that patients and caregivers would feel abandoned by the specialist team and fearful of loss of symptom control if the generalist team was unable or unwilling to continue the palliative plan of care established in the hospital. Generalists perceived that patients could feel abandoned if they as generalists were not engaged with the palliative specialist team in the management of their palliative needs at the end of life. Teams acting independently sometimes resulted in patients receiving conflicting messages from each team, which was perceived to create confusion and emotional distress for patients and caregivers. These inconsistencies made it difficult for patients and families to trust their care teams, from the perspective of the participant clinicians. An additional source of emotional distress for patients and their caregivers was perceived to come from their need to repeat emotionally difficult conversations and decisions about end of life care choices if the conversations and decisions made with the inpatient palliative specialist team was not carried over into the care provided in the community setting by the outpatient generalist team.

They're fearful, of maybe something that they heard from a local provider that isn't in the same, it isn't consistent, the message is different, and then they begin to mistrust, are not sure who they should trust. (Crash, ISPC RN)

It's such hard work for these people to work through all of their emotional things that, you know, lead to their decision making about end of life... and then to have, you know, someone come in and say, "Oh, but I have this one other treatment that we haven't tried that'll give you a 5% chance of maybe 2 more months"... It's exhausting emotionally. (Hill, ISPC physician)

Specialist and generalist clinicians also experienced emotional distress when the teams acted independently in providing palliative care to patients. This distress was expressed as frustration when specialists saw that there was no follow up after discharge to the plans they had laboured to establish with the patient and caregivers during hospitalisation. Others felt moral distress when they saw patients receive unwanted medical interventions or have uncontrolled symptoms because the teams did not work well together to collaborate on a plan of care. There was also a sense of loss and anxiety felt by specialists when they did not have any ongoing interaction with the generalist team after discharge and never learned what the outcomes for their shared patients were. Generalists felt they had not been present for their patients as they should have been when they were not involved in the palliative care provided by the specialist team.

It just kind of makes you feel like the work that you've done, and you know it's been really, really good work, that it stops when they walk out the door. That's how you feel. You don't have any way to follow that up to find out if that's the case or not. (Jean, ISPC SW)

I, as an old-fashioned doctor, like to be involved in all of that stuff with my patients, and so, you know, it feels like I wasn't present at a time when I should have been present for my patients. (JGG, OGC physician)

Despite the perceptions of these negative outcomes that result from inpatient palliative specialist teams and outpatient generalist teams acting independently, a positive outcome was noted by some generalist participants. Even if direct interaction or engagement with the inpatient palliative specialist team was lacking, generalists noted that reading the palliative specialist notes in the electronic health record could set the stage for a different focus for patient's medical care or stimulate further discussion with the patient and caregivers in their follow up visits in the community setting.

Maybe it helped me kind of have that insight as to what conversations took place in the hospital, and I could kind of continue that. I can recall reading the note, and being like, "Oh, okay..." so you know, maybe indirectly that helped me. (Lou, OGC RN)

3.3.2 "Acting as one team across boundaries"

"Acting as one team across boundaries" is the category used to describe the state of greater interdependence between teams in which teams actively and visibly worked collaboratively. Rather than transition of the responsibility for a patient's palliative care between hospital and community being characterised by a "passing of the baton" (Walter, ISPC physician) between inpatient palliative specialist and outpatient generalist teams, the transition was characterised by collaborative responsibility to continue to meet patients' needs, even though one team was more actively involved with the patient in a given setting. Participants acknowledged that functioning in this way required extra effort. This was made manifest between some teams by frequent bidirectional communication by email or telephone during and after a hospital stay to seek the other's perspectives on changes to the plan of care and clarify roles and responsibilities in carrying out the plan. Some teams participated in joint meetings with the patient, in which both inpatient palliative specialist team members and outpatient generalist team members were present. These occurred in both the hospital and the community settings. Some participants had not experienced this state of interdependence with the other team but voiced a desire for this type of engagement in the future and imagined that it would improve the care patients received.

Being there for the conversation, involved, to be able to provide a little bit of historical data to the palliative care practitioner, I think was helpful to her, but then also for me... the things that were discussed – the goals of care, the plan moving forward... to have that continuity to know that in a week, they know what we talked about. (Lou, OGC RN)

I worked on transitioning her over to methadone after talking to her primary care physician and making sure he'd be okay with that transition. (Hill, ISPC physician)

3.3.2.1 Contributors to acting as one team across boundaries

Attitudinal and physical proximity factors seemed to contribute to the state of acting as one team across setting boundaries. Clinicians who approached the other team with an attitude of humility promoted interdependent functioning. For example, some inpatient palliative specialist clinicians acknowledged that the outpatient generalist teams with long-standing relationships with patients would have more intimate knowledge of the patient that could impact clinical decision-making and reached out with curiosity to the generalists for help. Conversely, some generalists acknowledged that they may not be the best suited to have end of life conversations with patients with whom they have long-standing relationships due to their own emotions toward the patient and that palliative specialists, who may approach the patient with more objectivity, could be more helpful to the patient in that situation than they could. Respect was closely tied to humility in these interactions, as the other teams' work was seen as important and necessary for providing good clinical care. Characteristics of individual clinicians on teams were seen as contributory, with some professionals perceived as more receptive to engagement than others, particularly physician receptivity to engaging with non-physician members of teams. This receptivity incorporated both humility and respect, as clinicians perceived as being more receptive were not bound by hierarchical roles and were open to what other specialties or disciplines contributed to knowledge of patients and their care.

But there are gonna be times in which you gonna need the help of specialists, and that's where the humility piece really needs to come in. On BOTH sides. (Walter, ISPC physician)

Being in physical proximity to the other team with also contributed to teams acting as one across settings. Inpatient palliative specialist teams and outpatient generalist teams that had regular opportunities to see one another due to practicing in physical settings that included some shared space were more likely to act interdependently, as there were more occasions to interact regularly. However, some teams were able to create these interactions even when the other team was physically remote.

Visibility is huge. (Renee, ISPC NP)

No participants voiced having any standard team processes in place to ensure these interactions happened regularly. Instead, individual participants spoke of making the time to pursue connections with the other team because it was necessary for the best care of the patient.

3.3.2.2 Perceived outcomes of acting as one team across boundaries

When teams acted as one team across hospital/community boundaries, interdisciplinary clinicians on both teams perceived that patients received more coordinated care. Coordinated care meant that plans established by inpatient specialists were more likely to be carried out by the generalist team after discharge from hospital because the generalist team had been involved in care plan development, had a good understanding of the rationale for the plan and was aware of future contingencies for care if the patient's condition changed. These plans impacted patients' symptom management and preferences for future treatment choices. Specialist and generalist teams both had a stake in providing palliative care for patients and caregivers, rather than palliative care being seen only as a specialty practice that provided a consultation and then was no longer involved.

It definitely made me feel more confident in caring for the patient because I didn't have to worry about, you know, what if I wasn't available, and there was a crisis. Because the primary care physician was already so well informed about what our plan was, and how we were managing things. So, it was, you know, a team... (Hill, ISPC physician)

Clinicians perceived that patients' and caregivers' satisfaction with their care was greater when the specialist and generalist teams worked together as one team. Part of this perception was made manifest by the contrasting sensitivity to patient and caregiver distress when teams acted independently, noted earlier in the discussion of "acting independently." However, clinicians believed that patients valued assurance that their diverse healthcare teams were collaborating for the patients' benefit.

I think more people are extraordinarily appreciative to know that we're part of the same team.

(Walter, ISPC physician)

Professionals also experienced greater satisfaction in their work when teams acted as one. For generalists, particularly primary care teams, being fully engaged in the palliative care provided to a well-known patient was key to their work identity and gratification. Outpatient generalists from primary care felt strongly that caring well for patients through the end of life was an integral part of their role as primary care specialists. For palliative specialists, this satisfaction came from knowing that one's efforts were worthwhile and not wasted and impacted the care the patient received in another setting after hospital discharge.

I have a really strong bias... that palliative care is a big part of my job and that doing that well in the outpatient setting is really important part of my job... so to be included is a... really important part of my satisfaction, of my comfort... (JGG, OGC physician)

You feel like you've really given the best care possible. That you're not just shoving them out the door, and washing your hands of them, but you're really closing the loop. (Susan, ISPC RN)

3.3.3 Conditions that impact the degree of interdependence between teams

Initial analysis of the data suggested that three conditions cumulatively impact the degree of interdependence with which teams work. These conditions describe psychosocial processes that occur between these teams before, during and after times of patient transition between hospital and

community settings. Actualisation of these processes may differ over time between a given pair of specialist/generalist teams, thus teams may operationally move back and forth across the interdependence continuum over a period of time. The three conditions are “knowing the other team,” “communicating intentionally,” and “acknowledging the role and value of the other team.”

3.3.3.1 Condition 1: Knowing the other team

“Knowing the other team” is a multi-factorial condition that is the foundation of teams moving from “acting independently” toward “acting as one team across boundaries.” This condition was developed both through its presence and its absence in the data. In the most basic sense, it means being aware of who the other team is and how to contact them, even if only electronically. Participants spoke of searching the electronic health record to learn who the patient’s primary care team was and of searching the internet to find contact information for generalist team.

It’s really gonna come down to just knowing who your people you need to cc: the charts to.

(Sue, OGC RN)

So it went well, because me, the nurse... I just started googling the facility and numbers and names and ended up getting in touch with a social worker there who was very familiar with the patient. (Susan, ISPC RN)

Having physically met members of the other team and putting a face to a name increased the likelihood of interdependent practice. Having a personal relationship with a member of the other team, such as being friends or classmates outside the professional setting, made reaching out to the other team easier. Being professional acquaintances with clinicians on the other team through working together in the past increased trust and ease with which teams connected. Working in a smaller organisation allowed greater knowledge of the other team, as it was more likely that teams would encounter one another in their daily work. Being geographically separated was a barrier as there are fewer opportunities to meet face to face.

We're a lot smaller organisation, so you just kind of know people. (Andrea, OGC NP)

Another aspect of knowing the other team was having a basic understanding of the scope of practice of the other team. This included being aware of how their daily work is organised, what priorities guide their practice, and what kinds of treatments and interventions they utilise. For example, inpatient specialist palliative care team members who had worked in a particular generalist area prior to specialising in palliative care acknowledged that their personal understanding of the work and workflow of the generalist setting allowed them to interact and collaborate more meaningfully with the generalist team. When outpatient generalist teams had more knowledge of the specialist palliative care team's clinical scope of practice, interdependence was promoted as there were clearer role and responsibility definitions for each team. Knowing the interdisciplinary makeup of the other team, which raised awareness of what kind of support the other team is able to provide, was another component of understanding their scope of practice. Without this basic knowledge of the other's work, working together was hindered as one team's expectations for the other may not be realistic.

After they've seen that it helped their patients, then they've gone, "Oh... they know what they're talking about..." ... they've gotten to know us, they, we know them, we understand them, and we try to work together. (Renee, ISPC NP)

I didn't know the entire makeup of their team, you know. Probably assumed a lot – that you know, they had a social worker, they had a psychologist. I made that assumption. But there's a very real possibility that they didn't. (Dr. Zhivago, ISPC physician)

Knowing the other team was the most fundamental condition that must occur in order for any degree of interdependence between the teams to exist. Without the most basic aspect of knowing each other, awareness of a contact on the other team, the other conditions that supported the "acting as one team" level of interdependence were impossible. Intentional communication was not feasible, as an

intentional message requires an intended receiver. Without having some grasp of the other team's practice and capabilities, authentic acknowledgment of their role and value was also unattainable.

One of the hindrances is not knowing, not knowing each other. I always feel like, when people can put a name with a face, there's more thought behind the process. (Linda, OGC NP)

3.3.3.2 Condition 2: Communicating intentionally

As with "knowing the other team," the condition of "communicating intentionally" was evident both by its presence and its absence in the processes that occurred between inpatient palliative specialist and outpatient generalist teams. Some teams trusted in a passive process in which they expected that the other team would access their documentation about their interactions with the patient in the electronic health record of their own accord. However, for this to occur, a palliative specialist team member had to *know* who the generalist team was in order to go in and read the generalist team's past notes about the patient, or the generalist team had to *know* that a specialist palliative care consult occurred while the patient was in hospital in order to look for the consultation note in the record. Despite reliance on this passive, default process, clinicians doubted that it was effective.

I made some suggestions about things that I would do in my discharge summary note, but I'm not even really sure that anybody read that or saw it. (Rose, ISPC NP)

But then we are just relying on discharge notes. You know what I mean? There's no, like, follow up calls, or anything like that. (Andrea, OGC NP)

At times, teams took the initiative to communicate in more direct ways with the other team. Examples included an inpatient specialist sending a direct email to a primary care clinician notifying them that an inpatient palliative care consultation occurred and to alert them to the presence of a consultation note to review in the medical record, or by sending a copy of the consultation note directly to the generalist team. Yet this type of intentional communication was often unidirectional with no response from the receiver to the sender. For specialist senders, unidirectional communication was perceived

as less than optimal and dissatisfying, for they received no feedback from the generalist team about their response to the palliative care plan, or feasibility of carrying it out after discharge. For generalist receivers, this intentional communication was appreciated even if there was no response made to the sender. This intentional, though unidirectional, communication increased the chance that the other team would receive the intended communication and be more likely to incorporate knowledge of the other team's interaction with the patient into their own care of the patient, thus increasing interdependence between the two teams.

There's no formal process... it's not very good, it seems like it's almost one way... yeah, regrettably. (Duncan, ISPC physician)

They always send me notes. I always read them... you might kind of give me a heads up as to what happens, or what the gist of the consult was, but you know, I always read the consult, and I might answer back if there's a particular thing... (Sunshine, OGC physician)

Intentional communication that occurred deliberately and bidirectionally increased the degree of interdependence between the two teams. This most often occurred live via phone or face-to-face conversation, though sometimes through email exchange. Bidirectional intentional communication served to inform inpatient palliative specialist teams about the patient's history, personal or cultural worldview, baseline status, or any previous discussions that had been conducted by the outpatient generalist teams about the patient's care preferences, hopes, or worries, to help the inpatient team establish the most suitable plan for palliative care. These intentional interactions also provided opportunity for the inpatient palliative specialists and the outpatient generalist teams to co-develop a palliative plan of care which considered both teams' perspectives and capabilities. Communicating intentionally at the time of discharge often served to provide the outpatient generalist team with highlights of the specialist palliative consultation, rationale for clinical management decisions, and any potential problems anticipated in the future. Bidirectional intentional communication could occur for a short period of time before, during or after an inpatient specialist palliative consultation, or could

be ongoing after hospitalisation as teams continued to engage with each other to support palliative care provision for an individual patient.

The palliative care... physician... got called to do a consult on her, and I really, really, really appreciated that she called me and asked me to go over my understanding... that really felt good that there was sort of a combination of sharing the outpatient and inpatient experience. (JGG, OGC physician)

When she was ready for discharge back to her home...I made sure to touch base, well I kept him in the loop you know, by sending him copies of her notes, but then contacted him before discharge to come up with a plan for management. And so, every couple of months he would send me messages. (Hill, ISPC physician)

Interdisciplinary members of the specialist and generalist teams were involved in intentional communication in both directions. Sometimes a specific member of either team, usually a registered nurse or a social worker, served as a communication “bridge” between teams. Communication was enhanced when all disciplinary members of the teams were valued for their contributions by members of the other team. When input of some members of the team was discounted, communication was hindered.

The receiving team, it makes it a good connection if they don't care about titles, if it's not important for you to have the title of doctor or nurse practitioner. If they are willing to listen or have a conversation with, you know, “just the nurse” of the team. (Susan, ISPC RN)

3.3.3.3 Condition 3: Acknowledging the role and value of the other team

“Acknowledging the role and value of the other team” describes a process which occurred when a specialist or generalist clinician spoke to the patient about the other team in positive terms or demonstrated respect for the other team’s input in front of the patient by their actions. This acknowledgment with the patient could not occur unless the teams knew one another and were

communicating with each other regarding the patient's care, thus it is positioned as the third process in the progressive conditions leading to the state of "acting as one team across boundaries."

When inpatient specialists acknowledged with the patient the importance they placed on engaging with the patient's outpatient generalist team during hospitalisation, this was perceived to be meaningful for patients. For example, when inpatient palliative specialist teams took the effort to reach out to patients' generalist teams to have a conversation about the current clinical situation and get input from the generalist, patients felt that the inpatient team understood that their relationship with their generalist team was important to them. Others demonstrated, in front of the patient, the value they placed on the role and contribution of the other team by participating in combined clinical visits with the patient, either in the hospital or the clinic, in which one team made the effort to be present in a setting in which they were not typically present.

I think the patient felt that we were hearing him, we were listening to his concerns, and that we knew he had valued this person's opinion, and we made a contact with him. (Crash, ISPC RN)

He gives the perception to them of "we're doing this together, and I'm letting [Mae] know, and she knows that she can reach out to me if she needs it." (Mae, OGC NP)

Acknowledging the role and value of the other team with the patient also served to contextualise the patient's palliative care as situated in the past, present and future. Talking with the patient about the care they've received in the past, either from the outpatient generalist team or the inpatient palliative specialist team, and how it relates to current treatment plans and decision-making, created a sense of continuity over time. Acknowledging the role and value of the other team was also perceived to equalise the roles of specialists and generalists in the ongoing care of the patient, which facilitated teams acting interdependently. Both of these results of this psychosocial process promoted the ability of diverse teams to act interdependently across boundaries of hospital and community settings.

“I want to let you know I talked to your doctor back in little town, (state name), because I know he’s been caring for you for a lotta years and I just want to make sure that I had a good sense of the backstory here.” ...You have to represent the prior history through that medical team, as well as the future history with the receiving team once again. (Walter, ISPC physician)

That communication (to the patient) that I’m in the loop and I’ll continue to be in the loop. I think that’s the, communication – it’s just communication. And being deliberate about, that there’s communication that’s happening. (Mae, OGC NP)

3.5 A preliminary conceptual model of interdependence between inpatient palliative specialist and outpatient generalist care teams across hospital/community boundaries

These findings seem to suggest that when inpatient specialist palliative care teams and outpatient generalist teams know one another, communicate intentionally, and acknowledge the role and value of the other team with the patient, a progressive degree of interdependence in their mutual care of the patient is produced. The degree of interdependent functioning of the teams depends on which of the three conditions are present at any given time. When teams function least interdependently, a state termed “acting independently,” patients are perceived by professionals to receive more fragmented care and both patients and professionals experience distress. When teams act independently, however, there can still be a positive outcome of an inpatient palliative specialist team consultation setting the stage for ongoing palliative care provision by the outpatient generalist team who cares for the patient after discharge, if the generalist team is aware of the consultation. When teams function most interdependently, “acting as one team across boundaries,” patients are perceived to experience more coordinated care and greater satisfaction, and professionals find most satisfaction in their work. More coordinated care means that symptoms are better managed, and patients receive medical care that is better aligned with their preferences for care. A preliminary

conceptual model depicting the relationships between the states of functioning and the conditions which contribute to the degree of interdependent practice between teams was created (see Figure 4).

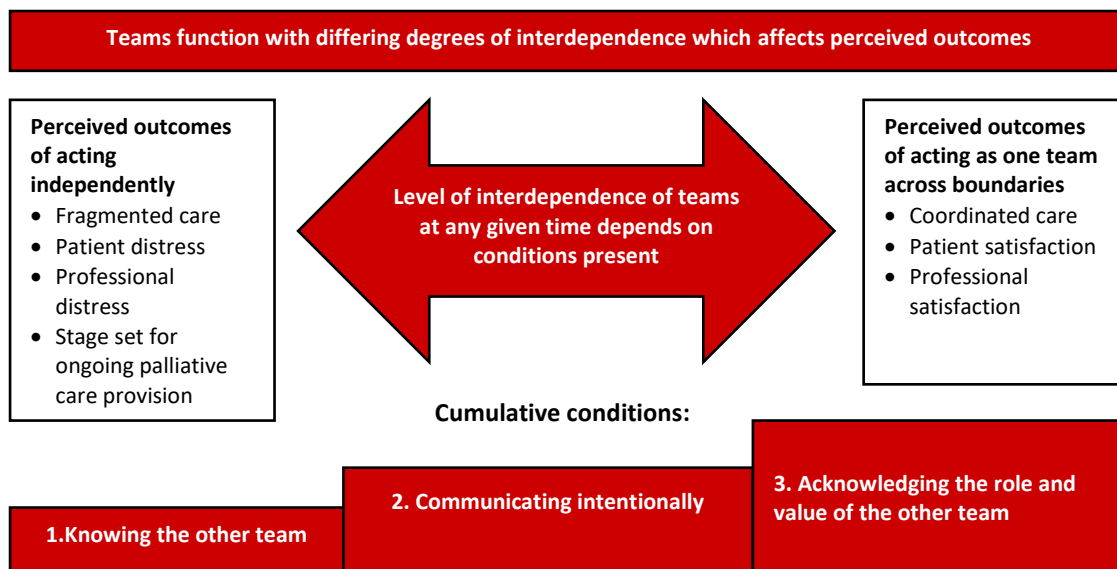


Figure 4: Preliminary conceptual model of interdependence between inpatient palliative specialist teams and outpatient generalist teams across hospital/community boundaries

3.6 Summary

Initial, focused, and theoretical analysis of the data generated from interviews with specialist and generalist palliative care team members in the U.S. resulted in the construction of a preliminary model of interdependence between these teams across hospital/community boundaries. The model illustrates the degrees of interdependence with which palliative specialist teams in the hospital and outpatient generalist teams in the community interact and work when caring for shared patients across the healthcare setting boundaries between the hospital and the community. The state of functioning with the least degree of interdependence is termed “acting independently” while the state of greatest degree of interdependence is termed “acting as one team across boundaries.” Clinicians perceived that when teams act independently, patients’ care is more fragmented and patients and professional experience distress, though sometimes the outpatient generalist team’s ongoing care for the patient’s palliative care needs is still stimulated by the inpatient specialist consultation. When teams act as one team across boundaries, clinicians perceived that care was more coordinated, and

both patients and professionals experienced greater satisfaction. Three psychosocial process conditions -- knowing the other team, communicating intentionally, and acknowledging the role and value of the other team -- are instrumental in moving teams along the continuum between “acting independently” to “acting as one team across boundaries.”

4 Critical interpretive synthesis of the literature

The purpose of Chapter 4 is to present the literature review that was undertaken to contribute additional conceptual understanding to the five categories and the preliminary conceptual model related to interdependence between inpatient palliative specialist and outpatient generalist healthcare teams that were described in Chapter 3. The report of the literature review is structured using the “Enhancing transparency in reporting the synthesis of qualitative research” (ENTREQ) domains of introduction, methods and methodology, literature search and selection, appraisal, and synthesis of findings (Tong, Flemming, McInnes, Oliver, & Craig, 2012).

4.1 Introduction

4.1.1 Literature review aim and question

The aim of the literature review was to purposefully mine the literature to find empirical research data that could help to strengthen the categories of the preliminary conceptual model presented in Chapter 3. The question guiding this literature review was “What does previous empirical research related to inpatient specialist and outpatient generalist teams working together across hospital discharge transitions have to contribute to the categories of teams acting independently, acting as one team across boundaries, knowing the other team, communicating intentionally, and acknowledging the role and value of the other team?”

4.1.2 Justification for the timing of the literature review

Timing of the literature review in grounded theory research has long been a point of debate. Classic grounded theorists support avoidance of literatures related to a study topic until the grounded theory has been generated from the data so that researchers avoid “forcing” their analysis into a framework established by others’ research and theories (Dunne, 2011). The Charmazian constructivist approach to grounded theory does not dictate whether the literature review should be conducted before or after data analysis, but holds that all theories, whether extracted from previous literature or

developed within a current study, are provisional and are subject to interpretation and revision. This perspective on the literature requires reflexivity on the part of the researcher toward both the literature and their own data, no matter at what stage of a study the literature is reviewed (Charmaz, 2014b).

The literature review for this study was positioned after initial interview data analysis. Prior to interview data analysis, it was not yet known what conceptual ideas would be developed from the data as key categories. By positioning the literature review after preliminary construction of categories and a conceptual model, the categories constructed from primary data analysis could guide literature selection and serve as a framework with which to critically analyse the extant literature. With this approach, findings from the literature served as additional data to enhance or challenge the constructed categories and raise the level of abstraction (Charmaz, 2014a).

Thornberg proposed that the literature review serves as an "open, critical and pluralistic conversation between the researcher, the literature, the data, and the 'emerging' body of concepts and ideas" (Thornberg, 2012, p. 250) in which the extant literature is used critically as a building block for developing grounded theory. One can run the risk in this process, however, of giving greater credence to pre-existing theories in the literature than one's own data, especially as a novice researcher (Dunne, 2011). Positioning the literature review after initial conceptual categories have been constructed from the data helps to ensure prioritisation of the data over theories in the extant literature, so that the resultant grounded theory is indeed grounded in the primary data (Ramalho, Adams, Huggard, & Hoare, 2015). For this reason also, the literature review for this study was conducted after the initial data analysis was complete.

4.2 Methods and methodology

4.2.1 Synthesis methodology

This literature review was designed following critical interpretive synthesis methods originally outlined by Dixon-Woods and colleagues (Dixon-Woods et al., 2006). Selection of this methodology

for literature review and synthesis was guided by the philosophical underpinnings of this research study, the role of the researcher, the desired heterogeneity of literature to be included in the review, the nature of the literature sampling process, and the desired output of the literature review. Critical interpretive synthesis is based on the philosophical stance of subjective idealism, in which there are multiple realities possible, relative to subjective human constructions (Tong et al., 2012), similar to the relativism and interpretivist philosophical underpinnings of this study. The reviewer's own reflexivity serves as a tool in critical interpretive synthesis (Dixon-Woods et al., 2006), aligning with constructivist grounded theory in which the researcher subjectively plays a part in constructing theory (Charmaz, 2014a). The critical interpretive synthesis approach emphasises selecting a broad, purposive sample of relevant research from various methodologies that will contribute to theory construction. This helps to capture the broadest perspectives on complex phenomena, such as the focus of this study, the interactions between interdisciplinary specialist and generalist healthcare teams across multiple settings (Hong, Pluye, Bujold, & Wassef, 2017). Critical interpretive synthesis methods also call for an iterative, emergent approach to literature sampling consistent with the iterative nature of grounded theory research, as compared to other literature search methods which call for a fixed, pre-determined search strategy (Entwistle, Firnigl, Ryan, Francis, & Kinghorn, 2012; McFerran, Hense, Medcalf, Murphy, & Fairchild, 2017). Finally, critical interpretive synthesis is designed to result in new theoretical conceptualisation, which supports the aim of this review to further develop the preliminary theoretical categories constructed through initial data analysis (Tong et al., 2012).

Other methods for literature review and synthesis were considered but ruled out as options due to limitations on types of literature that are included in these methods. Because the brief review of the literature prior to commencement of the study indicated that previous research related to collaboration between specialist and generalist healthcare teams included qualitative research, any methods that exclusively focus on quantitative research, such as meta-analysis, were ruled out (Hong et al., 2017). Literature review and synthesis methods that incorporate only qualitative research, such

as meta-ethnography, meta-synthesis, or grounded theory synthesis, were ruled out, as an approach was needed that allowed for the broadest possible sampling of studies, including quantitative studies, for the strongest enhancement of theoretical concept construction (Barnett-Page & Thomas, 2009; Dixon-Woods et al., 2006; Hong et al., 2017).

Other literature synthesis methods allow for inclusion of qualitative, quantitative, and mixed methods studies, but result in outputs that do not align with the aim of this literature synthesis and study. Thematic synthesis was developed as a method to address questions about particular interventions (Barnett-Page & Thomas, 2009) and aims to develop analytic themes which can contribute to a conceptual framework (Hong et al., 2017). Narrative synthesis is designed to result in a summary or explanation of findings in selected studies (Hong et al., 2017). Framework synthesis is used to produce a new framework through the application of a very structured approach to data (Barnett-Page & Thomas, 2009). None of these methods propose to investigate the literature with a purpose of generating new theoretical constructs or theory, which is the aim of this synthesis.

While the aim of critical interpretive synthesis is inductive theory generation (Dixon-Woods et al., 2006; Hong et al., 2017), it has been used to perform synthesis of literature using a pre-existing framework as a guide (Morgan, Kelley, Guyatt, Johnson, & Lavis, 2018). Given the positioning of the literature review after initial data analysis and preliminary construction of categories in this grounded theory study, this approach was taken, using the preliminary categories as a coding structure with which to explore the literature. I incorporated perspectives on the interplay of extant literature with primary study data espoused by Thornberg in his description of informed grounded theory development into the critical interpretive synthesis (Thornberg, 2012). This approach emphasises the practice of abduction over pure induction; that is, using a process that moves back and forth between pre-existing knowledge and the data to creatively search for “new patterns and best explanations” (Thornberg, 2012, p. 247) with the goal of a more robust conceptual theory. By incorporating Thornberg’s integrative process with my data and the literature, I diverged from the critical

interpretive synthesis goal of synthesising a line of argument and construct strictly from the literature (Dixon-Woods et al., 2006). However, the outcome, construction of a more robust theory that transforms the evidence into a “new conceptual form” (Dixon-Woods et al., 2006, p. 5), remains philosophically congruent with critical interpretive synthesis methods.

4.2.2 Literature inclusion and exclusion criteria

Criteria for including and excluding literature from this review are outlined in Table 9. Literature from any timeframe was included as interactions between healthcare teams represent a social phenomenon that was assumed to be timeless.

Table 9: Literature inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
<ul style="list-style-type: none"> • Quantitative or qualitative empirical research • Meets critical interpretive synthesis quality criteria • Published in a peer-reviewed journal or as a doctoral thesis • Paper addresses all 3 elements of <i>teamwork</i> between <i>inpatient specialists and outpatient generalists across hospital discharge</i> context • Includes healthcare provider perspectives • Full text available in English • Any date/year of publication 	<ul style="list-style-type: none"> • Not empirical research • Does not meet critical interpretive synthesis quality criteria • Quality/practice improvement projects • Conference or poster abstracts • Systematic reviews* • Paper does not include all 3 concepts of <i>teamwork</i> between <i>inpatient specialists and outpatient generalists across hospital discharge</i> context • Does not include healthcare provider perspectives • Full text not available in English
<p>*Set aside for reference review if otherwise met inclusion criteria</p>	

4.3 Literature search and selection

4.3.1 Data sources

The databases MEDLINE, CINAHL, EMBASE, PsycINFO, and ProQuest Dissertations and Theses were utilised. ProQuest was searched in December of 2018 and all other databases were searched in March of 2019. Reference lists of papers that met inclusion criteria were manually reviewed. Reference lists of excluded systematic reviews that otherwise met inclusion criteria were also manually reviewed to identify any relevant primary research.

4.3.2 Approach to searching

An iterative approach, rather than a strictly pre-determined approach, to searching the literature was undertaken to allow for theoretical sampling of the literature, consistent with the methods of critical interpretive synthesis. This provides the flexibility to search for additional concepts that may become apparent as important to furthering theory development throughout the course of the literature review (Dixon-Woods et al., 2006; Tong et al., 2012). The initial search strategy used key terms related to the essential components of the research question (palliative care, teamwork between specialist and generalist teams, and hospital discharge). Throughout the search process, it became evident through review of initial returns from three databases that a combination of terms excluding the specific discipline of “palliative care” would result in a more thorough theoretical exploration of helpful concepts in the literature. Drawing on a wider body of literature is consistent with the Charmaz’s recommendation to explore literature of diverse fields (Charmaz, 2014b). Secondly, additional search terms were added after reference review of the first selected papers revealed that some relevant concepts had not been captured in the initial search. Both of these iterative adaptations to the search strategy ensured better capture of theoretical concepts and richer contributions by the literature to theoretical development.

4.3.3 Electronic search strategy

Search strings related to the three main areas of interest for this review were adapted from previous Cochrane reviews related to hospital discharge, palliative care, and the interface between primary and specialty care (Gonçalves-Bradley, Lannin, Clemson, Cameron, & Shepperd, 2016; Haun et al., 2017; Smith, Cousins, Clyne, Allwright, & O'Dowd, 2017). A research librarian assisted with search terms and strategy. Search terms used in CINAHL are shown in Table 10 as an example. Search terms used in other databases are listed in Appendix R.

Table 10: CINAHL search terms

Concept: Palliative Care	
S1	AB palliate* OR AB ((terminal* AND ill)) OR AB ((terminal* AND caring)) OR AB ((terminal* AND care)) OR AB bereave* OR AB hospice* OR AB (("end of life" AND care)) OR AB (("end of life" AND caring))
Concept: Hospital Discharge	
S2	TI ((discharge and (plan* or service? or program* or intervention?)) OR MH "discharge planning"
S3	MM "patient discharge" OR MM "early patient discharge"
S4	TI patient* n2 discharge* OR AB patient* n2 discharge*
S5	TI hospital n2 discharge OR AB hospital n2 discharge
S6	TI discharge* n2 plan* OR AB discharge* n2 plan*
S7	TI discharge service* OR AB discharge service*
S8	TI discharge program* OR AB discharge program*
S9	TI discharge procedure* OR AB discharge procedure*
S10	"transitional care"
S11	"patient handoff" OR "patient hand off"
S12	"patient hand over"
	S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12
Concept: Teamwork between specialist and generalist teams	
S13	TI ((shared care or collaborat\$ care)) OR AB ((shared care or collaborat\$ care))
S14	TI (integrated care or coordinated care or co-ordinated care)
S15	TI (specialist and (primary n2 (care or healthcare or health care)))

S16	TI specialist* n4 (community or "family doctor*" or generalist* or "family physician*" or "general practitioner*" or "family practice")
S17	TI shared n2 care OR AB shared n2 care
S18	AB specialist* n4 (community or "family doctor*" or generalist* or "family physician*" or "general practitioner*" or "family practice")
S19	TI specialist* n4 (continuity n2 care) OR AB specialist* n4 (continuity n2 care)
S20	TI ((collaborat* or cooperativ* or co-operativ*) n3 (care or "disease management" or "patient management" or "health care" or healthcare or specialist*)) OR AB ((collaborat* or cooperativ* or co-operativ*) n3 (care or "disease management" or "patient management" or "health care" or healthcare or specialist*))
S21	TI (integrated n4 (care or treatment or management)) OR AB (integrated n4 (care or treatment or management))
S22	TI (integrated n3 (care or management or treatment)) OR AB (integrated n3 (care or management or treatment))
S23	TI ((collaborativ* or cooperativ* or co-operativ*) and (model* or practice*)) AND AB ((collaborativ* or cooperativ* or co-operativ*) n2 (model* or practice*))
S24	TI ((collaborat* or cooperativ* or co-operativ*) n12 ("family practitioner*" or "family physician*" or family doctor*" or "general practitioner*" or "primary care physician*" or "primary care doctor" or "primary care practitioner*") OR AB ((collaborat* or cooperativ* or co-operativ*) n12 ("family practitioner*" or "family physician*" or family doctor*" or "general practitioner*" or "primary care physician*" or "primary care doctor" or "primary care practitioner*")
S25	TI ((interdisciplin* or inter-disciplin*) n2 (assessment* or care or treatment or team* or "primary care" or specialist*)) OR AB ((interdisciplin* or inter-disciplin*) n2 (assessment* or care or treatment or team* or "primary care" or specialist*))
S26	TI ((coordinat* or co-ordinat* or team) n9 care) OR AB ((coordinat* or co-ordinat* or team) n9 care)
S27	TI (integrated and (care or healthcare or management or treatment)) OR AB (integrated and (care or healthcare or management or treatment))

S28	TI collaborat* n3 care OR TI collaborative n2 (approach*) OR AB collaborat* n3 care OR AB collaborative n2 (approach*)
S29	TI integrat* and (primary n2 care)
S30	"cooperative behavior"
S31	AB interdisciplinary communication OR AB (interprofessional relations or cooperative behavior or patient care team or collaboration)
S32	"patient care team"
	S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31
Combined concepts	
All 3 concepts	S1 AND S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 AND S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31
Excluding Palliative Care concept	S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 AND S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31

4.3.4 Study screening methods and selection results

Searches returned 2525 unique papers which were saved using EndNote X8 software (Clarivate Analytics, 2019) . Titles and abstracts were screened for relevance, utilising the literature review question and inclusion/exclusion criteria as a guide (see Table 9). After screening of titles and abstracts, full texts of remaining papers were reviewed to screen for inclusion. Most papers were screened solely by the primary investigator. Papers were reviewed with research supervisors if appropriateness for inclusion was unclear. Reference lists of included papers and of relevant systematic reviews were manually screened for relevant titles for potential inclusion. See the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flow diagram in Figure 5 for numbers of papers screened, excluded, and included, and reasons for exclusion (Moher, Liberati, Tetzlaff, Altman, & Group, 2009).

4.4 PRISMA flow diagram

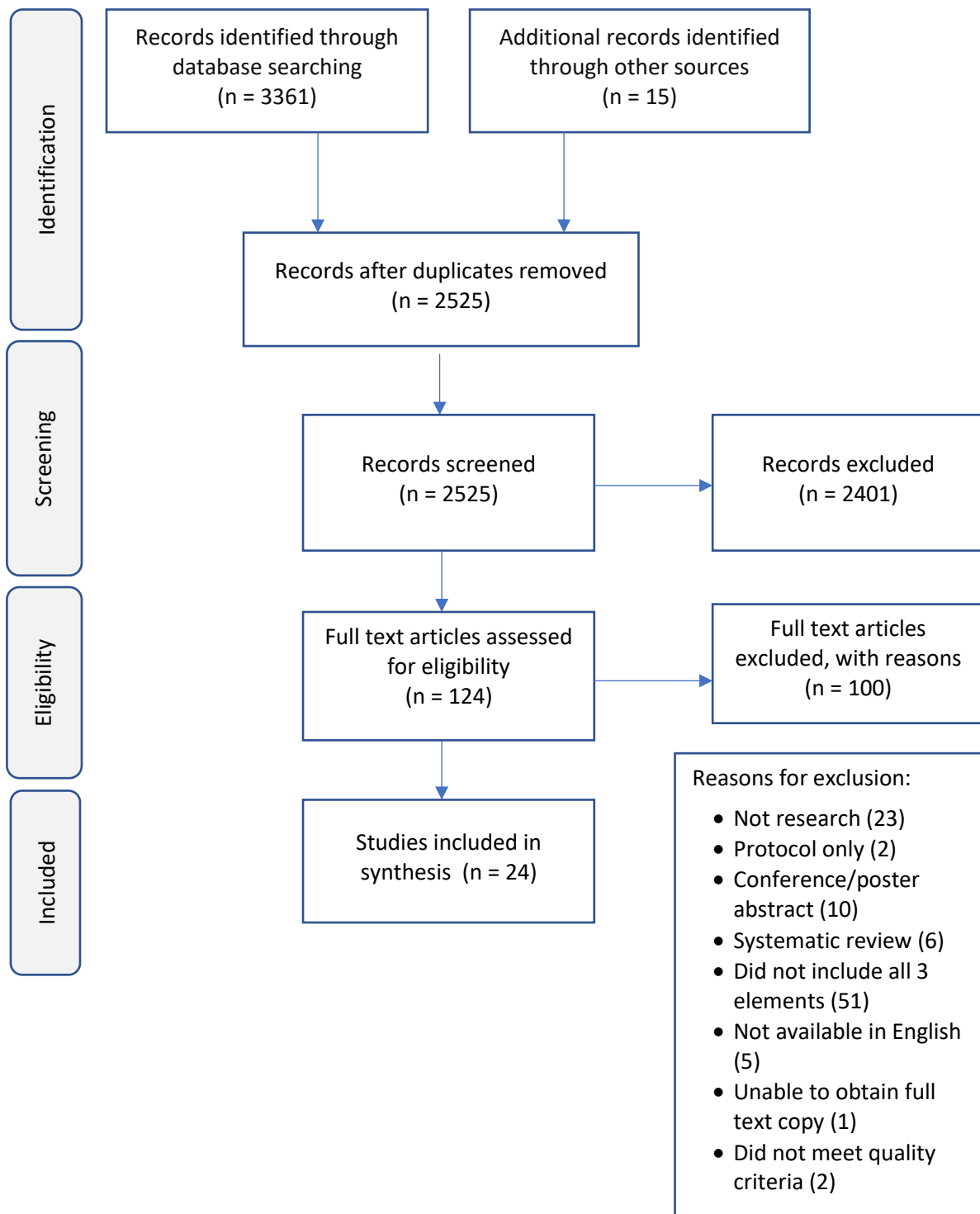


Figure 5: PRISMA flow diagram of literature selection

4.5 Appraisal and data extraction

Potentially eligible papers were evaluated using the quality criteria proposed by Dixon-Woods and colleagues (2006) to eliminate papers with “fatal flaws” and for conceptual relevance. In critical interpretive synthesis, conceptual relevance is prioritised over methodological rigour so quality appraisal is based on broad evaluation for major defects in scientific process (Entwistle et al., 2012).

Five questions inform judgment about study quality in critical interpretive synthesis:

- Are the aims and objectives of the research clearly stated?
- Is the research design clearly specified and appropriate for the aims and objectives of the research?
- Do the researchers provide a clear account of the process by which their findings were produced?
- Do the researchers display enough data to support their interpretations and conclusions?
- Is the method of analysis appropriate and adequately explained? (Dixon-Woods et al., 2006, p. 4)

Details of each study were extracted to a table as recommended in critical interpretive synthesis to ensure systematic review of included literature (Dixon-Woods et al., 2006). Extracted details included authors and publication year, country of origin of the study, characteristics of study participants, methods of data collection and analysis, titles of categories and subcategories (when applicable), and a summary of major findings (Dixon-Woods et al., 2006). See Table 11 for data extraction for included studies.

4.6 Data analysis

Each included paper was uploaded into NVivo (QSR International, 2019) and coded using a process that paralleled the coding process used with interview transcripts. I coded findings and discussions of all papers line by line for content using the categories of the preliminary conceptual model as a coding framework. At the same time, any new data or concepts related to interdependence between

inpatient specialist and outpatient generalist teams across hospital discharge transitions that may not have been evident in my interview data analysis were coded as well. Results of coding, presented in codebook format, were reviewed and discussed with research supervisors. See Appendix T for codebook from the literature review.

The process of full text review, data extraction, and coding was performed iteratively. Each paper was coded before the next was reviewed, extracted, and coded to allow for constant comparison and building on previous papers' codes. Throughout the process, memoing captured my reflections on meanings of the findings of reviewed studies and how these studies relate to each other (see Appendix U for sample memos from the literature review process). In addition to data extraction, coding and memoing, sticky note sorting of findings from the data extraction spreadsheet, manual sorting of NVivo codes cut from codebook, and whiteboard and pen and paper diagramming were used to abductively construct categories and concepts (see Appendix V). This sequence reflected the reflexive and interactive approach of critical interpretive synthesis (Entwistle et al., 2012) – see Figure 6.

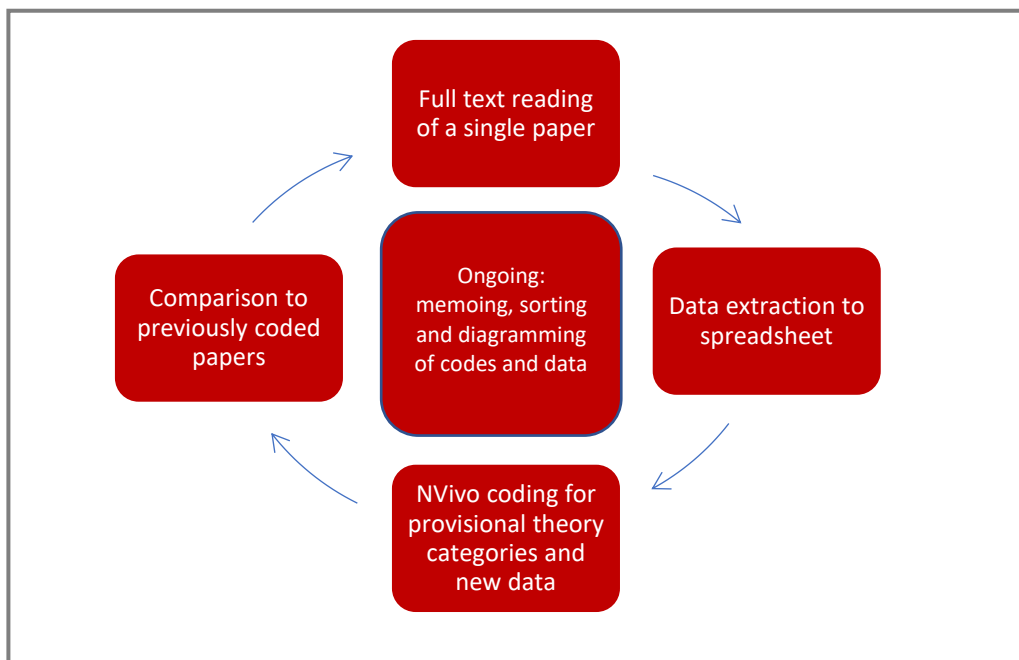


Figure 6: Iterative literature analysis process

4.7 Synthesis of findings

4.7.1 Summary of included studies

All included studies explored perspectives of inpatient specialist and/or outpatient generalist healthcare professionals related to teamwork across discharge transitions. Half of the studies (12) included perspectives of interdisciplinary team members including physicians, nurses, social workers and others. Ten of the studies reported on perspectives of physicians only and two on nurses only. Two studies mentioned specialist palliative care (Keane et al., 2017; Mason et al., 2013); all others had to do with outpatient generalists' teamworking with other inpatient specialists, primarily hospitalist teams. Studies were conducted in Europe (10), the U.S. (8), Australia (3), Brazil (1), New Zealand (1), and one study included both U.S. and European participants (1). See Table 11 for details of included studies. Table 11 provides the result of quality assessment for included papers, while Appendix S presents the detailed quality criteria review of included papers.

Table 11: Literature data extraction

Author (year), country	Does paper meet CIS* quality criteria?	Research question or aim	Participants	Methods of data collection and analysis	Relevant categories or themes in qualitative studies	Key findings relevant to the aim of this literature review
Abu et al. (2018), USA.	Yes	To explore factors influencing care transitions of patients experiencing unplanned hospitalization from the perspective of healthcare providers	Physicians Nurse practitioners Nurses Patient care assistant All hospital based; multiple specialties	<u>Qualitative:</u> Semi-structured interviews; Iterative coding structure development	Comprehensiveness and clarity of discharge information; timing of discharge conversation; communication breakdown; informal caregiver involvement	Need for direct communication between hospitalists and primary care providers (PCPs) beyond the discharge summary; Provider to provider miscommunication across inpatient/outpatient boundaries attributed to working independently and lack of continuity
Acosta, Camara, Weber, and Fontenele (2018), Brazil.	Yes	To analyse activities carried out by hospital nurses during hospital discharge transitions and identify challenges	Inpatient nurses	<u>Quantitative:</u> Likert-scale questionnaire; Descriptive statistics	n/a	Hospital nurses rarely communicated with primary care team regarding discharge before or after transition; communication between professionals was difficult
Balla and Jamieson (1994), Australia.	Yes	To explore reasons for lack of hospital teams' understanding of how to utilize skills of general practitioners (GPs)	Hospital physicians, nurses and social workers; GPs for hospitalised patients	<u>Qualitative:</u> Ethnographic observation; semi-structured interviews; focus	<u>Hospital staff:</u> Mistrust of unknown GP; believed some conditions didn't require GP	Hospital staff didn't see need or value of GP involvement. GP saw bigger picture and would

Author (year), country	Does paper meet CIS* quality criteria?	Research question or aim	Participants	Methods of data collection and analysis	Relevant categories or themes in qualitative studies	Key findings relevant to the aim of this literature review
				groups; review of case notes. Interview data classified and categorized.	involvement; need to accomplish everything during hospital stay; <i>didn't regard GP as part of system.</i> <i>GPs: didn't see self as part of hospital system</i> due to lack of communication, not being seen by inpatient staff as part of team, lack of time and reimbursement	appreciate more interaction.
Bell et al. (2009), USA.	Yes	To determine whether primary care physicians' (PCPs') knowledge of their patient's hospital admission, receipt of discharge summary, and direct communication with the inpatient medical team are associated with 30-day patient clinical outcomes	Patients and PCPs	<u>Quantitative:</u> Questionnaire surveys; National Death Index mortality data. Statistics for association between variables	n/a	Less than 25% of inpatient teams and PCPs communicated with each other directly; less than half of PCPs received a discharge summary within 2 weeks; no significant differences in 30-day patient outcomes.
Blackford and Street (2001), Australia.	Yes	To explore role of palliative care nurse consultants (PCNC) in acute hospitals in	Nurses from specialist palliative care services; PCNCs (both	<u>Qualitative:</u> Focus group and individual interviews	Coordination of care; professional territorialism;	PCNCs played major role in communication with post-acute care healthcare teams (GPs,

Author (year), country	Does paper meet CIS* quality criteria?	Research question or aim	Participants	Methods of data collection and analysis	Relevant categories or themes in qualitative studies	Key findings relevant to the aim of this literature review
		maintaining continuity of care across the acute care/community interface	inpatient and community-based)	Qualitative content analysis; coding and text unit analysis.	expectations of the PCNC role	community nurses); PCNCs encountered cross-discipline and organisational cultural barriers in communicating with GPs, and developed workarounds; GPs appreciated communication with PCNCs but inpatient specialist physicians did not.
Bull and Roberts (2001), United Kingdom.	Yes	To identify components of effective discharge planning for elders and factors that impede this process	Hospital and community healthcare providers; patients; family caregiver	<u>Qualitative:</u> Semi-structured individual interviews; review of discharge documentation. Categories developed from interviews; Documents reviewed for congruence with interview data.	Characteristics of effective teamwork; intersecting circles of communication	Effective discharge occurs in stages, characterized by inclusion of all IDT members, "interacting circles of communication," and enough time to include all stakeholders. All IDT members bring expertise and perspective, but through trust and valuing of each other's perspectives, a more effective discharge

Author (year), country	Does paper meet CIS* quality criteria?	Research question or aim	Participants	Methods of data collection and analysis	Relevant categories or themes in qualitative studies	Key findings relevant to the aim of this literature review
						occurred for the pt/family.
Canary and Wilkins (2017), USA.	Yes	How do parent and physician participants describe their paediatric hospital discharge experiences? What are the post-discharge experiences of parents and physicians? What is the role of communication in the discharge, and post-discharge, experience for the various participant groups?	PCPs; Hospitalist physicians; Parents of recently discharged children	<u>Qualitative:</u> Individual interviews and focus groups. Constant comparative analysis.	Discharge problems; teamwork; ideal discharge; care chasm; discharge paradox	Communication emerged as key characteristic of all themes identified; “communication triad” of parent, hospitalist and PCP needs to be robust and multi-directional but often is not; systemwide communication strategies needed to improve patient/family experiences and outcomes. Four tensions surrounding discharge identified.
Göbel et al. (2012), Netherlands.	Yes	To apply a microsystem lens to gain insight into gaps in handover process from hospital to community and develop recommendations for improvement	Patients and for each patient, one hospital physician and nurse and GP	<u>Qualitative:</u> Semi-structured individual interviews. Sets of interviews (patient, inpatient physician and nurse, and GP) analysed as microsystems	Lack of adequate information; healthcare professionals’ availability for personal contact; feedback, teaching and protocols related to handover; information technology facilitated communication	All microsystems demonstrated ineffective handovers resulting in discharge without adequate information for patients and professionals, creating potential for suboptimal care. Reasons for miscommunication included individual professional factors,

Author (year), country	Does paper meet CIS* quality criteria?	Research question or aim	Participants	Methods of data collection and analysis	Relevant categories or themes in qualitative studies	Key findings relevant to the aim of this literature review
				using thematic analysis		organizational and technical factors, social context and patient behaviour.
Groene, Orrego, Suñol, Barach, and Groene (2012), Spain.	Yes	To explore the role and engagement of vulnerable patients in the hospital discharge handover process	Patients and their hospital and primary care physicians and nurses	<u>Qualitative:</u> Individual interviews with patients and healthcare professionals post-discharge. Coding with category development	Information transfer and communication; use of discharge and/or referral letters as handover tools; use of other handover artefacts such as shared electronic health records (EHRs)	Lack of standardized process for discharge handovers; quality of handover depends on individual initiative, professionals' "good will" and inter-professional relationships.
Hesselink, Schoonhoven, Plas, Wollersheim, and Vernooij-Dassen (2013), Netherlands.	Yes	To identify barriers experienced by hospital and community physicians, nurses, and patients and families. How is hospital discharge experienced in daily practice? What is perceived to be important in the handover process at discharge?	Patients, family members, hospital physicians and nurses, GPs, community nurses.	<u>Mixed methods:</u> Focus groups; individual interviews; surveys. Systematic content analysis for qualitative data; logistic regression analysis for survey data.	Quality of information exchange; coordination of care; communication between hospital and community care providers	Important barriers: inadequate information exchange about meds, treatment and follow-up (all professionals); lack of knowledge of patient's home environment, inadequate coordination of tasks and unclear contact person between settings, delayed information exchange (all physicians); discharge follow up (GPs).

Author (year), country	Does paper meet CIS* quality criteria?	Research question or aim	Participants	Methods of data collection and analysis	Relevant categories or themes in qualitative studies	Key findings relevant to the aim of this literature review
Hesselink, Vernooij-Dassen, et al. (2013), Netherlands, Spain, Poland, Sweden, Italy.	Yes	To gain insight into impact of organisational culture on quality and safety of handovers at hospital to community discharge	Patients, family members, hospital physicians and nurses, GPs, community nurses.	<u>Qualitative:</u> Semi-structured interviews and focus groups. Grounded theory coding and categorization.	Fragmented hospital-primary care interface; undervaluing administrative tasks relative to clinical tasks in the discharge process;	Hospital and PCPs within same organisation have “separate professional tribes” with different values and beliefs; lack of shared goals, knowledge and respect impact communication between the two groups; hospital teams less aware of concerns as they don’t experience the impact of poor handovers; clinical and administrative tasks conflict at time of handover; professionals not willing to confront each other with inefficiencies.
Huby, van Teijlingen, Porter, and Bury (1997), United Kingdom.	Yes	To document services used after discharge by people with AIDS, identify gaps and overlaps in services, and evaluate liaisons between hospital and community services.	Patients, GPs, “outpatient department physicians,” hospital counsellors and social workers, hospital/community liaison nurses	<u>Mixed methods:</u> Questionnaires via post or interview. Direct observation of hospital processes and informal discussions with hospital nurses.	n/a	GPs made little contact with hospital teams though often involved in post-discharge patient care; GPs not integrated into larger systems of care; GPs’ care is “parallel to” hospital care provision.

Author (year), country	Does paper meet CIS* quality criteria?	Research question or aim	Participants	Methods of data collection and analysis	Relevant categories or themes in qualitative studies	Key findings relevant to the aim of this literature review
				Descriptive statistics and qualitative data analysis		
Johnson et al. (2012), USA, Spain, Poland, Sweden, Italy, Netherlands.	Yes	To demonstrate how process mapping can illustrate current handover practices between hospital and ambulatory settings, identify barriers and facilitators and highlight areas for improvement	Hospitalists, internal medicine residents and primary care providers (PCPs); multidisciplinary teams	<u>Qualitative:</u> Focus groups Co-generation of process map; analysis of focus group transcripts	n/a	Barriers: complexity of inpatient treatment; PCPs unaware of admission; no contact information for PCP on record; inpatient team perception that PCP ignores hospital; interprofessional hierarchies; diverse roles; lack of time; different perceptions of patient needs; lack of procedure for handover. Facilitators: accurate timely communication between teams; PCPs' familiarity with patient; hospital team knowing PCP; clear criteria for hospital to GP communication at discharge; inpatient and community nurses

Author (year), country	Does paper meet CIS* quality criteria?	Research question or aim	Participants	Methods of data collection and analysis	Relevant categories or themes in qualitative studies	Key findings relevant to the aim of this literature review
						communicate and understand each other's practice.
Jones et al. (2015), USA	Yes	To understand hospitalists' and PCPs' perceptions of challenges to care coordination for hospitalized patients	Hospitalists and primary care team members	<u>Qualitative:</u> Focus groups Constant comparative analysis	Care coordination challenges; accountability challenges; care coordination solutions; accountability solutions	Many shared perspectives identified between groups; if a perspective was unique to one group, often related to an issue unknown by other groups. Identified need for ongoing personal relationships and direct connections between groups. Communication is infrequent and perceived to be associated with in serious patient impact.
Keane et al. (2017), New Zealand.	Yes	To explore how GP and specialist palliative care teams view their partnership working relationship and identify barriers and enablers to effective partnership working	Generalist practice physicians, nurses, manager; hospital physicians, nurses, educators, manager, allied health staff.	<u>Qualitative:</u> Focus groups General inductive analysis with coding and categorization	Sense of identity; rules of engagement; sustaining the partnership	"Relationship brokers" key to promote collaborative working. Partnership working requires constant attention to be maintained. GP teams saw de-skilling as inconvenience rather than major problem -

Author (year), country	Does paper meet CIS* quality criteria?	Research question or aim	Participants	Methods of data collection and analysis	Relevant categories or themes in qualitative studies	Key findings relevant to the aim of this literature review
						saw role of GP more as coordinator rather than expert in everything. There is lack of clarity about referral criteria. Trust, respect, personal acquaintance all facilitators of partnership working. Specialist palliative nurses address power imbalance, actively manage relationships between teams, nurture collaboration.
Marks, Hynson, and Karabatsos (1999), Australia.	Yes	To test hypothesis that actively involving GPs in post-discharge care of patients would increase their satisfaction with communication with hospital team	Parents of paediatric patients and GPs	<u>Mixed methods:</u> Likert scale surveys post-discharge; open ended questions included on GPs' surveys; Hospital records review. Statistical analysis and thematic analysis	n/a	Phone call from hospital at or before discharge significantly increased GP satisfaction with communication from hospital, understanding of hospital treatment, and own involvement in post discharge care. No differences in patient outcomes.

Author (year), country	Does paper meet CIS* quality criteria?	Research question or aim	Participants	Methods of data collection and analysis	Relevant categories or themes in qualitative studies	Key findings relevant to the aim of this literature review
Mason et al. (2013), United Kingdom	Yes	To identify how end-of-life care is coordinated in generalist settings for patients with advanced progressive illness	Inpatient and outpatient Interdisciplinary team members, patients, and caregivers	<u>Qualitative:</u> Ethnographic observations; semi-structured interviews Thematic analysis	Patients, family carers, specialist nurses as care coordinators; transitions and communication between care settings challenge coordination; service organisations' structures challenge coordination	"Nurse specialists" identified as key to coordination more than GP. Clinicians universally have difficulty communicating across institutional boundaries. Lack of uniformity of care delivery systems adds confusion and contact information often unclear. Professionals not wanting to impose on others' autonomy limited coordination.
Nguyen, Kruger, Greysen, Lyndon, and Goldman (2014), USA.	Yes	To understand primary care leaders' perceptions about barriers and facilitators to collaboration with hospitals	Primary care executives, clinic directors, care coordination or quality improvement experts	<u>Qualitative:</u> Semi-structured interviews. Thematic analysis	Barriers: Lack of institutional financial incentives; Competing priorities limit primary care's focus on care transitions; mismatched expectations about the role and capacity of primary care in care transitions. Facilitators: informal, personal affiliations	Barriers to collaboration: lack of financial incentives; competing priorities; mismatched expectations about role and capacity of primary care; poor communication infrastructure. Facilitators: interpersonal networking and EHRs

Author (year), country	Does paper meet CIS* quality criteria?	Research question or aim	Participants	Methods of data collection and analysis	Relevant categories or themes in qualitative studies	Key findings relevant to the aim of this literature review
					and partnerships; EHRs improve communication between hospitals and primary care.	
Pantilat, Lindenauer, Katz, and Wachter (2001), USA	Yes	To determine PCP perspectives on ideal timing, frequency, method, and content of communication with hospitalists To assess PCP attitudes regarding desire to be involved in inpatient decision making and satisfaction with communication with hospitalists	Primary care physicians	<u>Quantitative:</u> Postal survey Statistical analysis	n/a	Most PCPs wanted to hear about their hospitalized patients at admit, discharge and with major intervention or change in condition via phone call on the same day. More than 1/3 wanted input into resuscitation decisions.
Ruth, Geskey, Shaffer, Bramley, and Paul (2011), USA.	Yes	To characterize the satisfaction and preferences of paediatric providers for effective transfers between inpatient and outpatient settings	Paediatric hospitalists and PCPs	<u>Quantitative:</u> Electronic survey Statistical analysis	n/a	PCPs more likely to: Find communication with hospitalists easier during hospitalization than after discharge Want daily communication during hospitalization Hospitalists more likely to:

Author (year), country	Does paper meet CIS* quality criteria?	Research question or aim	Participants	Methods of data collection and analysis	Relevant categories or themes in qualitative studies	Key findings relevant to the aim of this literature review
						Want to communicate at discharge or major events See PCP as responsible for post-discharge issues Email preferred method for both groups.
Rydeman and Törnkvist (2006), Sweden.	Yes	To achieve deeper understanding of the experience of discharge process among hospital nurses, district nurses, home-care nurses and social workers	Hospital nurses, district nurses, home-care nurses and social workers	<u>Qualitative:</u> Focus groups Phenomenological analysis	Framework: general and local; basic values; patient resources	Framework serves as basis for clinicians' discharge actions, including clarity about roles, accountabilities, work cultures and professional knowledge. Values provide ethical guidance, differ between people and organisations. Discharge plans may be centred on organisational rather than patient needs. Emphasizes need for "conscious, basic values in common" among interdisciplinary groups.
Sampson, Barbour, and Wilson (2016),	Yes	To explore perspectives of GPs and hospital specialists on how relational connections	GPs and hospitalist physicians	<u>Qualitative:</u> Semi-structured interviews	Communication; conduct; relationships; unrealistic expectations	Continuity of care limited when clinicians didn't perceive themselves to

Author (year), country	Does paper meet CIS* quality criteria?	Research question or aim	Participants	Methods of data collection and analysis	Relevant categories or themes in qualitative studies	Key findings relevant to the aim of this literature review
United Kingdom.		between primary and secondary care may influence patient care		Constant comparative, thematic analysis		be part of a larger team caring for the patient. Both groups concerned about access to other group for communication; inappropriate workload transfer: creating unrealistic expectations. PCPs wanted specialists to understand their environment better; Specialists wanted holistic details about patient from PCP and worried about lack of PCP continuity.
Sheu, Fung, Mourad, Ranji, and Wu (2015), USA.	Yes	To understand current discharge communication practices and PCP satisfaction within a shared EHR and identify areas for improvement	Internal Medicine PCPs	<u>Quantitative:</u> Electronic survey Descriptive statistical analysis	n/a	50% wanted direct communication beyond discharge summary; 39% felt EHR communication was adequate; >75% wanted email or verbal report beyond EHR communication for complex patients.
Tandjung, Rosemann, and	Yes	To assess GPs' experiences of cooperation with	GPs	<u>Qualitative:</u> Focus groups	Negative experiences; positive experiences; comparison of	Patient lost to the GP while hospitalised. GPs want notification at

Author (year), country	Does paper meet CIS* quality criteria?	Research question or aim	Participants	Methods of data collection and analysis	Relevant categories or themes in qualitative studies	Key findings relevant to the aim of this literature review
Badertscher (2011), Switzerland.		hospital and needs and barriers regarding information flow		Summative content analysis	experiences with other hospitals/benchmarks; expectations for future cooperation	admission and during hospitalization if complications occur or long-term decisions are being made; flexible re: method of notification, but often absent. GPs see themselves as part of the medical team, desire inclusion; GPs have long term knowledge of patient to contribute. GPs want discharge paperwork within one day. Discussion includes differentiation of "transfer of information" vs. "interaction between 2 medical teams"
*CIS: Critical Interpretive Synthesis						

4.7.2 Contributions to theoretical development

Critical analysis of the literature introduced a more conceptual view of the preliminary categories of “acting independently,” “acting as one team across boundaries,” “knowing the other team,” “communicating intentionally,” and “acknowledging the role and value of the other team.” Analysis of literature findings revealed that how professionals viewed their own reality and place in the professional world affected how they acted and could transform interaction from a transactional event to a relational one. What differentiated teams that “act independently” from those that “act as one team” at any given time was their self-perception as a team or team member, either as working within their own boundaries or belonging to a broader team. “Seeing the team within boundaries” is the conceptual term created to incorporate the category of “acting independently” and the related subcategories, while “seeing and belonging to a cross-boundary team” is the conceptual term constructed to encompass the key category of “acting as one team across boundaries” and its supporting subcategories. This line of thinking from the literature will now be elucidated, beginning with the more commonly occurring “seeing the team within boundaries” concept.

4.7.3 “Seeing the team within boundaries”

4.7.3.1 *Concept overview*

“Seeing the team within boundaries” is the theoretical concept that explains the category of acting independently and its contributing subcategories (see Table 12). This was the default state of most inpatient and outpatient teams in the literature (Göbel et al., 2012; Rydeman & Törnkvist, 2006; Sheu et al., 2015).

Table 12: Categories and subcategories that constitute the concept "seeing the team within boundaries"

Concept: "seeing the team within boundaries"	Categories and subcategories subsumed by this concept:
	<p>"Acting independently"</p> <ul style="list-style-type: none"> • "acting independently – contributors" • "acting independently – outcomes" • "knowing each other – barriers" • "communicating intentionally – barriers" • "acknowledging the role and value – barriers" • "acting as one team – barriers"

Language used in the literature to describe this state of working include teams functioning as "separate professional tribes" (Hesselink, Vernooij-Dassen, et al., 2013, p. 96) and "separate entities" (Hesselink, Vernooij-Dassen, et al., 2013, p. 93). The words "separate" and "tribes" suggest a distinct boundary existing between groups. Hospital physicians and nurses are described as having an "inward focus" on the "here and now" (Hesselink, Vernooij-Dassen, et al., 2013, p. 93) which hinders them from seeing themselves as part of a larger whole.

"Our findings indicate that hospital and primary care providers, both members of the same virtual 'handover organization,' have separate 'professional tribes' and have different, often incompatible values and beliefs that threaten to undermine the effectiveness and safety of patient transitions." (Hesselink, Vernooij-Dassen, et al., 2013, p. 96)

Team members' visions of themselves as functioning within distinct physical and professional boundaries impacted the way teams act in relation to the other team, leading to more independent than interdependent practice.

4.7.3.2 *Characteristics of “seeing the team within boundaries”*

“Seeing the team within boundaries” as a concept was exhibited in the literature through the actions and perspectives of professional teams who emphasised tasks and transactions in the context of teamwork across discharge transitions. Teams relied on routine processes, such as written discharge summaries or automatic notifications through the electronic health record, for exchange of information at discharge, despite having lack of confidence that these processes work (Jones et al., 2015; Sheu et al., 2015). These routine processes often did not incorporate intentional personal communication (Acosta et al., 2018; Bell et al., 2009; Groene et al., 2012) though primary care providers indicated desire for direct communication with inpatient teams (Hesselink, Vernooij-Dassen, et al., 2013; Pantilat et al., 2001; Sheu et al., 2015). They reported lacking knowledge of what had occurred in hospital (Johnson et al., 2012; Jones et al., 2015). These teams viewed their work as happening in parallel, rather than in unison, with other teams caring for shared patients across settings.

Personal perspectives of professionals also demonstrated the concept of “seeing the team within boundaries.” Many professionals felt ambiguity about their roles and responsibilities as patients moved from one setting to another (Göbel et al., 2012; Jones et al., 2015; Ruth et al., 2011; Rydeman & Törnkvist, 2006) which limited collaboration. Primary care teams reported feeling undervalued by inpatient specialists (including palliative specialists) (Jones et al., 2015; Keane et al., 2017; Nguyen et al., 2014) and excluded from what happened to their patients while hospitalised (Balla & Jamieson, 1994; Keane et al., 2017; Tandjung et al., 2011). A sense of isolation was reported by both inpatient and outpatient teams (Göbel et al., 2012) as well as perception of a care chasm between the hospital and community settings by hospitalists (Canary & Wilkins, 2017) which reflects a strong sense of boundary rather than unity.

“Each healthcare professional attempted to provide the best care possible, but largely did so in isolation, and without the benefit of the knowledge and input of the other members of their respective microsystem” (Göbel et al., 2012, p. i111)

In different ways, professionals on each side of discharge transitions recognised the boundaries.

4.7.3.3 Contributors to “seeing the team within boundaries”

From the literature, contributors to the state of “seeing the team within boundaries” were grouped into four domains: procedural, interpersonal, disciplinary, and organisational, outlined in Table 13. The procedural domain relates to factors that have to do with operational processes that are utilised in the course of professional work. The interpersonal domain includes factors that have to do with relationships between team members and how they interact. Factors in the disciplinary domain have to do with differences in knowledge, professional culture, or values and beliefs between team members with different professional roles (for example, physicians and nurses) or from different specialities (for example, primary care or hospital medicine practice). The organisational domain captures factors that relate to broader system level issues, such as healthcare finances or education.

Table 13: Domains of factors that contribute to concept "seeing the team within boundaries"

Procedural domain
<ul style="list-style-type: none"> • Difficulty knowing who to contact on the other team and how to contact them (Hesselink, Schoonhoven, et al., 2013; Johnson et al., 2012; Jones et al., 2015; Mason et al., 2013; Ruth et al., 2011; Sampson et al., 2016) • Lack of a standard process for discharge communication (Göbel et al., 2012; Groene et al., 2012; Hesselink, Vernooij-Dassen, et al., 2013; Johnson et al., 2012) • Lack of a common EHR (Göbel et al., 2012; Groene et al., 2012; Johnson et al., 2012)

Interpersonal domain
<ul style="list-style-type: none"> • Lack of relationship with the other team (Hesselink, Vernooij-Dassen, et al., 2013; Jones et al., 2015) • Geographical distances between teams (Mason et al., 2013) • Lack of collaborative attitude (Hesselink, Vernooij-Dassen, et al., 2013) • “Resistance” on the part of outpatient generalists to shared care relationships (Sampson et al., 2016, p. 4) • Inpatient providers’ belief that outpatient generalists have nothing to contribute to hospital care (Balla & Jamieson, 1994; Hesselink, Vernooij-Dassen, et al., 2013; Keane et al., 2017) or are indifferent (Johnson et al., 2012) • Lack of trust or respect between teams (Balla & Jamieson, 1994; Hesselink, Vernooij-Dassen, et al., 2013; Keane et al., 2017; Rydeman & Törnkvist, 2006)
Disciplinary domain
<ul style="list-style-type: none"> • Lack of awareness of: <ul style="list-style-type: none"> ○ other team’s practices, priorities, and skills (Bull & Roberts, 2001; Hesselink, Schoonhoven, et al., 2013; Hesselink, Vernooij-Dassen, et al., 2013; Sampson et al., 2016) ○ impact of poor transitions outside their own setting (Göbel et al., 2012; Hesselink, Vernooij-Dassen, et al., 2013) • Interdisciplinary hierarchy of specialists over generalists or physicians over nurses (Blackford & Street, 2001; Keane et al., 2017) • Professional autonomy – teams reluctant to impose their recommendations on, or reach out for clarification from, the other team (Göbel et al., 2012; Mason et al., 2013) • Incompatible goals, values and beliefs between inpatient and outpatient teams (Hesselink, Vernooij-Dassen, et al., 2013)
Organisational domain
<ul style="list-style-type: none"> • Resource restraints and no financial incentive to collaborate (Balla & Jamieson, 1994; Nguyen et al., 2014; Rydeman & Törnkvist, 2006) • Lack of time to collaborate and pressure to maximize productivity (Johnson et al., 2012; Jones et al., 2015; Keane et al., 2017; Mason et al., 2013; Nguyen et al., 2014; Sampson et al., 2016) • Coordination between teams at discharge perceived as administrative burden not clinical care (Göbel et al., 2012; Hesselink, Vernooij-Dassen, et al., 2013) • Lack of training in collaborating across boundaries (Göbel et al., 2012)

These factors prohibit professionals from developing connections and shared understanding across disciplines and settings. Without these, teams focus their work within disciplinary and physical boundaries.

4.7.3.4 *Outcomes of “seeing the team within boundaries”*

When teams worked independently, within their own practice boundaries, clinical care and patient and professional satisfaction were impacted negatively. Without community teams’ input, hospital care decisions were often made without the benefit of knowing the patient’s historical story and values which may affect the quality of those decisions (Sampson et al., 2016; Tandjung et al., 2011). Primary care teams did not have adequate knowledge to follow through on the plan of care established during hospitalisation (Abu et al., 2018; Rydeman & Törnkvist, 2006) which could lead to frustration (Göbel et al., 2012; Sampson et al., 2016) and additional stress and duplication of work (Johnson et al., 2012) for the primary care team.

“The lack of adequate and timely communication between hospital physicians and GPs led to dissatisfaction in the group of GPs but may also have a negative impact on treatment decisions in the hospital, when important information about patients’ background, setting, and ethical values are needed.” (Tandjung et al., 2011, p. 776)

Potential patient harm was identified as a possible outcome of teams working independently within boundaries as well (Canary & Wilkins, 2017; Göbel et al., 2012; Groene et al., 2012; Sheu et al., 2015). Additionally, emotional and mental distress for the patient and family resulted when there was a lack of collaboration between settings (Canary & Wilkins, 2017; Hesselink, Schoonhoven, et al., 2013; Jones et al., 2015). One exception was noted in that some patients felt that they received more personal, less-controlling healthcare when the primary care provider worked independently from the hospital team (Huby et al., 1997). This was the only positive impact of “seeing the team within boundaries” noted in the literature.

Analysis of findings from the literature suggested that teams that work independently within their own boundaries create a self-perpetuating cycle of independent, within-boundaries work patterns. Working independently was shown to result in further miscommunication between teams (Abu et al., 2018) and primary care teams' perception of not belonging to the hospital system (Balla & Jamieson, 1994). This suggests that without deliberate action on the part of healthcare team members, it is likely that teams will continue to practice on the independent end of the interdependence spectrum.

4.7.4 "Seeing and belonging to a cross-boundary team"

4.7.4.1 *Concept overview*

"Seeing and belonging to a cross-boundary team" is the conceptual term that depicts the key category of "acting as one team" on the interdependence spectrum and its associated subcategories (see Table 14). This concept illuminates what it looks like when a team perceives their work across discharge transitions through a more relational lens, instead of as a transactional exchange of information or a handoff of duties. The word "seeing" was chosen over "viewing" as it conveys a broader meaning beyond the act of looking at and considering something; instead, "seeing" can imply having experience or grasping a mental understanding of something (Merriam-Webster, 2019).

"In order for informational and management continuity to operate well at the interface for the patient, both primary and secondary care teams need to be helped to see that they are working as one larger team..." (Sampson et al., 2016, p. 8)

Implied is an element of a team's self-perception: "Do we see ourselves as belonging to something bigger than our local team?" Canary and Wilkins referred to this as "systems mindfulness" (2017, p. 1229).

Table 14: Categories and subcategories that constitute the concept "seeing and belonging to a cross-boundary team"

Concept: "Seeing and belonging to a cross-boundary team"	Categories and subcategories subsumed by this concept:
	<p>"Acting as one team"</p> <ul style="list-style-type: none"> • "acting as one team – contributors" • "acting as one team – outcomes" • "knowing each other" • "knowing each other – outcomes" • "communicating intentionally" • "communicating intentionally – outcomes" • "acknowledging the role and value of the other team"

In the literature, language used to describe this way of teamworking across the hospital/community transition reflected the relational lens that these teams used in their work. For example, phrases like a partnership approach (Keane et al., 2017), establishing accountability (Jones et al., 2015), building and maintaining relationships (Jones et al., 2015), and "handover microsystem" (Göbel et al., 2012, p. i107) were used. These phrases suggest ongoing connections between teams, rather than a one-time transaction for the purpose of information exchange at the time of hospital discharge.

4.7.4.2 Characteristics of "seeing and belonging to a cross-boundary team"

Actions of teams that functioned in this way demonstrated a broader focus outside their own immediate setting. Teams that perceived that they belong to a larger, cross-boundary team prioritised ongoing relationships with the other team (Sampson et al., 2016). One example of this prioritisation was holding cross-boundary team care conferences (Bull & Roberts, 2001). Several studies identified a designated team member on either side of the discharge transition that was responsible for facilitating relationships between teams (Bull & Roberts, 2001; Johnson et al., 2012; Keane et al., 2017), which reflected a value placed on promoting connections between the two groups. Blurring of disciplinary roles and boundaries was a characteristic of teams that have this cross-boundary view

(Bull & Roberts, 2001) and these teams tended to eschew territorial “turf” battles (Keane et al., 2017). Another characteristic of teams that saw themselves as part of a larger team across boundaries was the willingness to adapt their skill sets to adjust to the needs of colleagues and accommodate collaboration (Keane et al., 2017).

4.7.4.3 Contributor: “Knowing each other”

The literature provided additional data to enhance the subcategory “knowing each other” as both a contributor to and an outcome of “see and belonging to a cross-boundary team.” From the literature, knowing each other was shown to mean that teams have a relationship with their counterparts in the opposite setting (hospital or community) from working together in the past (Jones et al., 2015; Mason et al., 2013) or having had networking opportunities (Bull & Roberts, 2001; Groene et al., 2012; Jones et al., 2015; Nguyen et al., 2014). Working in affiliated hospitals and community practices, sometimes with co-location of staff in one physical setting, promoted teams knowing each other (Nguyen et al., 2014; Sampson et al., 2016). Another element of knowing the other team was understanding the work setting and practices of the other (Bull & Roberts, 2001; Göbel et al., 2012).

Attitudinally, teams in the literature that exhibited the condition of knowing each other worked with a sense of trust, respect, and “good will” (Groene et al., 2012, p. i73; Keane et al., 2017). This sense of trust and good will not only characterized these teams, but when teams functioned in this way, the sense of trust was augmented as a result – creating another self-perpetuating cycle. Another outcome of knowing each other was more direct and positive communication with the other team and a positive desire to help the other (Sampson et al., 2016) which led to the second contributing category, “communicating intentionally.”

4.7.4.4 Contributors: communicating intentionally

The condition of communicating intentionally is one in which one or both teams take deliberate steps to communicate with the other team across the discharge transition, not passively relying on others to access and read clinical documentation. Aspects of this action are operational, such as choosing

particular means of communication, while others are relational, requiring respect, honesty and bidirectional communication. Intentional communication as a true exchange was differentiated in the literature from a simple transfer of information (Ruth et al., 2011; Tandjung et al., 2011).

In the literature, transactional aspects of “communicating intentionally” was evidenced by teams that made direct phone calls which were preferred by primary care providers (Balla & Jamieson, 1994; Blackford & Street, 2001; Bull & Roberts, 2001), or used direct messaging within the electronic health record or email (Groene et al., 2012; Jones et al., 2015) as opposed to expecting the other team to independently access documentation in the health record. Planning joint care conferences with participants from across inpatient/outpatient boundaries also demonstrated this intentional approach to communication (Bull & Roberts, 2001).

Relational aspects of “communicating intentionally” in the literature were characterised by active listening with respectful, honest, timely, and bidirectional communication with the other team (Bull & Roberts, 2001; Tandjung et al., 2011). Sometimes this was accomplished by designating a team member to serve as facilitator to that communication (Blackford & Street, 2001; Johnson et al., 2012). Language used in the literature to describe modes of intentional communication included “circles of communication” (Bull & Roberts, 2001, p. 574) which depict the overlapping parties that need to interact throughout the discharge process for the best outcomes. These circles involved the inpatient team, the community team, and the patient . “Handover microsystems” (Göbel et al., 2012, p. i107) was another term used to describe the complexities of intentional communication that need to occur inter-professionally as patients transition between settings. The idea of microsystems in the literature contributed to the development of the concept of working across boundaries and seeing oneself as part of a larger whole.

Demonstrated outcomes of “communicating intentionally” included maintenance of trust and willingness to be flexible with and cover for each other (Keane et al., 2017) which leads back to both the trust inherent in the category of “knowing the other team” and the characteristic of blurred lines

between disciplines and teams. Again, a self-perpetuating cycle is seen as communicating intentionally also led to creation of better communication networks (Blackford & Street, 2001). Primary care providers were more satisfied with the inpatient team's communication and discharge plans are perceived to be more effective when intentional communication occurred (Marks et al., 1999).

4.7.4.5 Contributor: *"Acknowledging the role and value of the other team"*

The final contributor to teams achieving the state of "seeing and belonging to a cross-boundary team" is the category of "acknowledging the role and value of the other team." In the literature, this was evidenced when a team recognised the unique and valuable contribution the other team made to the care of the patient; for example, when the inpatient team recognises that the primary care team may have a deeper knowledge of a patient as a whole that could impact inpatient care (Tandjung et al., 2011). Teams who acknowledged the role and value of the other learned from each other and relied on each other to fulfil their roles and responsibilities and relied on the other team's judgment (Bull & Roberts, 2001). When teams functioned in this way, teams would publicly defend the other team when they were disregarded (Keane et al., 2017) indicating a personal sense of connection and positive regard. In one study, this valuing crossed disciplinary lines, with generalist physicians expressing high regard for and dependence on the specialist palliative care nurse (Keane et al., 2017).

The condition of acknowledging and valuing of the other team sometimes developed over time, as teams accumulated positive experiences of working together across boundaries. As with the other conditions, "acknowledging and valuing the role of the other team" could result in a cyclical pattern of self-perpetuation. In this case, increasing positive regard for the other team led to increased knowledge of the other team and the likelihood of intentional communication and improved partnership working (Keane et al., 2017).

4.7.4.6 Outcomes of *"seeing and belonging to a cross-boundary team"*

When teams acted interdependently out of a perception that they belonged to a cross-boundary team when caring for shared patients across hospital discharge transitions, the benefits of this way of

working were perpetuated. The literature demonstrated that the working from the perspective of this self-perception lead to:

- increasing and maintained trust (Groene et al., 2012; Keane et al., 2017)
- increasing knowledge of the other team (Keane et al., 2017)
- more direct and positive communication networks and likelihood to continue communicating in this way (Blackford & Street, 2001; Keane et al., 2017; Sampson et al., 2016)
- willingness to be flexible and help the other team (Keane et al., 2017; Sampson et al., 2016)
- increased primary care provider satisfaction and perception of more effective discharge plans (Marks et al., 1999)
- smoother, more satisfying transitions for patient (Bull & Roberts, 2001)
- avoidance of patient readmission (Bull & Roberts, 2001).

These outcomes demonstrated in the literature added depth to the preliminary conceptual model proposed from the initial data analysis by suggesting potential perpetuating relationships between the key categories and the conditions which support them.

4.7.5 Discussion

This critical interpretive synthesis contributed to the categories and preliminary conceptual model constructed from the initial analysis of interview data in several ways. First, the synthesis suggested a higher level of abstraction for the key categories presented in the preliminary model in Chapter 3. Analysis of the literature added the idea that teams may act in a certain way because of how they perceive themselves within or across hospital and community boundaries, suggesting a shift from “acting” categories to “perception” concepts. In addition, the literature suggested self-perpetuating relationships between the conditions and concepts that had not been captured in the initial data analysis.

Figure 7 depicts the concepts, conditions, and relationships between them that were demonstrated in the literature. In summary, when teams lack relational knowledge of the other team, communicate passively, and do not value the other's contributions, clinical care is provided by teams in parallel ("acting independently"). Teams functioning in this way tend to perceive their work as happening within the boundaries of their healthcare setting ("seeing the team within boundaries"). When teams know each other, take the initiative to communicate directly, and acknowledge the other team has a valuable role and contribution to make, they can provide care in unison ("acting as one team across boundaries"). These teams tend to perceive themselves as working as part of a team that crosses healthcare setting boundaries ("seeing and belonging to a cross-boundary team").

These team self-perceptions and ways of working are self-perpetuating. When teams act independently, they tend to continue to experience miscommunication and perceive themselves as separate teams. In turn, when teams act as one team across healthcare setting boundaries they grow in knowledge and trust of each other and appreciation of the role and contributions of the other team. Knowing each other leads to increased frequency of and desire for intentional communication. Intentional communication between teams perpetuates trust and relationships between teams. When teams come to recognise and value the role the other team plays and their contribution to shared care of patients, likelihood of intentional communication increases.

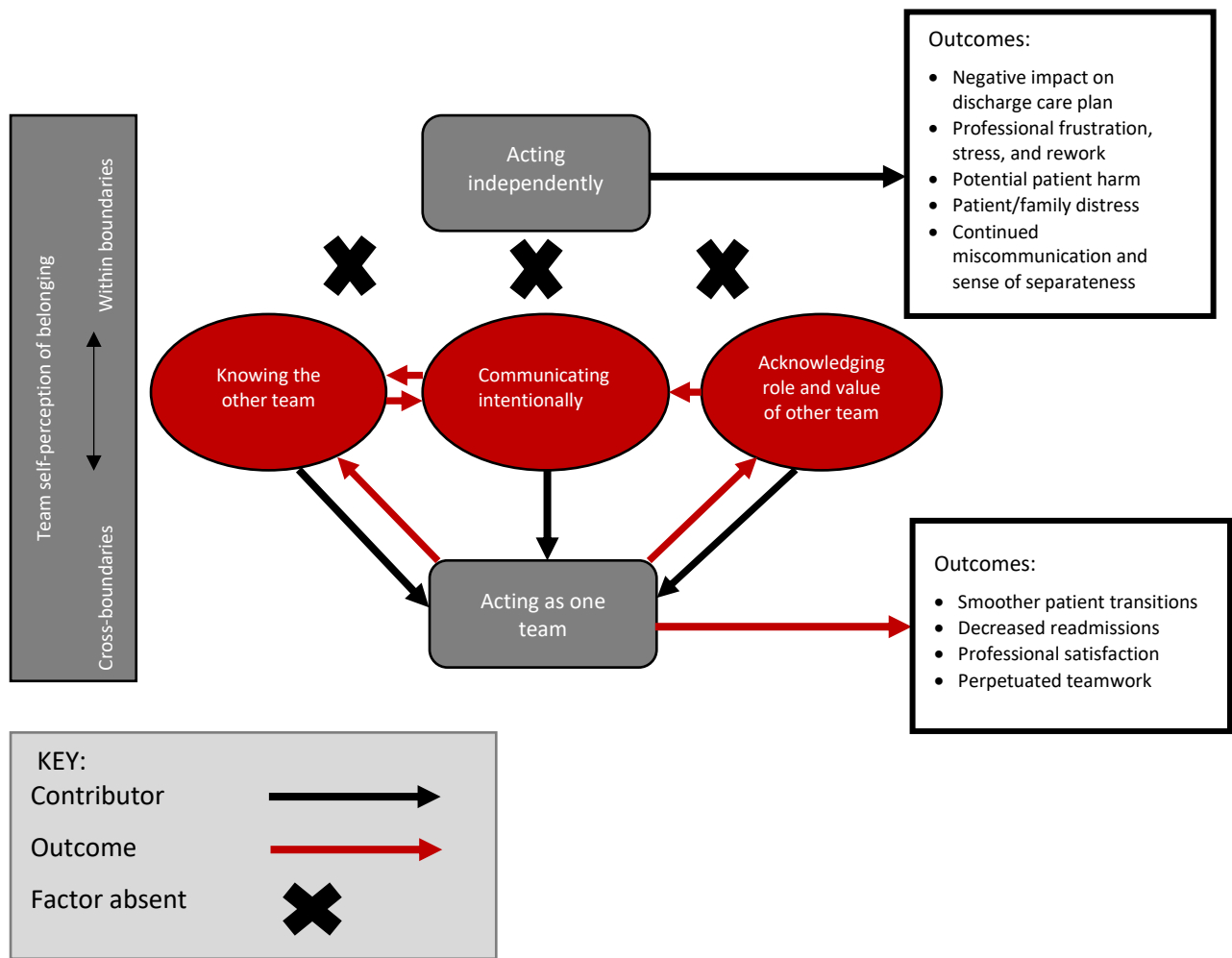


Figure 7: Graphic representation of conceptualised theory of interdependence between inpatient specialist and outpatient generalist teams from synthesis of the literature

4.7.6 Critical reflection

Critical reflection is vital in the critical interpretive synthesis approach to literature review. Reflection on the included studies revealed that a main focus in the included literature was on procedural aspects of information transfer at discharge, such as timing of the discharge summary reaching the primary care provider (Bell et al., 2009) or impact of an electronic health record (Groene et al., 2012). One result from this literature review is recognition that a broader focus, beyond procedure to interpersonal interactions and teams' self-perceptions, may better explain teamwork and collaboration across discharge transitions. Tandjung and colleagues suggest this, noting that transitions between hospital and community teams should not only be "seen as a transfer of information... but also as an interaction between two medical teams, both responsible for the medical treatment of their patient" (Tandjung et al., 2011, p. 777). In this statement, the language of teams (plural) caring for their patient (singular) evokes the question of whether these teams, both focused on a singular patient, could function as one.

Another critique of the literature is that half of the included studies had only physician or nurse participants (see Table 11). While physicians and nurses play a key role in the transitions under study, neither discipline practices in a vacuum; conceptual findings related to teamwork would be stronger if all disciplines are included. Had there been inclusion of more interdisciplinary team members' perspectives, a more in-depth understanding of relational aspects of inter-team dynamics may have been possible.

4.8 Summary

This chapter has presented a critical interpretive synthesis of literature representing research related to teamwork between inpatient specialist and outpatient generalist healthcare teams across hospital and community boundaries in the context of patient discharge from hospital. Justification of the timing, philosophical underpinnings of the synthesis, and methodological approaches were described. Findings from the literature provided additional theoretical building blocks for the construction of the

categories, conditions, and preliminary conceptual model developed through initial analysis of interview data. The literature synthesis has raised the level of conceptualisation from describing the way teams work (“acting independently” or “acting as one team”) to explaining the perceptual realities which may influence why teams work in these ways.

5 Final abductive analysis of data resulting in a grounded theory of interdependence between teams in palliative care provision across settings

The initial analysis of interview data using constructivist grounded theory methods was presented in Chapter 3 with five constructed categories and a preliminary conceptual model proposed (see Figure 4 in Chapter 3). In Chapter 4, a critical interpretive synthesis of related literature was described. The review of the literature was designed to identify and analyse previous empirical research findings that could contribute data to help build the conceptual categories and strengthen or challenge the proposed conceptual model. Analysis of pre-existing research findings provided a higher level of abstraction, raising two initial categories to the level of concepts, and suggested more complex relationships between categories than had been originally noted in the primary interview data. The concepts and relationships constructed through abductive interplay of interview data and literature findings were depicted in Figure 7 in Chapter 4. Now in Chapter 5, the final stage of analysis leading to construction of a theory of interdependence between inpatient specialist palliative care and outpatient generalist healthcare teams across hospital and community boundaries will be addressed.

5.1 Primary data, the literature and abduction

After the review of the literature, I recoded all interview transcripts to determine what findings from the critical interpretive synthesis were usable and relevant to the data from the current study. The notions of abduction and cumulativeness were the foundations of this process, aligning with the philosophical stance of Charmaz that all theory is provisional and modifiable, and is built through interactive and ongoing engagement with participants, one's own interpretations as a researcher, and the work of others (Charmaz, 2014a; Thornberg, 2012). The purpose of the re-examination of the primary data was to review the data again with two new lenses: one of team self-perception and one of self-perpetuation of the categories and conditions, based on the contributions from the literature.

This process ensured that findings from the literature were incorporated into the theory of interdependence between inpatient specialist palliative care and outpatient generalist teams across hospital and community boundaries only if the literature findings aligned with the primary data (Giles, King, & de Lacey, 2013).

5.2 Language of self-perception in the data

Interview transcripts were coded again looking for participants' language that demonstrated how they perceived themselves and their team in relation to the corresponding team in the opposite setting who was also providing palliative care to a shared patient. All interviews with both inpatient specialist and outpatient generalist palliative care team members were recoded. Language that reflected a perception of themselves or their team as separate from teams that practice outside their own boundaries was coded as "exclusionary" language, while that which reflected a perception of themselves or their team belonging to a broader, cross-boundary team was coded as "inclusionary."

5.2.1 Exclusionary team language

In the first analysis of the interview data, more evidence was found that teams worked independently than that they worked together as one team. Similarly, re-analysing the data revealed more exclusionary than inclusionary language. Some of the language was obvious, as when participants used words that indicated a clear distinction between the two teams. Other language identified in the interview data was more subtle, signifying a perceived disconnection between the two teams resulting from multiple factors including geography, diverse disciplinary approaches, strict role boundaries, or pre-existing clinician-patient relationships. These perceptions reflected more than a simple acknowledgment of operational factors, such as working in different physical locales, but suggest an awareness of a negative impact that these factors had on the overall care provided to patients and families.

Both specialists and generalists expressed that a team's care often was isolated to a physical location and does not carry over beyond those borders. Words like "go back to them," "a rural hospital doing

their own thing” and “then they move on” when referring to the other team reflected the disconnection of teams across boundaries. The way that participants talked about the other team indicated a perceived separateness having to do with physical locale but implying a separateness of purpose and function between the two types of teams as well.

“Well, palliative care started this regimen, so you need to back and talk to them...” They start, you know, ‘they took care of you so go back to them, and call them,’ instead of trying to sort it out right there at home. (Crash, ISPC RN)

I don’t work that closely with them, so I guess it’s just a rural hospital doing their own thing. (Rose, ISPC NP)

Their discharge planning needs are being met in the hospital, and you’re kind of meeting that, like, having that conversation while they’re there, and then they move on. (Lacy, OGC SW)

The language demonstrating perceptions of disconnection between the teams also reflected individuals’ protection of distinct role responsibilities. Words like “my job” and “your job” indicate clear perceived boundaries between teams’ functions. Other language indicated that teams perceived professional turf tensions and were resistant to working across disciplinary turf boundaries. The boundaries indicated in the participants’ words reflected different disciplinary or specialty approaches to care that did not align with the approaches of the other team involved in the patient’s care.

Everyone wants to be... responsible for what they’re responsible for. And nothing else. I’m the same way. You know, I want to do my job and I don’t want to do your job. (Linda, OGC NP)

There’s a few primary care providers that I feel like don’t, you know, appreciate palliative care being involved in their patients’ care, and I suppose that’s been, you know, when that’s been a more frustrating situation, where I’ve tried to reach out, and you know, it’s not really welcome. (Hill, ISPC physician)

Disciplinary territorialism was evident in participants' reports of sensing that the other team disapproves of or judges their abilities or actions. This sense of judgment increased a sense of boundaries between teams and inhibited the ability of teams to work together. This territorialism was sometimes influenced by one team's relationship with the patient and the tendency to view the care of a patient strictly from one's own disciplinary viewpoint. The idea of territory implies that there are boundaries separating those territories.

In family medicine a lot of times, when specialists are called to the table, there's... "Oh, you're doing this wrong" ... and you know, there's not an accounting for previous conversations you may have had with the family – previous understandings you may have had... there can sometimes not be that sense of teamwork. (JGG, OGC physician)

There was a dismissiveness, maybe, in not taking, maybe an air of "Well, I know this patient really well, so, you know, I'm gonna make the decision that I want to make." (Susan, ISPC RN)

5.2.2 Inclusionary team language

Language that reflected perceptions of team members as belonging to a larger team that crosses physical and disciplinary boundaries was also present in the interview data, though to a lesser extent. Both specialist and generalist participants spoke of being on the same team, aiming to work as one team, or working together with the other team to come to agreement on a mutual plan of palliative care for the patient. Inclusionary language, like "we've been caring for *your* patient," and "we wanted to connect and share," demonstrated a willingness to cross disciplinary or specialty turf boundaries and to put aside a possessive, exclusionary approach to a relationship with a patient.

"We've been caring for your patient, we wanted to connect and share with you, you know, what we've been doing and talking about and how can we work together? Who would you, you know, how can we be part of, you know, how can we be of help to you?" (Crash, ISPC RN)

Both inpatient palliative specialist clinicians and those on generalist teams in the community not only used language that reflected the perception themselves of functioning as one team with the other, but also described presentation of that image of one collaborative cross-boundary team to patients and families in the language they used. They reported that patients and families highly valued this presentation of the two teams functioning as one team across geographic and disciplinary boundaries.

He gives the perception to them of “we’re doing this together, and I’m letting [Mae] know, and she knows that she can reach out to me if she needs it.” (Mae, OGC NP)

I think more people are extraordinarily appreciative to know that we’re part of the same team. (Walter, ISPC physician)

As in the literature, language was present in the data that reflected a blurring of disciplinary roles and boundaries between the specialist and generalist palliative care teams interviewed. These blurred boundaries allowed for teams to cover for each other and share patient care responsibilities. Inclusionary language on the part of specialists included an effort and focus on supporting and maintaining the patient’s and family’s connection with their generalist teams whilst providing specialist palliative care services.

Because the primary care physician was already so well informed about what our plan was, and how we were managing things. So, it was, you know, a team – so if I wasn’t available, her primary always was. (Hill, ISPC physician)

I really emphasize that notion that we don’t replace any of the other doctors, but we work with them. (Duncan, ISPC physician)

A recoding of the primary interview data revealed that participants on both specialist and generalist teams used exclusionary and inclusionary language which reflected a perception of functioning either within or across boundaries as a team, respectively. This lends support for including the concepts of “within boundaries” and “across boundaries” functioning of teams, as synthesised from the literature,

in the final grounded theory of interdependence of inpatient specialist palliative care teams and outpatient generalist healthcare teams.

5.3 Self-perpetuation of concepts and conditions in the data

The preliminary conceptual model constructed from the first round of interview data constant comparative analysis of interview data (presented in Chapter 3) proposed that the conditions contributing to the categories of teams acting independently or as one team are cumulative, building progressively. The literature challenged this, by suggesting that the relationships between the conditions are not linear and cumulative, but rather reciprocal and self-perpetuating. The second focus of recoding the interview data after the literature synthesis was to look for any support for reciprocal relationships between the concepts and categories of the conceptual model, as were demonstrated in the literature.

5.3.1 Self-perpetuation of the “within boundaries” concept

Within the concept of “seeing the team within boundaries,” interview data supported the idea that the conditions that contribute to teams acting independently do not do so unidirectionally, that is, progressively in one direction. Recoding of the interview data suggested that some of the conditions in this conceptual model can perpetuate other conditions, and the state of acting independently can contribute to the conditions continuing to persist. For example, participants’ perspectives indicated that lack of knowing the other team lead to ongoing lack of intentional communication. When team members did not know or understand the other team, they were less likely to reach out and make deliberate contact with the other.

So I had a hard time trying to figure out what is the criteria to qualify for what they see as palliative care? I guess that was my previous experience was one thing that kept me from trying to actively contact them. (Kay, OGC RN)

The preliminary conceptual model in Chapter 3 demonstrated that not knowing the other team was the first condition that led to teams acting independently. After the literature synthesis suggested

reciprocal relationships between conditions and teams' states of functioning, re-analysis of the interview data affirmed that this idea of reciprocity and perpetuation between conditions and states of functioning fit with the perceptions of participants. Lack of knowing or understanding the work of the other team not only contributed to teams acting independently, but when teams acted independently, lack of knowing persisted. Similarly, not only did lack of valuing the role of other team contribute to teams acting independently, but when teams acted independently, the sense of lack of valuing of the other team was maintained and prolonged.

I know that his belief of both palliative medicine and hospice is that our goal is to give people a bunch of morphine and hasten their death. But it's just unfortunately, the only reason he has this image of us is because the only time he refers his patients to us is when they're imminent.
(Hill, ISPC physician)

I, as an old-fashioned doctor, like to be involved in all of that stuff with my patients, and so, you know, it feels like I wasn't present at a time when I should have been present for my patients. You know, it makes you feel... less valued, I guess, as a team member. *(JGG, OGC physician)*

Figure 8 graphically represents the perpetuating relationships that were demonstrated in the data between category and conditions that fall under the "seeing the team within boundaries" concept.

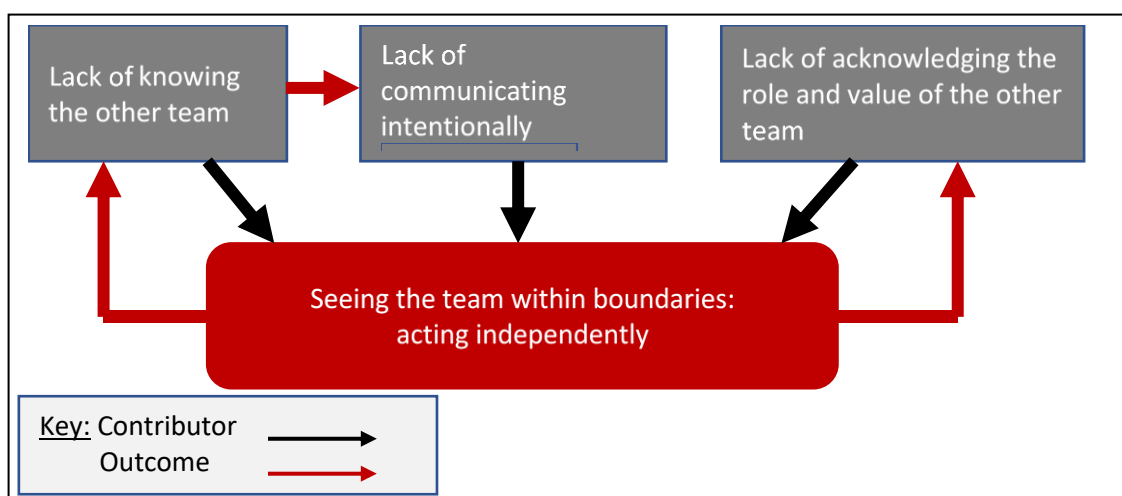


Figure 8: Reciprocal relationships between "seeing the team within boundaries" and related conditions

5.3.2 Self-perpetuation of “cross-boundaries” category and conditions

A re-coding of the data also demonstrated support for the idea, synthesised from the literature, that the category and conditions subsumed in the concept “seeing and belonging to a cross-boundary team” affect each other in a reciprocal, perpetual way. From the perspectives of participants, conditions in the preliminary conceptual model not only contributed to the state of teams acting as one team across boundaries, but the state of functioning as one team in turn led to the conditions being reinforced and maintained.

5.3.2.1 *Relationships between the category of “acting as one team across boundaries” and the contributing conditions*

It was noted in the preliminary conceptual model that the condition of knowing the other team contributes to the state of acting as one team. Recoding of the data demonstrated that the relationship between the condition of knowing the other team and the state of acting as one team across boundaries is a self-perpetuating one, in that when teams acted as one team across boundaries, their knowledge of the other team’s practice and capabilities increased. This then informed and facilitated future working together.

I think we learn, especially those providers that we coordinate with often, we learn who can do things better than others. (Sally, ISPC SW)

Similarly, while the condition of acknowledging the role and value of the other team contributes to the state of acting as one team in the preliminary model, recoding of the data demonstrated that the state of two teams acting as one team across boundaries reinforced the condition of valuing the other team.

I feel like the reason why we get a lot of really good referrals from them is that they’ve come to see, they do a lot of what we do, so they’ve come to value that, that extra pair of hands, or that extra thought process to go in to help patients. (Jean, ISPC SW)

5.3.2.2 Relationships among the contributing conditions to “acting as one team across boundaries”

The process of self-perpetuation occurred between the conditions themselves as well. For example, teams that had experienced knowing and understanding the other team tended to continue to communicate intentionally when they had future opportunities to care for shared patients requiring palliative care across settings. This was apparent from perspectives of both specialist palliative and generalist healthcare team members.

Again, it was face to face – we were both on the floor at the same time. So I’m gonna say in the future, it’s definitely gonna be, rather than, “Okay, go off and be in the world,” I will probably talk to her and it’ll be like either phone or face to face. And I will reach out to her to say, “Here’s who’s coming, this is what we’ve done.” (Renee, ISPC NP)

When the knowing and understanding of the other team was a positive experience that resulted in valuing the other team’s role in a patient’s care, this too perpetuated future intentional communication.

I have some positive interaction with her. And I saved her email address, so if I do have someone to refer, I will contact her again. (Kay, OGC RN)

When teams fulfilled the condition of communicating intentionally, the condition of acknowledging the role and value of the other team was reinforced.

I think we’re some of the only teams that really prioritize reaching out to other local teams... So when we have reached out, or when we do, the person on the other receiving end is often very, more often than not, are very grateful and very appreciative to have the update... (Susan, ISPC RN)

The only directly reciprocal relationship from the literature synthesis that was not supported in the re-coding of the interview data was the idea that an outcome of “communicating intentionally” is “knowing the other team.” However, in my model, “communicating intentionally” does perpetuate

further “acting as one team,” which then leads to teams “knowing the other team.” So, while not explicitly supported in the data, this reciprocal relationship was present indirectly. These reciprocal, cyclical relationships between the state of “acting as one team” within the concept of “seeing and belong to a cross-boundary team” and the conditions associated with this state of team functioning, as demonstrated in the interview data, are demonstrated in Figure 9.

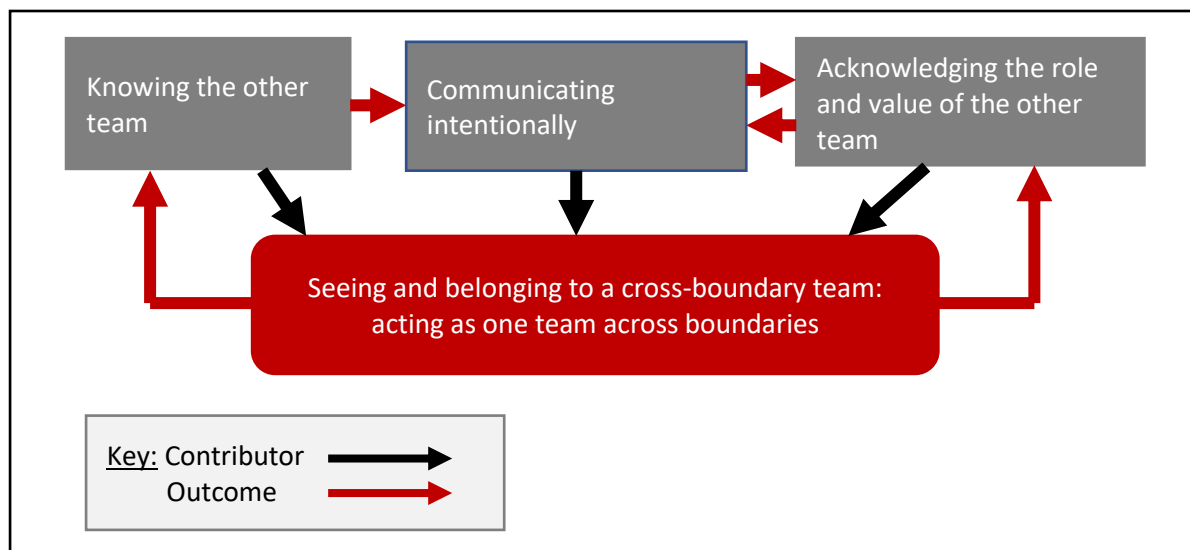


Figure 9: Reciprocal relationships between "seeing and belonging to a cross-boundary team" and related conditions

5.4 Final theory construction

The final construction of a constructivist grounded theory of interdependence between inpatient specialist palliative care and outpatient generalist healthcare teams across hospital/community boundaries was completed after three iterative stages of initial interview inductive data analysis, literature synthesis, and abductive re-analysis of the interview data based on findings from the literature. The initial data analysis provided for construction of a preliminary conceptual model. The preliminary model categories provided a framework for analysing the literature to synthesise additional concepts for theory development. Re-coding of the interview data using the additional insights from the literature demonstrated that, overall, findings in the literature related to healthcare

professionals' perceptions of specialist/generalist interactions across healthcare settings in the context of hospital discharge are consistent and fit with the perceptions of the participants in this study. This iterative process of moving back and forth between analysis of the data and the literature resulted in eventual development of a theory truly grounded in the data. The theory incorporates the work of researchers in broader fields yet prioritises the specific experiences and perceptions of interdisciplinary professionals made visible in this study in the particular context of palliative care provision (Thornberg, 2012).

5.5 The final product: a theory of interdependence between inpatient specialist palliative care and outpatient generalist teams across hospital/community boundaries

As a theory generated through constructivist grounded theory methods from an interpretivist philosophical approach, the final product of this research process is an attempt to put into words and graphics a deeper understanding of the phenomenon studied. It is not an attempt to explain cause and effects between variables, but to offer a new way of comprehending the complexities and patterns of social processes that occur between teams of interdisciplinary healthcare professionals in a specific setting and context. This is not intended to be a universal theory, applicable in all settings at all times; instead, it offers a conceptual understanding of the realities experienced by the participants in this study, as interpreted through interactions with this researcher and augmented by findings of previous research in separate but related fields.

This theory offers one way to understand the psychosocial processes that occur between specialist palliative care teams who practice in the hospital setting and the generalist healthcare teams who practice in the community setting when the two teams are providing palliative care for shared patients, each in a different setting. Interdependence is the term used to describe the degree of interaction and collaboration between the two teams, expressed on a continuum, with a state of little or no interdependence on one end and a state of a high degree of interdependence on the other end.

Teams that practice with a low degree of interdependence tend to see themselves as a team that works within the boundaries of their particular work setting, such as the hospital or the community, and focuses on the needs of the team and the patient within that setting. These teams tend to act independently from, or in parallel to, the other team caring for the same patient in the other setting. Teams that practice with a high degree of interdependence tend to perceive themselves as belonging to a larger team that is not constrained by specific healthcare setting boundaries. They tend to think beyond the boundaries of their setting and consider the other team and the needs of patient outside of the present setting where they primarily interact with the patient. A team's self-perception as a smaller, narrower team versus a larger, broader team seems to correlate with the way the teams carry out their work and function in relation to the other team.

Several conditions, or the lack thereof, appear to contribute to a team's self-perception and way of functioning in relation to the other team. These conditions include knowing the other team (versus not knowing), communicating intentionally (versus communicating passively), and acknowledging the role and value of the other team (versus not valuing the role of the other team). While these conditions are seen to contribute to the self-perception of a team and the way in which a team functions in relation to the other team, the conditions are also perpetuated by the team's self-perception and state of functioning, creating a cyclical pattern that tends to maintain a given degree of interdependence.

Participants perceived particular outcomes to be associated with team functioning on each end of the interdependence continuum. When teams function with a low degree of interdependence, acting independently from each other across settings, impacts tend to be more negative. Negative impacts include poorly executed discharge care plans, potential for patient harm, patient and family distress, and professional distress and duplicated work. A low degree of interdependence tends to be preserved. When teams function with a high degree of interdependence, acting as one team across healthcare setting boundaries, impacts tend to be more positive. Positive impacts include smoother

patient transitions between settings with more coordinated care and follow through on established care plans, increased patient and family satisfaction with care, decreased readmissions to hospital, increased professional satisfaction with their work, and propagation of interdependence. Figure 10 graphically represents these theoretical concepts and the relationships between them.

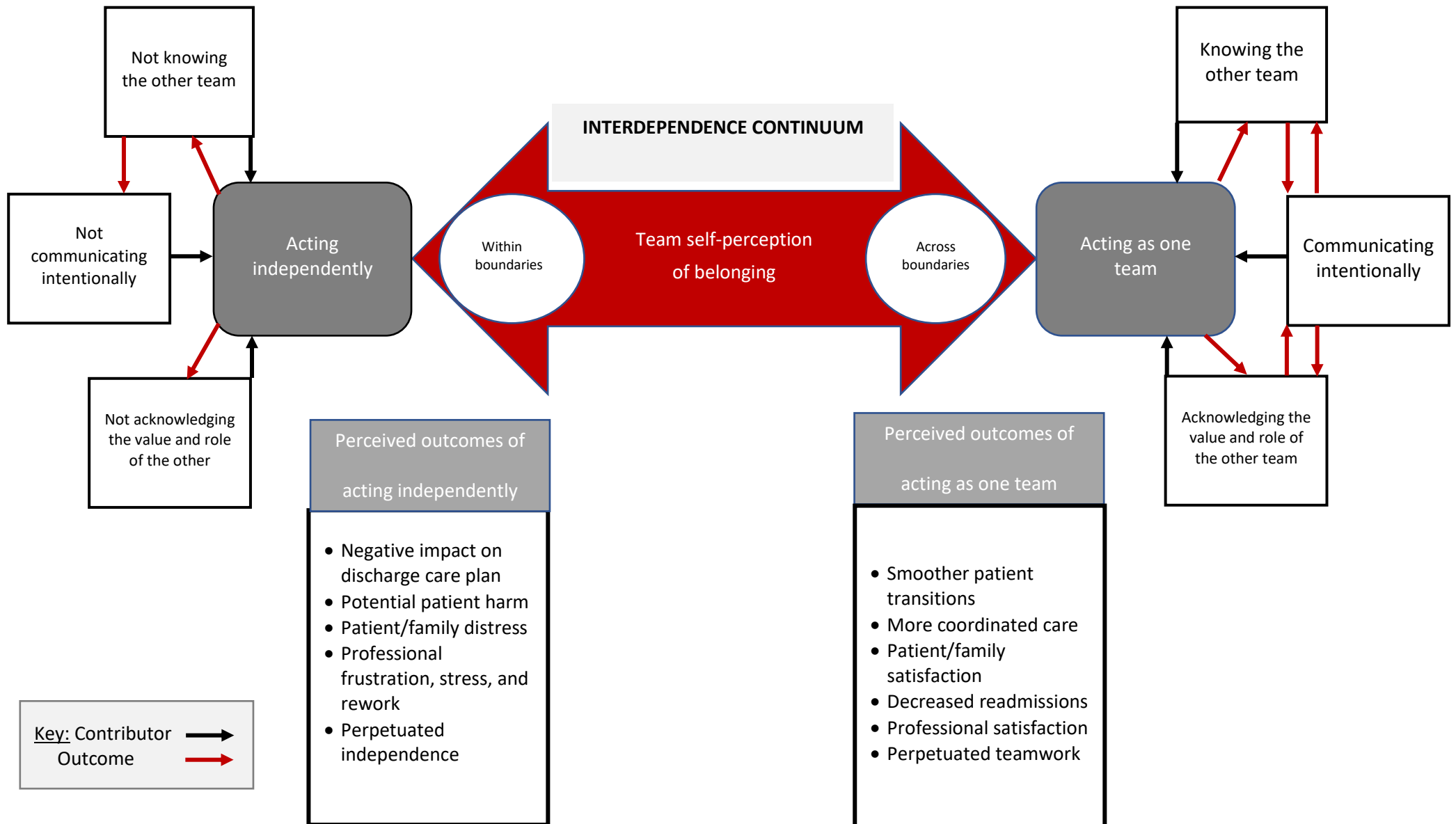


Figure 10: Graphic representation of the theory of interdependence between inpatient specialist palliative care and outpatient generalist healthcare teams across hospital/community boundaries

The main propositions of this theory are outlined below. All propositions relate to the interactions between inpatient specialist palliative care and outpatient generalist teams, in the context of a patient's transition between hospital and community settings in the U.S.

- A team's self-perception as belonging to a within-boundaries or across-boundaries team influences the level of interdependence with which the teams work.
- Teams that perceive themselves as belonging to a team within their own setting's boundaries tend to act independently of, or in parallel to, the corresponding team in the other setting.
- When teams see themselves as a within-boundaries team and act independently from the other team, negative patient outcomes may result, and patients and professionals may experience more stress and dissatisfaction.
- Teams that perceive themselves as belonging to a broader team that crosses clinical setting boundaries tend to act as one team, or in unison with, the corresponding team in the other setting.
- When teams see themselves as part of a broader cross-boundaries team and act as one team with the corresponding professionals in the opposite setting, patient outcomes tend to be more positive and patients and professionals experience more satisfaction.
- The conditions that prevent or enhance these team perceptions and states of functioning are self-perpetuating, meaning that the effects of teams acting in a certain way will tend to keep the team functioning in the same way over time.
- Perceiving one's team as part of a broader cross-boundary team requires a relational, versus transactional, view toward the other team.

5.6 Summary

In this chapter, the abductive process of integrating the empirical data with the literature synthesis was described. Results of recoding the primary data were portrayed, demonstrating that findings from the literature did not take precedence over the primary interview data but were evaluated for fit and

inclusion in the final theory construction. The final product of this study, a constructivist grounded theory of interdependence between inpatient specialist palliative care teams and outpatient generalist healthcare teams across hospital/community boundaries, was presented and displayed. Significance of this theory and implications for the future will be presented in Chapter 6.

6 Discussion

The overall aim for this study was to explore the psychosocial processes that occur between inpatient specialist palliative care teams and outpatient generalist teams in the U.S. when patients are discharged from hospital to the community setting after receiving a specialist palliative care consultation while an inpatient. The goal was to use constructivist grounded theory methods to develop a substantive theory which would provide deeper understanding of these processes and ultimately guide further work on improving the experience of both patients and professionals at the time of these transitions. In Chapter 5, the theory of interdependence between inpatient specialist palliative care teams and outpatient generalist healthcare teams across hospital/community boundaries was presented. In this chapter, the findings of this study are situated within the wider literature, including that related to self-construal, or one's conception of oneself that lends meaning to experiences (Gonçalves et al., 2017), and literature related to interdependence, or the way in which individuals' actions affect their own and others' outcomes (Balliet, Tybur, & Van Lange, 2016; Rusbult & Kubacka, 2009). Contributions to knowledge about specialist and generalist palliative care team collaboration and continuity of care across healthcare setting transitions are discussed. Finally, strengths, limitations, and implications of this study for practice, policy, education, and research are presented.

6.1 Contributions to knowledge

6.1.1 Self-construal and interdependence

Through this theory, I propose that specialist and generalist palliative care teams function with different degrees of interdependence in relation to other teams caring for shared patients based on how they see themselves as a team. They may see themselves as a smaller team functioning within healthcare setting boundaries or as a larger team that crosses those boundaries and includes those who work in other settings. In this theory, that perception is labelled "team self-perception." The theory also proposes that this self-perception influences the way that teams act and impacts

subjective outcomes of the teams' collaboration or lack of it. This theory adds a real-life exploration and application in the specific context of healthcare teams to a body of knowledge that has arisen out of experimental psychological research.

Research in the field of psychology has explored the importance of individuals' view of self, known as self-construal (Kühnen & Oyserman, 2002). This refers to the way one thinks about oneself, as either autonomous or as "embedded in a larger social whole" (Gardner, Gabriel, & Lee, 1999, p. 321). This dichotomy in one's way of thinking has also been described as context-dependent versus context-independent, individualist versus collectivist, or independent versus interdependent (Gardner et al., 1999). Others have defined this further as relational interdependent self-construal, originally focused on self-view within intimate relationships, but with applicability to broader relationships and implications for communication, conflict resolution, and organisational relationships (Cross, Morris, & Gore, 2002; Gonçalves et al., 2017). In healthcare, the concept has been tested comparing self-construal of nurses with that of physicians, with attention to differences in self-construal suggested as one means to improve collaboration and teamwork and decreased medication errors (Voyer & Reader, 2013).

Self-construal has been found to be influenced by culture, with individuals from Western, particularly North American, cultures having a more independent, individualist self-construal than those from Eastern cultures for whom the default self-construal tends to be more interdependent and collectivist (Choi, Connor, Wason, & Kahan, 2015; Gardner et al., 1999; Oyserman & Lee, 2008). This study, conducted in North America, demonstrated that for the specialist palliative and generalist team members who participated, perceiving themselves as independent from other teams was the default self-perception. This is not surprising given the cultural tendency demonstrated in experimental psychological research.

In experimental lab studies, self-construal as independent versus interdependent has been found to serve as a mediator of an individual's cognitive processing which impacts a person's judgment and

behaviours (Gardner et al., 1999), values (Oyserman & Lee, 2008), and self-definition (Cross et al., 2002). It also helps to explain, in patterns of automatic cognition, whether individuals take contextual factors into account when thinking about a situation (Choi et al., 2015; Kühnen, Hannover, & Schubert, 2001). Individuals with an interdependent, relational self-construal tend to think and behave in ways that preserve that interdependent self-view (Cross et al., 2002). Meta-analyses and experimental studies of collectivism and interdependence demonstrate similar findings in which individuals with a more interdependent view tend to act more cooperatively with others, demonstrate more flexibility in roles and responsibilities, share decision-making with others, and internalise common goals (McAtavey & Nikolovska, 2010). Some have described a subjective interdependence; that is, an individual's perception of how interdependent they are in relation to others, which influences individuals' thoughts and actions in many settings, including the workplace, and which varies along a continuum from high to low degrees of interdependence (Gerpott, Balliet, Columbus, Molho, & De Vries, 2018). This parallels several basic propositions of this theory, that inpatient specialist palliative teams and outpatient generalist teams function along a continuum of interdependence, that a team member's self-perception along that continuum as part of a narrow or broader team influences how they function and interact with the other team, and that the outcomes of that self-perception and way of functioning tend to perpetuate that self-perception and way of functioning.

Others have developed theories of interdependence founded in the fields of social, evolutionary, and gestalt psychology and applied to the study of intimate relationships, group functioning, business and industry, education and healthcare (Balliet et al., 2016; Johnson & Johnson, 2009; Rusbult, 2007; Rusbult & Kubacka, 2009). Interdependence has been defined within these theories as the way in which each individual's actions affect their own and others' outcomes (Rusbult & Kubacka, 2009). Interdependence theory proposes to explain human interactions through describing structural elements that demonstrate variations in interdependence in any given situation. Examples of structural elements include the degree to which each individual is dependent on the actions of the other to achieve their desired outcomes or the degree to which individuals share common goals

(Balliet et al., 2016; Rusbult, 2007). Positive interdependence exists when actions of individual people support the completion of shared, joint goals, resulting in cooperation and coordination; negative interdependence exists when individuals' actions obstruct others from achieving their goals, resulting in competition (D. W. Johnson & Johnson, 2009). In the theory of interdependence between specialist and generalist palliative care teams, the conditions of knowing the other team, communicating intentionally, and acknowledging the role and value of the other team are the actions that contribute to coordination between the teams and achievement of shared goals; that is, a smooth transition for the patient between healthcare settings, medical care that is consistent across settings, and the greatest level of job satisfaction for involved professionals. The right end of the large red arrow in the conceptual model aligns with the concept of positive interdependence.

Psychological theories of interdependence also posit interdependent processes that explain how human interactions are shaped by individuals' needs, thoughts and motives (Rusbult & Kubacka, 2009). Two of these are transformation and adaptation. Transformation is a process in which an individual, through repeated experiences that produce positive outcomes, chooses to set aside their own focused goals and opts to focus their efforts on goals that are broader and encompass the needs of others (Rusbult, 2007). Through the process of transformation, individuals' or groups' motivations change and are reconceptualised based on a bigger picture need (Van Lange & Vuolevi, 2010). These changes lead to adaptation, the process within individuals or groups in which repeated experiences with the same outcome leads to stable, enduring changes in team members' motivation to act in an interdependent way (Rusbult & Kubacka, 2009). In the theory of interdependence between specialist and generalist palliative care teams, this is demonstrated in the proposition that a team's self-perception and way of functioning in relation to the other team is self-perpetuating – that those teams whose members see themselves as part of a larger team across healthcare setting boundaries tend to continue to function as one larger team and support the ongoing conditions of knowing each other, communicating intentionally, and acknowledging the role and value of the other team.

This study and the theory of interdependence between inpatient specialist palliative care teams and outpatient generalist healthcare teams across hospital/community boundaries contributes to this knowledge and extant theories in multiple ways. First, this study was undertaken without using the ideas of self-construal and interdependence as a priori concepts to consider when analysing the data. The concepts of interdependence and team self-perception were developed inductively and abductively through the grounded theory process, apart from knowledge of these psychological concepts, and the proposed relationships between the concepts in my theory of interdependence align fairly consistently with propositions developed from experimental lab data. My research presents findings stemming from a different philosophical perspective than the experimental, positivist approaches of past psychological research, creating a triangulation of methods that strengthens what is already known about interdependence. Secondly, my theory suggests that propositions related to self-construal, interdependence, and their impact on thoughts and behaviours may not only apply to individuals *within* teams but may have relevance to interactions *between* teams and would warrant further investigation. Finally, to the best of my knowledge, no other mid-range theory has been proposed that integrates the concept of interdependence with the functioning of specialist and generalist healthcare teams in general, and within the context of palliative care in particular. This theory raises multiple questions that could trigger future research to explore and test implications in that context.

6.1.2 Specialist/generalist palliative care provision and collaboration

The theory of interdependence between inpatient specialist palliative teams and outpatient generalist teams across hospital/community boundaries, through the constructed conditions of knowing the other team, communicating intentionally, and acknowledging the role and value of the other team, supports previous findings related to collaborative palliative care provision between specialists and generalists in other settings. Others have found that knowing the other team contributes to strong collaboration and teamwork through established interpersonal relationships with members of the other team (Firn et al., 2017; Keane et al., 2017; Kirby et al., 2014; van der Plas et al., 2014; Walshe et

al., 2008). Being visible to one another and having opportunities for frequent interaction, which facilitates knowing each other, also enhance teamwork (Ewing et al., 2009; Kirby et al., 2014; Wright & Forbes, 2014); sometimes this is accomplished through joint meetings between the two teams (Gardiner et al., 2012; McCaughan et al., 2018; van der Plas et al., 2014). A clear knowledge of the nature of the other team's practice and roles has been shown to enrich collaboration as well, which aligns with the perceptions of participants in this study (Albers et al., 2016; Firn et al., 2017; Gardiner et al., 2012; Gott et al., 2011; Keane et al., 2017; McCaughan et al., 2018). The importance of communicating intentionally in promoting collaboration, as demonstrated in this theory, has been reported in the literature, specifically the value of frequent, proactive communication (Albers et al., 2016; Firn et al., 2016; Walshe et al., 2008). Use of a designated team member to serve as a liaison or bridge between teams has been demonstrated to be useful in promoting intentional communication (Albers et al., 2016; Keane et al., 2017), and was mentioned by several participants in this study as well. Previous research has also highlighted the influence that respecting and appreciating the contributions of the other team has on collaboration and teamwork (Firn et al., 2016; van der Plas et al., 2014), in parallel with the third contributor to interdependent practice identified in this theory, acknowledging the role and value of the other team.

Another key element in this context-situated theory of interdependence is the idea of boundaries between teams and the impact that one's perception of boundaries has on team functioning, collaboration, and perceived outcomes. In previous research with healthcare professionals providing primary palliative care, a "them and us' mentality" (Walshe et al., 2008, p. 269) has been noted, indicating the sense of boundaries between specialist and generalist palliative care teams. Others have noted a sense of territorialism or division, also suggesting distinct boundaries, sometimes plays a part when professionals are collaborating to provide palliative care for patients (Gardiner et al., 2012; Keane et al., 2017; Wright & Forbes, 2014). As in the current research and theory, when professionals have a strong sense of local boundaries, past research has suggested this view tends to have a more negative affect on outcomes such as partnership working (Gardiner et al., 2012; Keane et al., 2017).

Integrated, simultaneous as compared to linear, sequential approaches to providing specialist and generalist palliative care have been described, with the integrated approach facilitating collaborative working between the two groups (Firn et al., 2016). A sense of palliative specialist and generalist teams working together well has been described as taking a “joint care approach” (Wright & Forbes, 2014, p. 42) or “being part of the whole team” (Keane et al., 2017, p. 218).

This research supports previous research with many similar findings but provides a more thorough understanding of these previously acknowledged concepts in several ways. The grounded theory developed through this study pulls these ideas together into a congruent whole, proposing relationships between the concepts and conditions and the potential impact they have on palliative care specialists’ and generalists’ collaboration and on clinical outcomes and satisfaction for patients, families, and professionals. In addition, this theory raises the idea of working together as one team from a way that teams function to a more abstract concept of team self-perception in relation to other teams, which then, in turn, impacts the way the teams function. The self-perpetuating relationships between the way that teams perceive themselves and function and the conditions that contribute to that perception and way of functioning, described in the theory and demonstrated in the conceptual model in Chapter 5, have not been empirically identified in the past in the context of palliative care provision. This too is a unique contribution of this study. Finally, this study has been the first to explore the interface across hospital/community boundaries between inpatient palliative specialist teams and the outpatient generalist teams who provide non-specialist palliative care for patients after discharge from the hospital from the perspective of interdisciplinary specialist and generalist palliative care team members in the U.S.

6.1.3 Continuity of care across healthcare setting transitions

Transitions between healthcare settings are common and occur more frequently in the U.S. than in other countries for patients in the last three to six months of life (Bähler et al., 2016; Van den Block et al., 2015; Wang et al., 2017). Transitions between healthcare settings and teams often are

characterised by poor coordination of care and communication, which endangers patient safety and well-being and may compromise optimal outcomes for patients and their families (Cline, 2016; Davis et al., 2012). For patients requiring palliative care, transitions from the hospital to a nursing facility after a specialty palliative care consultation in the hospital were found to result in discontinuity of following patients' care preferences, discrepancies in messaging to the patient and caregivers about prognosis, and worsening symptom burden (Carpenter, Berry, & Ersek, 2017). This is similar to the findings of the current study which suggest that when patients leave the hospital after a specialist palliative care consultation it is not uncommon for care plans established in the hospital with the specialist palliative care teams to be inconsistent with the actual care provided after discharge by the generalist team and for symptom control to be compromised after discharge.

The evidence in this study suggests that when team members perceive themselves as belonging to one team that crosses healthcare setting boundaries and act in ways that perpetuate "acting as one team" ways of functioning, the risk of care transitions for people near the end of life could be minimised by improving coordination of care between healthcare settings, decreasing patient and caregiver distress and improving their satisfaction, and maximising symptom management outside the hospital setting. Indirectly, the findings suggest that the frequency of these care transitions and the associated risks could be reduced when a patient's preferences for care – for example, to pursue less aggressive medical treatment and avoid hospitalisation in the future – are known and followed in every healthcare setting.

Continuity of care is a concern at the time of transitions between settings. Defined as "the degree to which a series of discrete healthcare events is experienced as coherent and connected and consistent with the patient's medical needs and personal context" (Haggerty et al., 2003, p. 1221), continuity of care across transitions between healthcare settings and teams is assumed to be a desirable outcome. This study demonstrated that, according to the perceptions of inpatient specialist palliative team members and outpatient generalist team members, continuity of care is often compromised when

patients who have received specialist palliative care consultation in the hospital are discharged and return to the care of their generalist healthcare team in the community. However, the grounded theory constructed from the data offers a deeper understanding of what is happening between these teams and opens the door to further exploration of how continuity of care could be improved by considering the impact of team self-perception as belonging to a within-healthcare-setting-boundaries team or as belonging to a team that crosses healthcare setting boundaries and encompasses both the hospital and community teams. Previous research demonstrated that continuity of care has multiple dimensions, with continuity focused mainly on the dynamic partnership between the patient and professionals (Haggerty et al., 2003). This study supports those dimensions but expands on the concept of interdisciplinary, cross-boundary continuity (Alazri et al., 2007; Saultz, 2003) by suggesting that when teams from different specialities and settings perceive themselves as one cross-boundary team and know each other, communicate intentionally and value the other team, patient outcomes and professional satisfaction are perceived to be better.

6.2 Strengths of this study

Discussion of the strengths of this study is organised around criteria used to evaluate rigour in grounded theory research. Credibility is one of these criteria and means that findings or generated theory actually portray the experiences of participants in the study (Chiovitti & Piran, 2003). Credibility in this study is supported in multiple ways. First, as the study progressed, the interview guide was adapted based on the responses from initial participants. This increased the likelihood that the interviews focused on content that was most important to participants. My extended time in the data, through at least three readings of each interview and multiple rounds of coding and analysis, along with post-interview memoing and ongoing reflexive journaling throughout the process, helped to ensure that I was well-acquainted with the perspectives of participants and that I was cognizant of my own perceptions throughout the analysis and theory construction process. Including the participants' own words in the report of the research provides an opportunity for readers to judge for themselves whether my interpretive constructions align with participants' verbalised experiences. The iterative

analysis of the interview data after exploring the literature also provides triangulation of the data, the literature, and my interpretations, and ensures that findings from the literature, as a secondary source, were only included in construction if they fit with participants' perspectives and merited inclusion in the theory grounded in the data (Thornberg, 2012).

Three other criteria of rigour in grounded theory are auditability, fit or resonance, and usefulness (Charmaz, 2014a; Chiovitti & Piran, 2003). Auditability refers to whether readers can follow the methods used to analyse and construct the theory (Chiovitti & Piran, 2003). Clarity of inclusion and exclusion criteria for participants and for literature inclusion for this study and use of a consistent and demonstrable method of tracking and displaying the progression of coding through the use of NVivo codebooks contributed strength to the findings of this study. Fit or resonance, the characteristic of findings being found meaningful or making sense to non-participants who are in similar circumstances (Charmaz, 2014a; Chiovitti & Piran, 2003), was increased in this study by including a diverse sample of specialist and generalist participants from a range of disciplines, geographic regions of the U.S., and types of healthcare organisations. Fit was also strengthened by including demographic data of the participant sample, which allows readers to position the findings within their appropriate context. As this is a mid-range grounded theory, it is not expected to be universally generalisable but rather context specific. Several steps were taken to check for resonance throughout the study's development: presenting the preliminary conceptual model in development as a poster presentation at a national palliative care conference in the U.S. in autumn 2018 and receiving affirmative feedback of resonance with specialist palliative care clinicians at that stage; midway through the study, sharing the developing categories with participants after their interviews and hearing from them that they made sense related to their experiences; and sharing the resultant grounded theory informally with professional colleagues who positively confirmed the categories, concepts, and proposed relationships between them. Finally, usefulness is a measure of quality of a grounded theory study, meaning the extent to which the study offers interpretations that are usable in everyday life (Charmaz, 2014a). This theory offers an interpretation of how and why inpatient specialist palliative care teams

and outpatient generalist healthcare teams interact with each other as they do, and suggests potential impacts of on patient, family, and professional outcomes. The categories depict practical processes (for example, using a particular method to communicate intentionally) and more abstract concepts (for example, a team member's self-perception of belonging to a narrower or broader team) that could be used to propose changes to practice or to spark further research.

6.3 Limitations of this study

This study has multiple limitations related to the participant sample. Participants were all Caucasian and predominately female. These race and gender characteristics of participants are not surprising given the predominance of Caucasians in the U.S. Midwest (U.S. Census Bureau, 2018) and the typical U.S. gender ratios in the disciplines of nursing and social work (Budden, Zhong, Moulton, & Cimiotti, 2013; Salsberg et al., 2017). Psychosocial processes used by specialist and generalist healthcare team members of other ethnicities or gender may differ and may have resulted in a differently constructed conceptual model and theory. In addition, the majority of participants came from one large health system that functions in multiple states across the U.S. A predominance of participants from one healthcare organisation may have influenced construction of categories, concepts, and theory, due to similar institutional cultures, limiting the transferability of this theory to other healthcare settings. However, it was noted during analysis that the perceptions of participants from outside the predominant organisation were congruent with those from within. Only one generalist participant was from an oncology practice, despite recruitment efforts to a large group of oncology interdisciplinary team members. Perceptions of oncology team members may differ from those from primary care teams. It is possible that participants who chose to respond to recruitment efforts were more passionate or motivated because of positive or negative experiences related to the interactions between inpatient specialist palliative care teams and outpatient generalist teams; thus the findings may not be reflective of a different sample.

The grounded theory constructed from this study does not portray proven relationships or causality between the categories and concepts in the theory. Instead it proposes relationships and outcomes that require further exploration. The study only addresses the perceptions of patient outcomes from healthcare professionals. Whether professionals' perceptions match the actual outcomes and perspectives of patients and their families is not known. The patient and family outcomes proposed in the grounded theory must be understood as being only perceived outcomes; further research is necessary to understand actual patient and family perceptions of the impact of teams working independently or as one team.

6.4 Reflexivity as researcher

In constructivist grounded theory work, the researcher is an integral part of the methodology, as the researcher's perspectives and interpretations play a key role in construction of theory. This requires ongoing reflexivity through which the researcher considers and makes explicit their own positions, beliefs, and experiences in relation to the phenomenon being studied (Charmaz, 2014a). I kept a reflexive journal throughout the process and made memos after every interview to capture my cognitive and emotional responses to participants, the experiences they shared, and how they may or may not align with my own experiences and perspectives. I have been a clinician working in the hospital setting for over 30 years and have been a member of an inpatient specialist palliative care team since 2008. I have experienced situations of disconnection between the inpatient palliative team and the receiving generalist team in the community when a patient discharged from the hospital, resulting in frustration and poor clinical outcomes, which was one stimulus to consider this topic for research. Through reflexivity I acknowledged that I brought that experience to my engagement with the data and made a deliberate effort to be open to other perspectives. Similarly, I became aware that I brought an assumption to this study that continuity of care is always a positive condition and that "acting as one team" across healthcare settings is always preferred. Through reflexivity, I was challenged to consider if that was indeed the only perspective and to be ready to hear a different view.

As a researcher who is also a practicing clinician in the large health system from which most participants came, I had pre-existing relationships with some of the participants through clinical interactions and professional networking. In qualitative research, this can be a strength as it may more quickly facilitate a trusting relationship and rapport in which participants feel comfortable sharing their experiences (McDermid, Peters, Jackson, & Daly, 2014). Steps were taken to mitigate any barriers to transparency this may have created, by proactively acknowledging this pre-existing relationship and affirming confidentiality and non-judgment and that my interest was in their honest perceptions. None of the participants had a supervisory relationship with me nor I with them. A prior relationship may increase the risk of social desirability bias, in which participants tend to express what they believe is most socially acceptable. It may also make it more difficult for the researcher to be open to a known participant's story, if there is prior knowledge of that story (McDermid et al., 2014). Use of personal reflection on my part before, during and after interviews with known participants helped to make visible these potential risks. Triangulation of responses from previously known and unknown participants and saturation of the categories helped to minimize this risk as well.

6.5 Implications for practice, education, research and policy

6.5.1 Practice implications

The findings of this study and the resultant grounded theory make a strong case for clinicians investing time and energy in relationship development with clinicians from other teams who also provide palliative care to shared patients. Creating opportunities for these teams to make connections could produce valuable dividends such as:

- increased professional satisfaction with related improvement in staff retention and decreased burnout,
- increased patient and family satisfaction,
- improved clinical outcomes such as more coordinated care, better symptom management, and less patient/family distress, and

- financial benefits for healthcare institutions if better coordinated care results in fewer unnecessary hospitalisations.

As the study demonstrated that the actions that lead to teams acting as one and perceiving themselves as one cross-boundary team are in turn perpetuated by the very process of teams acting and perceiving themselves as one team, in theory, the investment could sustain itself over time.

Operationally, how these relationships are fostered may be unique to each organisation's structure and ethos and cannot be strictly defined. However, the findings of this study suggest several operational actions that could be considered to help facilitate the relationship-fostering process, including:

- making contact information for other teams (including names, roles, phone numbers, email addresses, and service hours) easily available,
- ensuring that the electronic health record has readily accessible and retrievable means for sending direct messages to another professional,
- using videoconferencing technologies to help professionals from each team connect with one another both verbally and visually to confer regarding a shared patient's care or to allow clinicians from the other team to participate in a joint meeting with a patient and their caregivers,
- emphasising taking time for interprofessional intentional communication in clinical workflow procedures, and
- identifying a team member who possesses strong communication skills and the capacity to facilitate relationships between specialist and generalist teams.

6.5.2 Education implications

This study points to a need for education for healthcare professionals on several fronts. Healthcare professionals of all disciplines and specialities who provide specialist or generalist palliative care need to understand the importance and impact of hospital/community transition processes on the overall

care of the patient and their family so that the value of investing time and energy into the process is clear. This should be provided in basic academic disciplinary curricula as well in the work setting, specific to the resources available in a particular organisation related to communication and coordination of palliative care between teams and settings. Thinking more broadly, educational curriculum that focuses not only on clinical practice but is also designed to influence knowledge, behaviours, and attitudes toward other healthcare disciplines and specialities to increase competence in collaborative practice should be incorporated into curricula design in formal basic academic programmes for all healthcare professionals (D'Amour & Oandasan, 2005). In addition to including this focus in basic academic preparation, this emphasis should be integrated into training and qualification criteria for both palliative and non-palliative subspecialty certifications for physicians, nurses, social workers, and others. This is necessary if we hope to mould the future of healthcare delivery toward a more collaborative, interdependent model of care that benefits both receivers and providers of healthcare.

6.5.3 Policy implications

This study provides U.S. healthcare system leaders with evidence to support policies that invest time and money in communication and relationship building between specialist and generalist palliative care teams across hospital/community setting boundaries. In the U.S. context, healthcare organisations' financial stability relies in large part on reimbursement from government and commercial insurers. Historically, reimbursement has been provided on a fee-for-service model, in which organisations received payment based on individual services and procedures provided by certain members of the healthcare team such as physicians. Services by other members of the team, such as nurses, generally did not result in revenue for the organisation. However, reimbursement models in the U.S. are gradually changing to base institutional reimbursement more on quality of care versus volume of services. In this model, policies that support investment in fostering teams' perceptions of belonging to a team that crosses healthcare setting boundaries make sense, given the

proposed outcomes of improved clinical quality. Based on the findings of this study, policies should include:

- an expectation that intentional communication and collaboration between these teams is a standard element of high-quality care,
- explicit support for investing time, finances, and energy in communication and relationship building between teams because of the return on investment in terms of patient outcomes and patient and professional satisfaction, and
- support for hiring interdisciplinary team members, such as nurses or social workers, whose primary responsibilities include facilitation of communication and ongoing relationships between these teams.

The importance of policy support for long-term sustenance of these types of initiatives has been noted since the mid-2000s in the context of general transitions of care from the hospital to the community (Coleman & Boulton, 2003; Health Research for Action, 2006). More recently, this has been emphasised in the context of palliative care, calling for institutional support for collaboration between geriatrics teams and specialist palliative care teams (European Association for Palliative Care, European Union Geriatric Medicine Society, & Maruzzo Foundation, no date). The World Health Organization calls for national policy standards and strategies to support broad palliative care provision by both specialists and generalists (World Health Organization & Worldwide Palliative Care Alliance, 2014); this study suggests that those policies should include an emphasis on interdependent practice. The theory constructed through this study suggests that an investment in opportunities for relationship building and communication between would create an ongoing return on investment in the form of self-perpetuating practices.

6.5.4 Research implications

This study provides a starting point from which many other research endeavours could be launched with the intended goal to improve continuity of palliative care provision across transitions between

hospital and community settings. It may be helpful to replicate this study in different contexts to explore whether the proposed grounded theory fits in another context; for example, in a country with a differently structured healthcare system or a culture with a more collectivist default self-construal mindset, or with a generalist sample that was exclusively drawn from community oncology teams, or with a more balanced gender distribution. Additional data from a broader contextual range could strengthen, deepen, or suggest needed modifications to the theory, potentially giving it a more universal application over time.

Complex interventions involving specialist and generalist palliative care teams' relationships and collaboration could be developed and tested based on this research. The Medical Research Council Framework for Developing and Evaluating Complex Interventions recommends starting with theory and engaging in a phase of "modelling" in which greater understanding is gained through various means to refine an intervention to then test and implement (Corry, Clarke, While, & Lalor, 2013; Medical Research Council, 2008). Multiple avenues should be pursued in order to move toward testing of a complex intervention that could impact how these teams perceive themselves and act as one team across settings, including:

- qualitative interviews or focus groups with key stakeholders such as inpatient specialist palliative care or outpatient generalist interdisciplinary team members, patients and caregivers, and institutional administrators to gain their perspectives on the most important elements of this theory to be incorporated into an intervention and on the acceptability and feasibility of such an intervention;
- qualitative interviews or focus groups with inpatient specialist palliative care and the community generalist team members to explore their level of motivation for investing time and energy into cultivating a self-perception of belonging to a cross-boundaries team;

- use of an existing tool to assess healthcare team members' level of interdependence related to belonging to an across-boundaries team, such as the Situational Interdependence Scale (Gerpott et al., 2018) or the InterPACT tool (Xyrichis, Reeves, & Zwarenstein, 2018);
- mixed methods exploration of actual outcomes associated with teams' level of interdependence as compared to the perceived outcomes voiced by participants in this study, such as
 - patients' and caregivers' perception of teams acting independently or as one team across settings and relationship to their satisfaction with their care,
 - quantitative impact of the degree of team interdependence on patients' symptom control after discharge, frequency of patients' expressed preferences for medical care being followed, rehospitalisation and emergency department utilisation rates, and professional satisfaction with their work;
- small pilot testing of potential elements of a complex intervention to increase team interdependence in specialist and generalist palliative care provision, for example:
 - impact of interprofessional, interspeciality face to face networking opportunities on frequency of direct communication between inpatient specialist and outpatient generalist teams;
 - effect of incorporating standardised direct phone calls or electronic messages between inpatient specialist palliative care teams and the patient's outpatient generalist team before and after an inpatient palliative care consultation and prior to discharge on patient/caregiver satisfaction, professional satisfaction, and clinical outcomes;
 - comparison of the effects of direct communication being operationalised by physician versus nurse versus social worker on patient/caregiver satisfaction, professional satisfaction, and clinical outcomes;

- feasibility, acceptability, and cost-effectiveness testing of videoconferencing for joint meetings including inpatient specialist palliative team members, outpatient generalist team members, and patients and caregivers;
- feasibility, acceptability, and cost-effectiveness testing of delegating a specific team member to serve as a “relationship broker” (Keane et al., 2017, p. 221) between inpatient specialist and outpatient generalist teams.

The theory of interdependence between inpatient specialist palliative care teams and outpatient generalist healthcare teams across hospital/community boundaries provides a catalyst and foundation for further research to benefit patients receiving palliative care and the professionals caring for them.

6.6 Conclusion

In 2016, Kamal stated “To date, neither consensus opinion nor empirical evidence have addressed in what ways healthcare professionals of different specialties should work together to deliver coordinated, efficient, and timely palliative care” (2016, p. e1). This study begins to establish a body of knowledge to address this gap. Some practical considerations for how we provide palliative care across healthcare specialities and settings are suggested by the findings, particularly related to the conditions of teams knowing each other, communicating intentionally, and acknowledging the role and value of the other team. Perhaps more importantly, the study provides a theoretical basis which inspires a new vision for interdependent practice between specialist and generalist palliative care teams, emphasising the essential factor of team members’ interdependent self-construal in relation to other teams providing palliative care to a shared patient and family. The challenge going forward is to discover how to foster interdependent self-construal in healthcare team members in order to sustain the conditions that impact the quality and consistency of palliative care provided to patients and their families as well as the joy and satisfaction experienced by the professionals engaged in this work.

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**Use your experience and wisdom
to make a difference in the way we provide Palliative Care!**

Are you part of a healthcare team that:

- **Provides specialized palliative care to patients in a hospital setting?**

OR

- **Provides outpatient primary care for patients who've received specialist palliative care in a hospital setting?**

I am conducting a study looking at the transition from inpatient specialist palliative care to generalist palliative care outside the hospital setting.

Interdisciplinary members of healthcare teams are needed to share their experiences related to meeting patients' palliative care needs.

Physicians, NPs, PAs, nurses, social workers, chaplains and other team members are welcome to participate.

Participating in this study involves a 30-60 minute interview with the researcher, either face to face, via telephone, or via secure videoconferencing.

**For more information about this study,
or to volunteer to participate, please contact:**

Mary Thelen, MSN, RN, CHPN

Phone: 715-456-6591

Email: m.thelen@lancaster.ac.uk

**Department of Health Research
Lancaster University, Lancaster, U.K.**



**Palliative & Supportive Care Service
Mayo Clinic Health System - NWWI**



This study has been reviewed and approved by the Mayo Clinic Institutional Review Board and the Lancaster University Research Ethics Committee and is part of a PhD in Palliative Care programme through Lancaster University.

Appendix B: Revised recruitment flyer for specialist palliative care team members

- ❖ **Are you a member of an inpatient specialist palliative care team?**
- ❖ **I'm looking for nurses, physicians, NP/PAs, social workers, chaplains, or others willing to talk to me about their experiences.**
- ❖ **I'm conducting a study looking at the transitions between hospital palliative care teams and the teams that care for patients after discharge.**



- ❖ **If you would be interested in sharing your experiences, please contact me at the number or email below:**

Mary Thelen, MSN RN CHPN

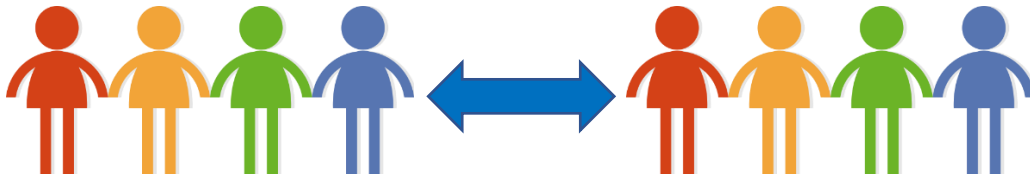
m.thelen@lancaster.ac.uk OR thelen.mary@mayo.edu

715-456-6591



This study has been reviewed and approved by the Mayo Clinic Institutional Review Board and the Lancaster University Research Ethics Committee and is part of the PhD in Palliative Care program through Lancaster University.

- ❖ **Are you a nurse, physician, NP/PA, social worker, or other health team member who cares for patients in the clinic who've had palliative care consultation in the hospital in the past?**
- ❖ **I'd really like to talk to you about your experiences! I'm conducting a study looking at the transitions between hospital palliative care teams and the teams that care for patients after discharge.**



- ❖ **If you would be interested in sharing your experiences, please contact me at the number or email below:**

Mary Thelen, MSN RN CHPN

m.thelen@lancaster.ac.uk OR thelen.mary@mayo.edu

715-456-6591



This study has been reviewed and approved by the Mayo Clinic Institutional Review Board and the Lancaster University Research Ethics Committee and is part of the PhD in Palliative Care program through Lancaster University.

Participant Information Sheet – Specialist Palliative Care

Perspectives of healthcare professionals on transitions of palliative care provision for individual patients from inpatient specialist palliative care to generalist palliative care outside the hospital in the United States: a grounded theory study.

My name is Mary Thelen and I am conducting this research as a student in the PhD in Palliative Care programme at Lancaster University, Lancaster, United Kingdom.

What is the study about?

The purpose of this study is to explore the processes that happen within and between healthcare team members when patients are discharged from the hospital and transition from receiving palliative care from a specialist palliative care team in the hospital to receiving palliative care from their primary health care team outside the hospital. The results will be used to develop a theory that helps to explain what happens during these transitions.

Why have I been approached?

You have been approached because you are part of a specialist palliative care team that provides care to patients in the hospital setting. I want to understand your perspectives about what happens when your patients leave the hospital and go on to have their palliative needs met by their primary care team.

Do I have to take part?

No. It's completely up to you whether or not you take part. There is no penalty for not participating. If you decide to participate, you would be free to withdraw from the study at any time before, during, or up to two weeks after participation.

What will I be asked to do if I take part?

If you decide you would like to take part, you would be asked to commit to one interview with me that will be audio recorded. Depending on where you live and work, the interview may take place face to face, or by telephone or secure videoconferencing. It is estimated that the interview will last between 30-60 minutes, although it may last longer.

In the interview, you would be asked to talk about your experiences caring for patients and families with palliative care needs and your perceptions of the transitions between the inpatient and outpatient settings.

Will my data be identifiable?

The information you provide will not be identifiable. Your name will not be connected with the information in any way (you will be able to select a pseudonym to attach to your data). If any direct quotes from you are used in the study report, every effort will be made to omit any details that could potentially make your identity known.

The data collected for this study will be managed as follows:

- Audio recordings and text files of interview content will be saved in a secure online repository available through Lancaster University. These files will be saved indefinitely.

- Paper files will be kept in a locked cabinet until they have been scanned and securely saved electronically in the same Lancaster repository. After that time, these files will be shredded.
- The files on the computer will be encrypted so that only the researcher will be able to access them and the computer itself password protected.
- The typed version of your interview will be made anonymous by removing any identifying information including your name. Anonymized direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them.
- All your personal data will be confidential and will be kept separately from your interview responses.
- Anonymised data and analysis records may be used for future research.

There are some limits to confidentiality: if what is said in the interview indicates that you, or someone else, are at significant risk of harm, I will have to break confidentiality and speak to my research supervisor about this. If possible, I will tell you if I have to do this. I would seek guidance from my research supervisor in this case.

What will happen to the results?

The results will be analysed and reported in a thesis and may be submitted for publication in an academic or professional journal. Results may also be submitted for presentation at a local or national professional conference.

Are there any risks?

There are no risks anticipated with participating in this study. However, if in the unlikely event you experience any distress during the interview, you will be free to stop at any time you wish. If you experience distress after the interview, you are encouraged to contact your Employee Assistance Program (EAP) through your employer or the researcher for support.

Are there any benefits to taking part?

Although you may find participating interesting, there are no direct benefits to you by taking part. Results may improve the care that patients with advanced illness receive in the United States in the future by impacting the way healthcare teams work together.

Who has reviewed the project?

This study has been reviewed and approved by the University Research Ethics Committee at Lancaster University, the Clinical Research Committee at Mayo Clinic Health System in Eau Claire, Wisconsin, and the Institutional Review Board at Mayo Clinic in Rochester, Minnesota.

Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the main researcher:

Mary Thelen, PhD student

m.thelen@lancaster.ac.uk

If you have any concerns, complaints, or general questions about research or your rights as a participant, please contact the Mayo Institutional Review Board (IRB) to speak to someone independent of the research team at 507-266-4000 or toll free at 866-273-4681.

If you have any questions or concerns about the researcher or the PhD program, please contact the student's research supervisors:

Dr. Sarah Brearley
Sarah.brearley@lancaster.ac.uk
44 1524 592574

Dr. Catherine Walshe
c.walshe@lancaster.ac.uk
44 1524 510124

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Prof. Bruce Hollingsworth Tel: +44 (0)1524 594154
Head of the Division of Health Research
b.hollingsworth@lancaster.ac.uk
Lancaster University
Lancaster
LA1 4YG

If you wish to speak to someone outside of the Blended PhD Doctorate Programme, you may also contact:

Professor Roger Pickup Tel: +44 (0)1524 593746
Associate Dean for Research Email: r.pickup@lancaster.ac.uk
Faculty of Health and Medicine
(Division of Biomedical and Life Sciences)
Lancaster University
Lancaster
LA1 4YG

Thank you for taking the time to read this information sheet.

Participant Information Sheet – Generalist Palliative Care

Perspectives of healthcare professionals on transitions of palliative care provision for individual patients from inpatient specialist palliative care to generalist palliative care outside the hospital in the United States: a grounded theory study.

My name is Mary Thelen and I am conducting this research as a student in the PhD in Palliative Care programme at Lancaster University, Lancaster, United Kingdom.

What is the study about?

The purpose of this study is to explore the processes that happen within and between healthcare team members when patients are discharged from the hospital and transition from receiving palliative care from a specialist palliative care team in the hospital to receiving palliative care from their primary health care team outside the hospital. The results will be used to develop a theory that helps to explain what happens during these transitions.

Why have I been approached?

You have been approached because you are part of a generalist health care team that provides primary care to patients outside the hospital setting. I want to understand your perspectives about what happens when you assume responsibility for meeting your patients' palliative needs after they have been hospitalized and had a specialist palliative care consultation during that hospitalization.

Do I have to take part?

No. It's completely up to you whether or not you take part. There is no penalty for not participating. If you decide to participate, you would be free to withdraw from the study at any time before, during, or up to two weeks after participation.

What will I be asked to do if I take part?

If you decide you would like to take part, you would be asked to commit to one interview with me that will be audio recorded. Depending on where you live and work, the interview may take place face to face, or by telephone or secure videoconferencing. It is estimated that the interview will last between 30-60 minutes, although it may last longer.

In the interview, you would be asked to talk about your experiences caring for patients and families with palliative care needs and how transitions between the inpatient and outpatient settings work in your practice.

Will my data be identifiable?

The information you provide will not be identifiable. Your name will not be connected with the information in any way (you will be able to select a pseudonym to attach to your data). If any direct quotes from you are used in the study report, every effort will be made to omit any details that could potentially make your identity known.

The data collected for this study will be managed as follows:

- Audio recordings and text files of interview content will be saved in a secure online repository available through Lancaster University. These files will be saved indefinitely.

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- The files on the computer will be encrypted so that only the researcher will be able to access them and the computer itself password protected.
- The typed version of your interview will be made anonymous by removing any identifying information including your name. Anonymized direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them.
- All your personal data will be confidential and will be kept separately from your interview responses.
- Anonymised data and analysis records may be used for future research.

There are some limits to confidentiality: if what is said in the interview indicates that you, or someone else, are at significant risk of harm, I will have to break confidentiality and speak to my research supervisor about this. If possible, I will tell you if I have to do this. I would seek guidance from my research supervisor in this case.

What will happen to the results?

The results will be analysed and reported in a thesis and may be submitted for publication in an academic or professional journal. Results may also be submitted for presentation at a local or national professional conference.

Are there any risks?

There are no risks anticipated with participating in this study. However, if in the unlikely event you experience any distress during the interview, you will be free to stop at any time you wish. If you experience distress after the interview, you are encouraged to contact your Employee Assistance Program (EAP) through your employer or the researcher for support.

Are there any benefits to taking part?

Although you may find participating interesting, there are no direct benefits to you by taking part. Results may improve the care that patients with advanced illness receive in the United States in the future by impacting the way healthcare teams work together.

Who has reviewed the project?

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Where can I obtain further information about the study if I need it?

If you have any questions about the study, please contact the main researcher:

Mary Thelen, PhD student

m.thelen@lancaster.ac.uk

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If you have any questions or concerns about the researcher or the PhD program, please contact the student's research supervisors:

Dr. Sarah Brearley

Sarah.brearley@lancaster.ac.uk

44 1524 592574

Dr. Catherine Walshe

c.walshe@lancaster.ac.uk

44 1524 510124

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Prof. Bruce Hollingsworth Tel: +44 (0)1524 594154

Head of the Division of Health Research

b.hollingsworth@lancaster.ac.uk

Lancaster University

Lancaster LA1 4YG

If you wish to speak to someone outside of the Blended PhD Doctorate Programme, you may also contact:

Professor Roger Pickup Tel: +44 (0)1524 593746

Associate Dean for Research Email: r.pickup@lancaster.ac.uk

Faculty of Health and Medicine

(Division of Biomedical and Life Sciences)

Lancaster University

Lancaster LA1 4YG

Thank you for taking the time to read this information sheet.

Appendix E: Consent form



Study Title: Perspectives of healthcare professionals on transitions of palliative care provision for individual patients from inpatient specialist palliative care to generalist palliative care outside the hospital in the United States: a grounded theory study.

I am asking if you would like to take part in a research project exploring the processes that happen within and between healthcare team members when patients are discharged from the hospital and transition from receiving palliative care from a specialist palliative care team in the hospital to receiving palliative care from their primary health care team outside the hospital.

Before you consent to participating in the study, I ask that you read the participant information sheet and mark each statement below with your initials if you agree. If you have any questions or queries before signing the consent form, please speak to me, the principal investigator, Mary Thelen.

Statement	Initials
I confirm that I have read the information sheet and understand what is expected of me within this study.	
I confirm that I have had the opportunity to ask any questions and to have them answered.	
I understand that my interview will be audio recorded and then made into an anonymised written transcript.	
I understand that audio and text files of my interview will be kept in a secure online repository and that my anonymous data may be used in future research.	
I understand that my participation is voluntary and that I am free to withdraw at any time up to two weeks after my interview, without giving any reason, without my legal rights being affected.	
I understand that once my data have been anonymised and incorporated into the analysis, 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.	
I understand that the information from my interview will be pooled with other participants' responses, anonymised and may be published.	
I consent to information and quotations from my interview being used in reports, conferences and training events.	
I understand that any information I give will remain strictly 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 her research supervisor.	
I consent to Lancaster University keeping electronic transcriptions of the interview after the study has finished.	
I consent to take part in the above study.	

Name of Participant _____ Date _____
 Signature of Participant _____
 Name of Researcher ___Mary Thelen_____ Date _____
 Signature of Researcher _____

Appendix F: Demographic data tool

Demographic Data Tool and Interview Guides

Demographic Data – all participants

Gender: Male Female

Age: 21-30 31-40 41-50 51-60 61-70 71-80

With what ethnic/racial group do you identify yourself?

White

Hispanic or Latino

Black or African American

Native American or American Indian

Asian / Pacific Islander

Other (specify): _____

Professional discipline:

Medicine Nursing Social work Chaplaincy

Other (specify): _____

Professional subspecialty (if any):

Family Medicine Internal Medicine

Palliative Medicine Other (specify): _____

Number of years experience in your subspecialty:

<5 5-15 16-25 26-35 >35

Do you have certification in palliative medicine/palliative care? yes no

Interview guide: Palliative Care Specialists

Date of interview _____ Time _____ to _____

Location of interview _____

Interviewer _____

Interviewee (pseudonym) _____

Introduction: Will affirm that their experiences and perceptions are important and that my goal is to understand these palliative care transitions from their perspectives.

The following questions will be used as an open-ended guide to the interviews. Other questions or probing statements, such as “Tell me more about that idea” may be used.

- Please tell me about a time that you provided palliative care for a patient in the hospital and the patient discharged from the hospital back to the care of his/her primary medical care team.
- How would you describe your relationship with the patient’s primary/usual care team.
- What helped that transition go well for you, for the other team, and for the patient?
- What could have gone better?
- Describe any worries or hopes you had when the patient left the hospital.
- Tell me about how the patient continued to have his or her palliative needs met after discharge.
- What impact did the transition have on your relationship with the patient?
- What else would you like to tell me related to the transitions of your patients from inpatient specialty palliative care to outpatient generalist palliative care?

Conclusion: Will thank the participant for sharing their experiences and perceptions and provide my contact information if they wish to contact me in the future.

Appendix H: Generalist interview tool, version 1

Interview guide: Palliative Care Generalists

Date of interview _____ Time _____ to _____

Location of interview _____

Interviewer _____

Interviewee (pseudonym) _____

Introduction: Will affirm that their experiences and perceptions are important and that my goal is to understand these palliative care transitions from their perspectives.

The following questions will be used as an open-ended guide to the interviews. Other questions or probing statements, such as “Tell me more about that idea” may be used.

- Please tell me about a time that you cared for a patient after hospital discharge who had received care from a specialist palliative care team in the hospital.
- How would you describe your relationship with the patient’s inpatient palliative care team.
- What helped that transition go well for you, for the other team, and for the patient?
- What could have gone better?
- Describe any worries or hopes you had about the patient’s involvement with the inpatient palliative care team.
- Tell me about how the patient continued to have his or her palliative needs met after discharge.
- What impact did the transition have on your relationship with the patient?
- What else would you like to tell me related to the transitions of your patients from inpatient specialty palliative care to outpatient generalist palliative care?

Conclusion: Will thank the participant for sharing their experiences and perceptions and provide my contact information if they wish to contact me in the future.

Appendix I: Revised specialist interview tool

Interview guide: Palliative Care Specialists

Date of interview _____ Time _____ to _____

Location of interview _____

Interviewer _____

Interviewee (pseudonym) _____

Introduction: Will affirm that their experiences and perceptions are important and that my goal is to understand these palliative care transitions from their perspectives.

Definitions: Will review what I mean by “specialist” and “generalist” palliative care.

The following questions will be used as an open-ended guide to the interviews. Other questions or probing statements, such as “Tell me more about that idea” may be used.

- Can you think of a time when you cared for a patient in the hospital, as part of the specialist palliative care team, and when the patient discharged from the hospital, you had a strong connection with that patient’s outpatient generalist team? Could you please tell me about that experience?
- What do you think contributed to that strong connection with the other team?
- What was that like for you, to have a strong connection with that team?
- Can you think of a time when you *didn’t* have a strong connection with the patient’s outpatient generalist team?
- What do you think got in the way of having a strong connection with the other team?
- What was that like for you, to not have a strong connection with that team?
- Is there anything else related to your team’s connection with the generalist team that you’d like to tell me about?

Conclusion: Will thank the participant for sharing their experiences and perceptions and provide my contact information if they wish to contact me in the future.

Appendix J: Revised generalist interview tool

Interview guide: Palliative Care Generalists

Date of interview _____ Time _____ to _____

Location of interview _____

Interviewer _____

Interviewee (pseudonym) _____

Introduction: Will affirm that their experiences and perceptions are important and that my goal is to understand these palliative care transitions from their perspectives.

Definitions: Will review what I mean by “specialist” and “generalist” palliative care.

The following questions will be used as an open-ended guide to the interviews. Other questions or probing statements, such as “Tell me more about that idea” may be used.

- Can you think of a time when you cared for a patient who had been in the hospital, and had a specialist palliative care consultation while in the hospital, and after the hospitalization you had a strong connection with that patient’s inpatient specialist palliative care team? Could you please tell me about that experience?
- What do you think contributed to that strong connection with the other team?
- What was that like for you, to have a strong connection with that team?
- Can you think of a time when you *didn’t* have a strong connection with the patient’s inpatient specialist palliative care team?
- What do you think got in the way of having a strong connection with the other team?
- What was that like for you, to not have a strong connection with that team?
- Is there anything else related to your team’s connection with the specialist team that you’d like to tell me about?

Conclusion: Will thank the participant for sharing their experiences and perceptions and provide my contact information if they wish to contact me in the future.

Appendix K: Sampling of reflective and analytic memos

A sample of reflective memos:

2 February 2018: Reflection after interview with Dr. Zhivago

After some 10 minutes of technical difficulties, we got going. Dr. Zhivago was articulate, eager, and engaged. I did have to redirect a bit to get to the “right” type of scenario – once again, the participant not quite grasping the situation or scenario I was looking for. She started out with a story of an outpatient palliative care patient she saw and sent back to their home community team... I asked then for a hospital based palliative care consultation story. Is this because the concept is complex? Still can’t help but wonder if I’m being unclear. In this case, it was a palliative medicine specialist, so I don’t think it was an issue of not understanding the primary palliative care concept (she indicated her understanding at one point by acknowledging I wasn’t probably looking for a transition to hospice services).

She emphasized the value of having the IDT involved in the transition – more than a purely clinical/medical handoff. Acknowledged the element of judgment (used that word specifically); shared a fairly vulnerable story. Acknowledged ways that she probably could have done things differently. She joked about having to “see my therapist” after this... but I think it did affect her emotionally. Almost seemed near tears once. She seemed to have somewhat of an “aha” moment near the end of the interview, of realizing the cost and difficulty of these transitions for palliative providers, related to the investment and bonds that develop. “Never really thought of this before your study....”

I made an assumption that paediatric palliative care team transitions would share some similarities with adult patient palliative care team transitions. Another assumption I've made is that transitions with a team at a long term care facility who, for at least the foreseeable future, would be this kid's primary care team, would have similarities with transitions to teams caring for patients who go directly home and are cared for by a PCP. One difference would be the lack of prior relationship with the receiving team (unlike most, but not all, PCP situations).

25 February 18: Memo on assumptions I bring to this research

Some of the assumptions that I am bringing to this research include, in no particular order:

- An assumption that similar principles will apply to paediatric palliative care transitions as do to adult scenarios. Clearly there will be differences (e.g. these situations may be more emotion-laden, more intense at times; different IDT members may be involved, such as child life specialists perhaps; quite possibly more likely to involve a transition between a tertiary centre and a primary care centre, given the less frequent occurrence of life-threatening childhood illness and the greater need for specialty treatment), but similarities exist (e.g. still needs to be communication between and among teams; still may be concerns about the capability of the generalist teams, about each team knowing the other team at all – maybe heightened, given the tertiary nature of the speciality PC; still a sense of “letting go”; each side of the transition may have had an opportunity to build a relationship with the patient and family, thus laying a foundation for the other to potentially build upon).
- Similarly, as a few of the participants have talked about the transition being between the specialty PC team in the hospital and the healthcare team at a skilled nursing facility (SNF) when a patient transitions out of the hospital, I have made an assumption that some of the same principles may apply. Initially, I did not think this would be within the scope of this study, being interested in the transitions back to the patient’s “primary care team” (defined in my mind as an office/community-based medical practice who oversaw the general

medical care of the patient). However, as I have talked with a few of the participants (e.g. Zhivago, Jean), who shared these types of transition experiences with patients, rather than eliminate these data, I'm making an assumption that there are valuable insights that apply to the overall idea behind this study. For Zhivago's scenario, particularly, the physician and team at the SNF received responsibility for the patient's care post-hospital discharge, they were in essence serving, for the time being, as the patient's primary care team, overseeing all of his care and needs.

- An assumption that interdisciplinary team members are valued equally in specialist and generalist teams; however, there has perhaps historically been a stronger emphasis on the IDT roles in specialist palliative care than there has been in generalist care (though this is growing with the primary care team-based model of Population Health / Accountable Care Organizations). *A bias I could possibly bring to this research, based on my personal experience as a registered nurse in settings where RNs have had a high level of responsibility and autonomy (ICU and serving as the lone Palliative Care consultant in the hospital initially for 2 years), is a high value on the autonomous role of the RN, in addition to the collaborative role on the IDT. I realize this could influence my interpretation of the data. I will continue to keep this in mind and will likely discuss with my supervisors to get feedback if I am fully taking into account the participants' perspectives in construction of the theory as we go.*
- An assumption that each of these teams have a common goal in mind, to provide the best, most appropriate care possible for each patient and their family; however there may be a different perspectives on what the "best, most appropriate care" means between (and even among) the teams.

26 April 18: Reflection after interview with Andrea

Andrea is a primary care nurse practitioner supervisor. I was sitting in my car, as I was unable to find a private place at the conference I was attending this day. It was quite hot and the sun was bright – but I could still see Andrea well, and felt we established a good rapport. She laughed about my circumstance sitting in my car. She was familiar with Zoom, which we used. She was in an office in a patient care area in Arizona, about 2 hours behind my time. We'd never met before this. She had just finished her doctorate (DNP, I would imagine), which may have influenced her willingness to participate (empathy for a fellow grad student). I did not end up asking all the questions straight through as on the interview guide, as she brought up contrasting scenarios without being asked. I did ask near the end of the interview about other interdisciplinary team members, as her perceptions really focused around the NP and provider roles.

Just a note to self: I have not been collecting level of education in my demographics. Wondering if educational level influences perceptions of interdisciplinary or interprofessional interactions or relationships... this may be a limitation of the study.

A sample of analytic memos related to theory development:

5 June 18: Memo on saturation throughout the analytic process

I have been thinking about saturation as something that comes nearer to the end of the analysis process, but as I have been reading this evening and reflecting on the work I've already done, I'm beginning to see that it is a continuous process that has already begun. It actually began as soon as I started sorting my long list of initial codes, and making decisions about what's "in" and what's "out" for this study, in terms of meaningful concepts. And as I have been sorting the data so far (even with 5 more transcripts to code even the first time), I've been saturating... supplying more examples, more incidents of, more definitions and properties of, the codes that have become clear as the most important in this particular data, as I have made decisions about the direction of my analysis.

I still have a lot of work to do. The current “big three” categories – the three “states of being” – are like three big buckets with a lot of miscellaneous examples and properties thrown in. As I do more thinking about these, and go back and examine the original texts and ask questions of the data like “what was happening here?” or “under which conditions is this true?” or “How?” or “When?” (Charmaz, 2014, p. 327), saturation will gradually “emerge” as the ideas congeal – come together, solidify – into clearer and clearer patterns.

Because of the philosophical stance of constructivist grounded theory, that any theory that is constructed is provisional, always open to revision by future study, I don’t believe that saturation can ever be said to be 100% complete. One could say that the constructed theory is saturated by the experiences and perceptions of *this researcher and these participants* to date. And this can be pronounced by demonstrating the process by which the theory was developed, using iterative reflection and critical examination of the developing ideas through comparison and questioning of the data at all stages of data collection and analysis. This idea of saturation also being provisional aligns with Dey’s idea of “theoretical sufficiency” (referenced in Charmaz, will need to find the original) versus claiming “saturation.”

22 September 18: Memo on theory – first attempt to write up the theory (prior to literature review)

“Being Intentional” is my key category. “**Being Intentional**” is the concept that seems to be the hinge on which the quality of inpatient specialist PC teams’ and outpatient generalist PC teams’ collaboration across hospital discharge transitions turns. When there is no intentionality on the part of the healthcare team members, the result is that both teams provide care for the patient and family, but they do so by “**Acting Independently**.” Overall, the perceived effects of acting independently are negative, both on the clinicians themselves and the patient’s and family’s wellbeing. A necessary component to move beyond this state of acting independently is “**Knowing the Other Team**.” However, if each team has knowledge of the other team, yet no intentional engagement occurs, team members still perceive that satisfaction and clinical care remain suboptimal. When there is intentional action taken by one or more members of each healthcare team to reach out and engage with the other team (“**Taking the Initiative to Communicate**”), a state of “**Bridging**” occurs, in which there is back and forth communication and interaction between the teams which enhances the perception of clinician satisfaction, patient/family satisfaction, and clinical outcomes. An additional level of intentionality is added when one or more members of each healthcare team overtly acknowledges the value of the other team with the patient (“**Acknowledging the Value of the Other Team**”). The result of this additional relational (*not sure that word captures what I mean – what I mean is that it’s more than an intentional action, like communicating, but an attitudinal stance toward the other – valuing their involvement enough to integrate them into the patient’s care*) level of intentionality is the two teams “**Acting as One Team**.” When this occurs, the level of professional satisfaction is higher due to a greater sense of having value to contribute to the bigger picture of the patient’s overall wellbeing.

“Being Intentional” is not a set-in-stone, permanent characteristic with which an ISPC or OPGC team functions always. Various factors cause a team to fluctuate between these states at any given time.

11 October 18: Memo on developing theory

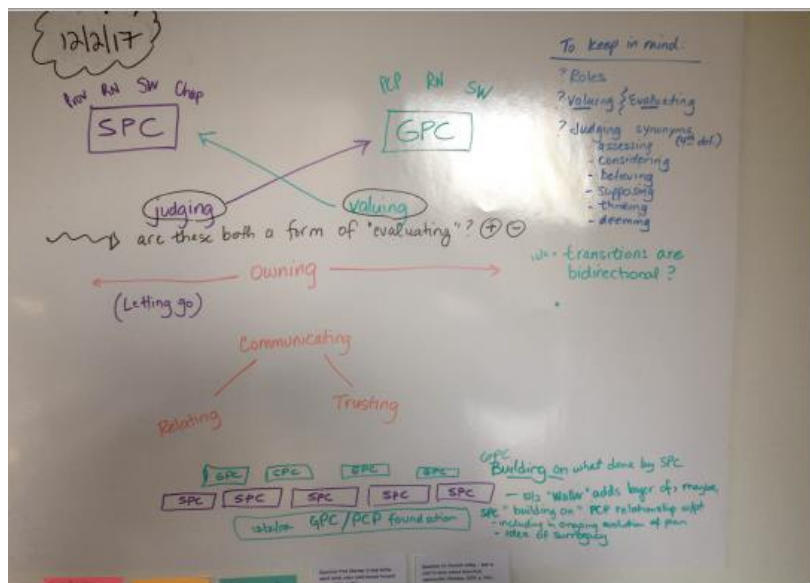
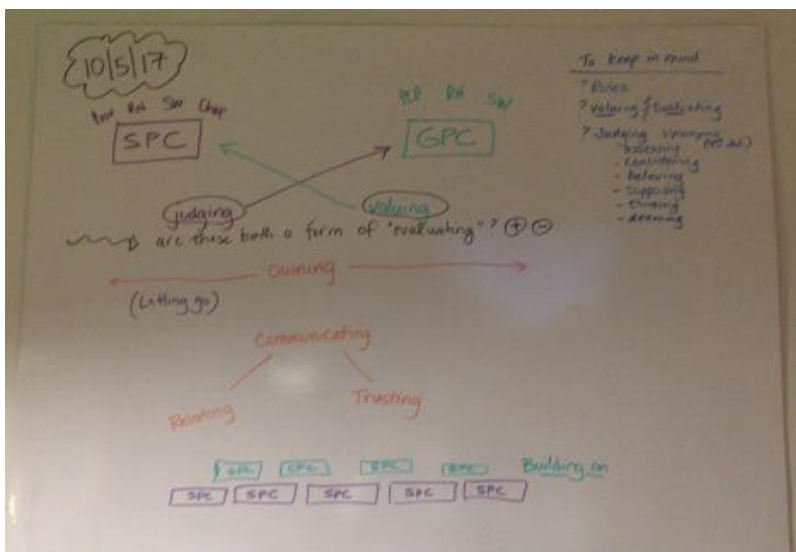
Driving back from Mankato in a quiet car today, pondered the theory again. Instead of “interprofessional intentionality” I think this is a theory of “interdependence” of the ISPC and OPGC teams. Intentionality is one of the conditions that leads to interdependence, not the key idea. The conditions, “knowing,” “taking the initiative to communicate” (or “communicating intentionally?”), and “acknowledging the value of the other team *in the presence of the patient*” (italics new), are cumulative, to an increasing state of interdependence. Interdependence at its fullest expression (in this data), appears to maximize both the patient and the professionals’ experience and has been characterised by the key category “acting as one team.”

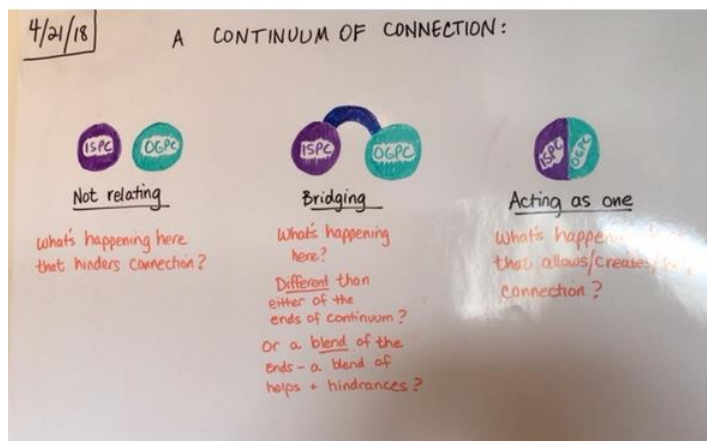
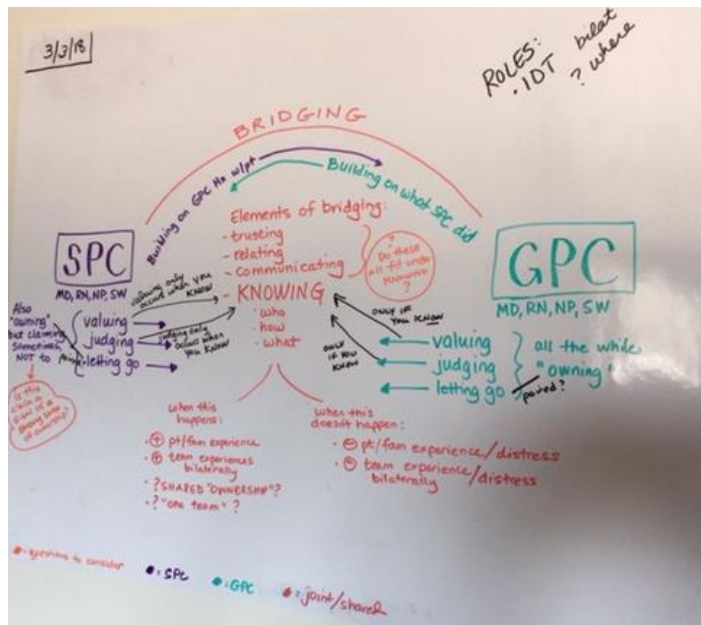
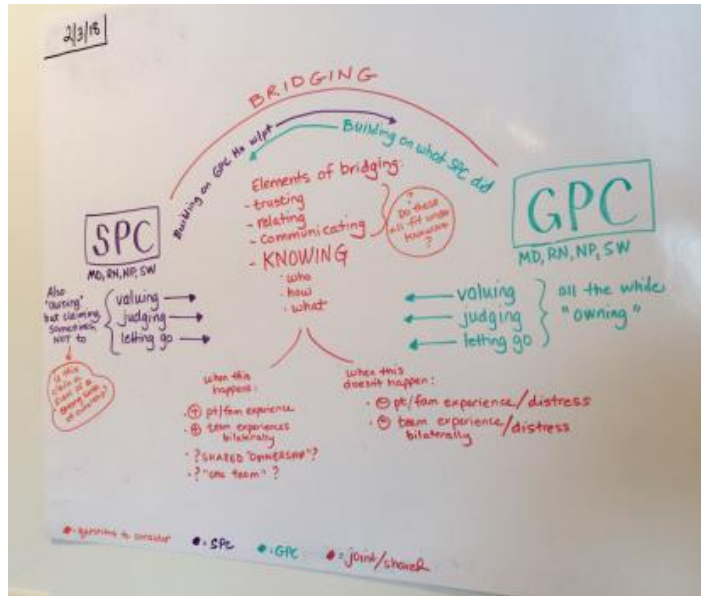
In this data, this key category was only demonstrated in a minority of cases, but was powerful, and was identified by participants who hadn't had this experience as the ideal. The most common (default) state was the "acting independently" and while this wouldn't be the key category, could I use this category as a contrast that helps to define the key category of "acting as one team"?

13 October 18: Update to theory: Interdependence between specialist and generalist palliative care teams

"Acting as one team" is the key category which demonstrates the fullest expression of interdependence between the inpatient specialist and outpatient generalist palliative care teams. When certain conditions exist, the inpatient specialist palliative care teams and the outpatient generalist palliative care teams provide care for the patient and family as one team. The perceived outcomes of this state of **"acting as one team"** from the perspective of the participants are that the patient and family receive optimal clinical care and that the professionals have optimal satisfaction with their work. The conditions that need to exist in order for the specialists and generalists to act as one team including **"knowing the other," "communicating intentionally,"** and **"acknowledging the value of the other in the presence of the patient."** In the absence of these conditions, **"acting independently"** is the default state of teams' working with poorer outcomes for both patient/family and professionals. The effect of these conditions is cumulative, with increasing expression of interdependence and increasing positive outcomes as the other team is known, intentional communication occurs, and the value of the other team is acknowledged overtly with the patient and family.

Appendix L: Photos of interview data analysis exercise






5/22/18


3 "STATES OF BEING" as teams (or "connection")

not a continuum that indicates some sort of progression?




Acting independently

- What's happening here that hinders connection?
- What are the circumstances that lead to this?
- Is it always a "negative" state (judgment)?
 - Some data definitely indicate this is less preferred, with negative impacts on pt care - clinician satisfaction. -- BUT MAYBE NOT ALWAYS ☹️



Bridging

- What's happening here?



Acting as one

- What's happening here that allows/creates/helps connection?

Most teams seem to function in more than one of these states at different times, depending on

- team roles?
- geography?
- relationships/knowing?

} yet TBD


• exploring to consider • ISPC • OGPC

?? FUTURE RESEARCH: linking effect of "state of connection" on pt outcomes ??

6/16/18

ideas in the last week:

current state seems to be (with volume of space suggestive of prevalence):



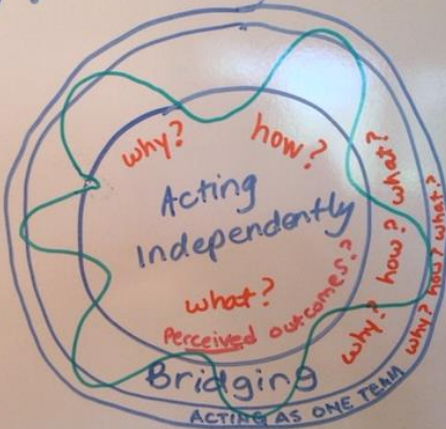
The why? how? what? will come out in the analysis of the coding - barriers, facilitators - what does it look like, how does it work?

Questions to consider:

- 1 Do I mainly focus ongoing analysis on the "acting independently" concept (could I use the data on the other "states of being" as contrasts to further the analysis?)
- 2 Could I focus on "Acting Independently" while still playing with the question of how the same team(s) could fluctuate between the 3 states?

prevalence):

6/23: green line added to indicate movement of a single team b/w the 3 states



The why? how? what? will come out in

Self

Self memo written 7.7.18 - evolving ideas
 Came to 3 provisional key categories
 leading to 3 states of being

- Knowing the other team (who to call, how to contact, personally knowing)
- Taking initiative to communicate intentionally
- Acknowledging role + value of the other team

	Knowing	Taking Initiative	Acknowledging Value
AI			
BR			
AOT			

~~AI could be~~ AI is default - even if none of the elements are there (≠ knowing)

9/11/18

Default

- passive discovery of context
- "fault in the system"
- outcome:

Add in knowing other team only

• those 2 may go together?

Add in condition of taking initiative to comm intentionally

- means
- roles
- active
- outcome:

Add in acknowledging/valuing other team

- means
- what does it look like
- roles
- language w/pt
- outcome:

go together?
 Is there a difference, or is AOT just a more thorough bridging?

10/1/18

interdependence

Culmination of components

- knowing the other
- communicating intentionally
- acking role + value of other in presence of the pt.

Acknowledging role + value in pt presence
 AOT in 1 step

AND

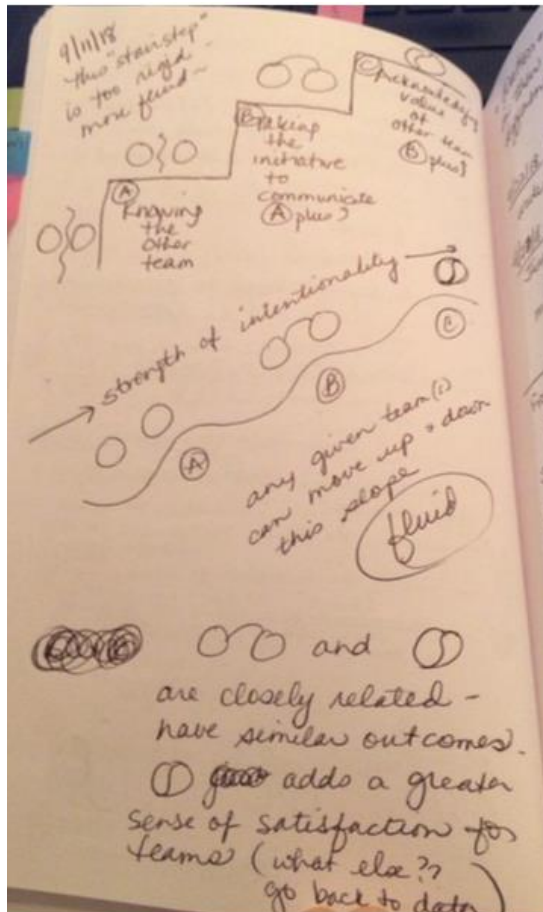
Interprofessional intentionality

- Knowing the other - prerequisite for any further. if absent, ^{social identity} social identity
- Taking the initiative to communicate
- ~~valuing~~ acknowledging the value of the other team (w/ the pt)

Default

ADDITIVE →

our shared language



Appendix M: Institutional Review Board submission

(starts on next page)

IRB Minimal Risk Protocol Template

Note: If this study establishes a human specimen repository (biobank) for research purposes, do not use this template. Use the Mayo Clinic Human Specimen Repository Protocol Template found on the IRB home page under Forms and Procedures at <http://intranet.mayo.edu/charlie/irb/>

First-time Use: Use this template to describe your study for a new IRB submission.

1. Complete the questions that apply to your study.
2. Save an electronic copy of this protocol for future revisions.
3. When completing your IRBe application, you will be asked to upload this document to the protocol section.

Modification: To modify this document after your study has been approved:

1. Open your study in IRBe. Click on the study 'Documents' tab and select the most recent version of the protocol. Save it to your files.
2. Open the saved document and activate "Track Changes".
3. Revise the protocol template to reflect the modification points, save the template to your files
4. Create an IRBe Modification for the study and upload the revised protocol template.

General Study Information

Principal Investigator: Mary Thelen, MSN, RN, CHPN

Study Title: Perspectives of healthcare professionals on transitions of palliative care provision for individual patients from inpatient specialist palliative care to generalist palliative care outside the hospital in the United States: a grounded theory study.

Protocol version number and date: Version 1. 5/29/2016

Research Question and Aims

Hypothesis: This is a qualitative, grounded theory study, so does not begin with a hypothesis, but rather a question: "What are the psychosocial processes that occur within and between health care professionals when patients in the United States transition from receiving palliative care from an inpatient specialist palliative care team to receiving palliative care from a generalist palliative care team outside the hospital setting?"

Secondary questions include:

- How do professionals personally experience the transition of responsibility for a patient's palliative care needs from one team to another?
- How do specialist and generalist palliative care professionals interact with one another when a shared patient makes the transition from inpatient specialist palliative care provision to generalist palliative care provision outside the hospital setting?

- What impact does the transition of responsibility for a patient’s palliative care needs have on the professional’s relationship with the patient and on their perception of how well the patient’s palliative care needs continue to be met?

Aims, purpose, or objectives:

The aim of this grounded theory research study is to explore the psychosocial processes that occur within and between health care professionals in the United States when the inpatient specialist palliative care team relinquishes responsibility for a patient’s palliative care needs at time of discharge, and the generalist palliative care team outside the hospital assumes that responsibility. The focus of the exploration is to understand perceptions of these processes from the perspectives of members of these specialist and generalist palliative care teams and to develop a substantive theory of these processes.

Background (*Include relevant experience, gaps in current knowledge, preliminary data, etc.*):

Palliative care is an approach to health care that focuses on enhancing quality of life for patients experiencing life-limiting illness and their families (Meier & McCormick, 2015). Palliative care providers enhance quality of life by preventing and relieving physical, psychosocial and spiritual suffering through the support of an interdisciplinary team at all phases of a patient’s illness (World Health Organization, 2015). In the U.S., palliative care has developed as a medical specialty which is closely related to, but differentiated from, hospice care, which is comfort-focused end-of-life care for patients with a six month or less prognosis (Carlson et al, 2008). In part due to U.S. governmental regulations that require adult patients who enrol in hospice to forego further life-sustaining therapies, palliative care as a specialty grew to meet the needs of seriously ill patients who did not yet qualify for hospice (Center to Advance Palliative Care, 2012).

Definitions

For purposes of this study, key terms are defined as listed below:

Table 1. Definitions

Palliative care	An approach to medical care that strives to enhance quality of life by preventing and relieving physical, psychosocial and spiritual suffering at all phases of a patient’s illness (World Health Organization, 2015). For the focus of this study, the term will refer to <i>non-hospice</i> palliative care.
Specialist palliative care teams	Interdisciplinary teams in hospitals whose practice is solely focused on meeting palliative care needs of patients. This may include team members who work part-time with a specialist palliative care team and part-time in another area; however, exploration will be of their perceptions while working as a specialist palliative care team member.
Generalist palliative care teams	Interdisciplinary teams who provide primary health care to patients with palliative care needs in any setting outside the hospital. This may refer to those who work in a primary care specialty (such as Family or Internal Medicine) or to those who work in a non-Palliative Care subspecialty such as Oncology or Nephrology but oversee the general health care needs of a particular patient.

Specialist and generalist palliative care in the literature

In the literature and in clinical practice, there is an increasing differentiation between “specialist” and “generalist” palliative care providers. Specialist palliative care professionals are those who have had specialized training or have obtained certification in palliative care and are members of a specialized palliative care team that works solely with patients with palliative care needs. Generalist palliative care professionals are those who practice in another medical discipline, but still provide care for patients and families with palliative care needs and strive to promote quality of life and minimize suffering (Gardiner et al, 2012; Quill & Abernethy, 2013).

In the U.S., specialist palliative care services have developed primarily in the inpatient hospital setting, with few specialist palliative care services outside the hospital setting which continue to provide specialised palliative care after discharge (Smith et al, 2015). While the broad concept of specialist versus generalist palliative care has increasingly been discussed in the literature (Firn et al, 2015; Gardiner et al, 2012; Quill & Abernethy, 2013; Smith et al, 2015), limited research has been undertaken in the U.S. that differentiates between specialist and generalist palliative care providers. Research around the idea of generalist palliative care in the U.S. has focused on the challenges faced by generalist clinical nurse specialists in advance care planning conversations (Boot & Wilson, 2014), consensus guidelines for primary palliative care provision in the setting of stroke (Holloway et al, 2014), outcomes of nurse practitioner-run combined primary and palliative care clinics (Murphy et al, 2013; Owens et al, 2012), and defining essential elements of palliative care to be included in basic medical education (Schaefer et al, 2014).

Research in the U.S. that has focused on the interface between non-palliative care providers and palliative care specialists tends to be hospital based. For example, there have been studies of the tensions involved in integrating specialist palliative care into non-palliative acute care in an academic hospital (Norton et al, 2011) or the factors affecting non-palliative physicians’ utilization of a hospital-based palliative care service (Snow et al, 2009). Firn et al (2015) conducted a systematic review of the literature which focused on collaboration between specialist and generalist palliative care teams within the hospital setting. Only four of the included 23 studies were based in the U.S., and all were focused on the inpatient acute care setting.

In countries other than the U.S., research into interactions between generalist and specialist palliative care professionals has occurred in a variety of settings, including outpatient and community settings. For example, Gardiner et al (2012) performed a systematic review that identified factors that promoted strong partnerships between those who provide specialist and generalist palliative care across inpatient and outpatient settings. However, none of the studies that were included reported research conducted in the U.S. (Gardiner, 2012). Without knowledge of how this interface occurs in the United States, especially during patient transitions out of the hospital, at which time patients in the U.S. most likely lose accessibility to specialist non-hospice palliative care services, patients are at risk of receiving uncoordinated, segmented, and ineffective care.

Reason for undertaking this research

In the U.S., as there is not yet a strong specialist non-hospice palliative care presence outside the hospital setting, it is not clear how provision of palliative care initiated in the hospital setting is carried over into the post-discharge care of the patient, managed by the patient’s primary care team. This research aims to provide better understanding of psychosocial processes that happen within and between health care professionals and teams when specialist palliative care teams relinquish and generalist palliative care teams accept responsibility for individuals’ palliative care needs at the time of discharge from the hospital. Without an understanding of this process, the best laid plans created with the patient in the hospital setting can “disintegrate on discharge” (Bull et al, 2012, p. 799) which may result in poor symptom control, suffering, unwanted aggressive interventions or hospitalisation, and confusion or frustration on the part of the patient, family and health care teams.

Study Design and Methods

Methods: *Describe, in detail, the research activities that will be conducted under this protocol:*

Methodology

Because there is very little research and no previously identified theories of transitions of palliative care provision in the U.S., a qualitative, constructivist grounded theory methodology has been chosen for this study. Qualitative approaches are most appropriate for studies that are looking the “why” and “how” of a process, and that take into account the complexity of contexts in which phenomena occur (Braun & Clarke, 2013). Grounded theory is particularly suited to studies which explore social actions and processes and in which the goal is to develop an explanatory theory of that process that is grounded and built upon what emerges in the data (Creswell, 2013).

A constructivist grounded theory approach assumes that the emergent theory is an interpretation of what is really happening based on the context and the constructions of both participant and the researcher (Charmaz, 2014). This aligns well with the aim of this study to understand a process about which little is known in the U.S. context. The goal is to enter into the inquiry with an open mind, rather than a preconceived idea of what is happening in the process, and build a theory from the data that emerges, which will include the perspectives of all participants as well as the researcher.

Setting

This study will primarily take place within the Mayo Clinic enterprise. Mayo Clinic is a health system that has six hospitals in the midwest, southeast and southwest United States (in Minnesota, Wisconsin, Florida and Arizona) that have specialist inpatient palliative care teams. Also included in the Mayo Clinic system are outpatient primary and subspecialty clinics in more than 70 communities of varying sizes (Mayo Clinic, 2016). The study may also include some participants from hospitals or outpatient medical practices outside the Mayo Clinic system, from across the United States, as recruited through professional networking organisations.

Sampling strategy

Initial sampling will identify specialist palliative care providers in the hospital setting and generalist palliative care providers in the outpatient setting who have experienced the process of transition of palliative care provision being explored in this study (Charmaz, 2014). A hallmark of grounded theory methods is an ongoing, iterative process of data collection, analysis, and sampling (Charmaz, 2014). As key concepts begin to emerge from the data, theoretical sampling, another hallmark of grounded theory methods, will be used to select participants who can provide insights that will help refine and develop the emerging concepts, categories, and theory (Charmaz, 2014).

Recruitment

Participants will be recruited through the following means:

1. A flyer describing the study, inviting participants, and providing the researcher’s contact information will be emailed to all inpatient specialist palliative care professionals and all outpatient primary care professionals in the Mayo Clinic enterprise by the researcher. This method is accepted as recruitment tool within this organization (Mrozinski, 2016, pers. comm.). This pool of professionals includes a range of disciplines, including physicians, advanced practice nurses and physicians’ assistants, registered nurses, licensed practical nurses, medical assistants, social workers, and chaplains; a range of geographic regions of the United States (midwest, southeast, and southwest); and a range of institution types, from small community medical practices to a large quaternary medical center. See Appendix A for the recruitment flyer.

2. A flyer with a description of the study, invitation to participate and the researcher's contact information will be posted on the online forum of the Palliative Care Network of Wisconsin (PCNOW) by the forum manager. The PCNOW membership is composed of specialist and generalist professionals interested in palliative care from a variety of disciplines, including medicine, nursing, social work and chaplaincy, from across the United States and the world (even though it is a Wisconsin-based organisation). Permission has been granted for this by the PCNOW Board Chair (Jessick, 2016, pers. comm.).
3. A flyer with a description of the study, invitation to participate and the researcher's contact information will be sent to the membership of the Wisconsin Academy of Family Physicians (WAFP) via email initiated by the leadership of the academy. The WAFP is a Wisconsin-based organisation of family physicians, medical residents and students. Permission has been granted for this by the executive director of WAFP (Pheifer, 2016, pers. comm.).
4. Participants will be invited to nominate colleagues who have experience with transitions of responsibility for palliative care needs of patients from specialty inpatient to generalist care outside the hospital setting for possible participation in the study. Of particular interest would be generalist colleagues of specialists, or specialist colleagues of generalists, to or from whom they have relinquished or assumed this responsibility.

If needed, initial recruitment sources (outlined above) may be revisited during theoretical sampling in order to seek out participants who have particular experience with any of the emergent concepts or ideas.

Consent

All potential participants will be given a Participant Information Sheet (PIS) explaining the study's aim and research methods, how data will be used, and how confidentiality and data security will be maintained (see Appendices C.1 and C.2) prior to giving consent. All participants will sign a consent form, indicating that they understand the information provided about the study and that they give consent for their interview to be recorded and transcribed. They will be informed that they can withdraw from the study before, during, or up to two weeks after the interview (after which time, data will be incorporated into the constant comparative analysis). See Appendix D for the consent form.

Data collection

Because the aim of this study concerns perceptions of certain groups, in depth interviews will be used to explore individuals' perceptions of transitions of palliative care provision and to obtain an "insider view" (Charmaz, 2014 p. 24). Intensive interviews, as described by Charmaz, are open-ended and allow flexibility to pursue new ideas or insights provided by the participants (2014).

Participants' demographic data, including gender, age range, ethnicity, professional discipline, professional subspecialty, years of experience and palliative care certification status will be collected in order to be able to describe characteristics of the participant group. These data will not be linked to interview data.

Where possible, interviews will be conducted face to face in a private work setting of the participant's choice, to allow observation of non-verbal cues (Braun & Clarke, 2014). However, to maximize recruitment, telephone or secure videoconferenced interviews using Jabber software (Cisco, 2015) will be utilized to minimize the demand on participants who live geographically distant (Creswell, 2013; Payne, 2007).

All interviews will be digitally audio recorded using an encrypted device and transcribed verbatim by the researcher or an experienced transcriptionist as they are completed. Interview text will be anonymised by removing any participant identifiers and stored and organized using NVivo 10 software (Bleck et al, 2015; QSR International, n.d.).

In line with the constructivist grounded theory approach, interviews will be conducted using a general topic guide instead of a rigid schedule of questions (Speziale & Carpenter, 2003) (see Appendix B for interview guide). This topic guide may be adapted as the data and analysis unfold (Charmaz, 2014) in order to incorporate emerging theoretical concepts and elicit specific aspects of participants' experiences related to the emerging theory (Braun & Clarke, 2014).

As a supplement to interview data, the researcher will keep a reflexive journal with memos about observations during interviews, decisions made about sampling and interview topics, thoughts about emerging categories and theory, and her own perceptions. These memos will be incorporated into data analysis in line with constructivist grounded theory principles (Charmaz, 2014).

Resources: *Describe the available resources to conduct the research (personnel, time, facilities, mentor commitment, etc.):*

This research will be conducted for completion of a PhD in Palliative Care through Lancaster University in Lancaster, England, using the principle investigator's time and resources outside of normal work time as a Mayo Clinic employee. Some of the interviews with geographically distant participants may be conducted using secure Jabber software available on the PI's Mayo Clinic computer.

The PI will be meeting at least monthly with two research supervisors from Lancaster University via Zoom or Skype technology. These supervisors are available at any time via email or Zoom/Skype to assist with any questions or difficulties that arise.

(1a) This is a multisite study involving Mayo Clinic and non Mayo Clinic sites. *When checked, describe in detail the research procedures or activities that will be conducted by Mayo Clinic study staff.*

Research participants (health care professionals) may be included from non-Mayo sites (see recruitment plan, under "Methods"). If so, these participants would be engaged in a 30-60 minute interview with the Mayo Clinic PI either face to face, via phone, or via secure videoconferencing.

(1b) Mayo Clinic study staff will be engaged in research activity at a non Mayo Clinic site. *When checked, provide a detailed description of the activity that will be conducted by Mayo Clinic study staff.*

Subject Information

Target accrual is the proposed total number of subjects to be included in this study at Mayo Clinic. A "Subject" may include medical records, images, or specimens generated at Mayo Clinic and/or received from external sources.

Target accrual:

At least 10 specialist inpatient palliative care professionals and at least 10 generalist palliative care professionals from the outpatient setting; may be more, depending on theory development through constant comparative data analysis.

Subject population (children, adults, groups):

Professional members of interdisciplinary health care teams providing either specialist palliative care in a hospital setting or generalist palliative care outside the hospital setting. These team members may include but are not limited to physicians, nurse practitioners, nurses, social workers, or chaplains.

Inclusion Criteria:

Exclusion Criteria:

	Palliative care specialists	Palliative care generalists
Inclusion criteria	<ul style="list-style-type: none"> • Being a member of a specialist palliative care team in a hospital setting in the United States • Having provided specialist inpatient palliative care for at least one patient for whom the patient's primary care team assumed responsibility for palliative care needs after hospital discharge 	<ul style="list-style-type: none"> • Being a member of a health care team providing primary care outside the hospital setting in the United States • Having cared for at least one patient who previously received specialist inpatient palliative care consultation
Exclusion criteria	<ul style="list-style-type: none"> • Non-English speaker • Having a specialist palliative care practice in which responsibility for patients' post-hospital palliative care needs always continue to be met by a specialist palliative care team 	<ul style="list-style-type: none"> • Non-English speaker • Having extensive training or certification in palliative care

Research Activity

Check all that apply and complete the appropriate sections as instructed.

1. **Drug & Device:** Drugs for which an investigational new drug application is not required. Device for which (i) an investigational device exemption application is not required; or the medical device is cleared/approved for marketing and being used in accordance with its cleared/approved labeling. (Specify in the Methods section)
2. **Blood:** Collection of blood samples by finger stick, heel stick, ear stick, or venipuncture.
3. **Biological specimens other than blood:** Prospective collection of human biological specimens by noninvasive means that may include: urine, sweat, saliva, buccal scraping, oral/anal/vaginal swab, sputum, hair and nail clippings, etc.
4. **Tests & Procedures:** Collection of data through noninvasive tests and procedures routinely employed in clinical practice that may include: MRI, surface EEG, echo, ultrasound, moderate exercise, muscular strength & flexibility testing, biometrics, cognition testing, eye exam, etc. (Specify in the Methods section)

5. **Data** (medical record, images, or specimens): Research involving use of existing and/or prospectively collected data.
6. **Digital Record**: Collection of electronic data from voice, video, digital, or image recording. (Specify in the Methods section)
7. **Survey, Interview, Focus Group** : Research on individual or group characteristics or behavior, survey, interview, oral history, focus group, program evaluation, etc. (Specify in the Methods section)

NIH has issued a *Certificate of Confidentiality (COC)*. When checked, provide the institution and investigator named on the COC and explain why one was requested.

Biospecimens – Categories 2 and 3

(2) Collection of blood samples. When multiple groups are involved copy and paste the appropriate section below for example repeat section b when drawing blood from children and adults with cancer.

- a. **From healthy, non-pregnant, adult subjects who weigh at least 110 pounds.** For a minimal risk application, the amount of blood drawn from these subjects may not exceed 550ml in an 8 week period and collection may not occur more frequently than 2 times per week.

Volume per blood draw: _____ml

Frequency of blood draw (e.g. single draw, time(s) per week, per year, etc.)

- b. **From other adults and children considering age, weight, and health of subject.** For a minimal risk application, the amount of blood drawn from these subjects may not exceed the lesser of 50 ml or 3 ml per kg in an 8 week period, and collection may not occur more frequently than 2 times per week.

Volume per blood draw: _____ml

Frequency of blood draw (e.g. single draw, time(s) per week, per year, etc.)

(3) Prospective collection of biological specimens other than blood:

Review of medical records, images, specimens – Category 5

For review of existing data: provide a date range or an end date for when the data was generated. The end date can be the date this application was submitted to the IRB. Example: 01/01/1999 to 12/31/2015 or all records through mm/dd/yyyy.

Date Range: N/A – No medical records will be utilized in this study

Check all that apply (data includes medical records, images, specimens).

- (5a) No data will be collected beyond the IRB submission date.

(5b) The study involves data that exist at the time of IRB submission **and** data that will be collected after IRB submission. Include this activity in the Methods section.

Examples

- The study plans to conduct a retrospective chart review and ask subjects to complete a questionnaire.
- The study plans to include subjects previously diagnosed with a specific disease and add newly diagnosed subjects in the future.

(5c) The study will use data that have been collected under another IRB protocol. Include in the Methods section and enter the IRB number from which the research material will be obtained. *When appropriate, note when subjects have provided consent for future use of their data and/or specimens as described in this protocol.*

Enter one IRB number per line, add more lines as needed

Data Specimens Data & Specimens

Data Specimens Data & Specimens

Data Specimens Data & Specimens

(5d) This study will obtain data generated from other sources. Examples may include receiving data from participating sites or an external collaborator, accessing an external database or registry, etc. Explain the source and how the data will be used in the Methods section.

(6) Video audio recording: *Describe the plan to maintain subject privacy and data confidentiality, transcription, store or destroy, etc.*

<u>HIPAA Identifiers and Protected Health Information (PHI)</u>
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Protected health information is medical data that can be linked to the subject directly or through a combination of indirect identifiers.

Maintaining identifiers (including a code) during the conduct of the study allows you to return to the medical record or data source to delete duplicate subjects, check a missing or questionable entry, add new data points, etc. De-identified data is medical information that has been stripped of all HIPAA identifiers so that it cannot be linked back to the subject. De-identified data is **rarely** used in the conduct of a research study involving a chart review.

Review the list of subject identifiers below and, if applicable, check the box next to each HIPAA identifier being recorded at the time of data collection or abstraction. Identifiers apply to any subject enrolled in the study including Mayo Clinic staff, patients and their relatives and household members.

Internal refers to the subject's identifier that will be maintained at Mayo Clinic by the study staff.

External refers to the subject's identifier that will be shared outside of Mayo Clinic.

Check all that apply:	INTERNAL	EXTERNAL
Name		
Mayo Clinic medical record or patient registration number, lab accession, specimen or radiologic image number		
Subject ID, subject code or any other person-specific unique identifying number, characteristic or code that can link the subject to their medical data		
Dates: All elements of dates [month, day, and year] directly related to an individual, their birth date, date of death, date of diagnosis, etc. Note: Recording a year only is not a unique identifier.		
Social Security number		
Medical device identifiers and serial numbers		
Biometric identifiers, including finger and voice prints, full face photographic images and any comparable images		
Web Universal Resource Locators (URLs), Internet Protocol (IP) address numbers, email address		
Street address, city, county, precinct, zip code, and their equivalent geocodes		
Phone or fax numbers		
Account, member, certificate or professional license numbers, health beneficiary numbers		
Vehicle identifiers and serial numbers, including license plate numbers		
Check 'None' when none of the identifiers listed above will be recorded, maintained, or shared during the conduct of this study. (exempt category 4)	<input checked="" type="checkbox"/> None	<input checked="" type="checkbox"/> None

Data Analysis

Power analyses and study endpoints are not required for minimal risk research, pilot or feasibility studies.

No statistical information. *If checked, please explain:* This is a qualitative study without any statistical analyses to be conducted.

Power Statement:

Data Analysis Plan:

Endpoints

Primary:

Secondary:

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Appendix N: Letters of approval from the Mayo Clinic Institutional Review Board and
the Lancaster Research Ethics Committee

From: Mayo Clinic IRB
To: Mary Thelen
Re: **IRB Application #:** [16-004490](#)

Title: Perspectives of healthcare professionals on transitions of palliative care for individual patients from inpatient specialist palliative care to generalist palliative care outside the hospital in the United States: a grounded theory study.

IRBe Protocol Version: 0.01
IRBe Version Date: 6/5/2016 8:18 PM

IRB Approval Date: 6/24/2016
IRB Expiration Date:

The above referenced application was reviewed by expedited review procedures and is determined to be exempt from the requirement for IRB approval (45 CFR 46.101b, item 2). Continued IRB review of this study is not required as it is currently written. However, any modifications to the study design or procedures must be submitted to the IRB to determine whether the study continues to be exempt.

The recruitment flyer, Participant Information Sheets, consent document and interview guide were reviewed and accepted.

AS THE PRINCIPAL INVESTIGATOR OF THIS PROJECT, YOU ARE RESPONSIBLE FOR THE FOLLOWING RELATING TO THIS STUDY.

- 1) When applicable, use only IRB approved materials which are located under the documents tab of the IRBe workspace. Materials include consent forms, HIPAA, questionnaires, contact letters, advertisements, etc.
- 2) Submission to the IRB of any modifications to approved research along with any supporting documents for review and approval prior to initiation of the changes.
- 3) Submission to the IRB of all Unanticipated Problems Involving Risks to Subjects or Others (UPIRTSO).
- 4) Compliance with Mayo Clinic Institutional Policies.

Mayo Clinic Institutional Reviewer

Applicant: Mary Thelen
Supervisors: Sarah Brearley and Catherine Walshe
Department: Health Research
FHMREC Reference: FHMREC15124

19 July 2016

Dear Mary

Re: Perspectives of healthcare professionals on transitions of palliative care provision for individual patients from inpatient specialist palliative care to generalist palliative care outside the hospital in the United States: a grounded theory study.

Thank you for submitting your research ethics application for the above project for review by the Faculty of Health and Medicine Research Ethics Committee (FHMREC). The application was recommended for approval by FHMREC, and on behalf of the Chair of the Committee, I can confirm that approval has been granted for this research project.

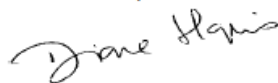
As principal investigator your responsibilities include:

- ensuring that (where applicable) all the necessary legal and regulatory requirements in order to conduct the research are met, and the necessary licenses 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 details of proposed substantive amendments to the protocol to the Research Ethics Officer for approval.

Please contact me if you have any queries or require further information.

Tel:- 01542 592838
Email:- fhmresearchsupport@lancaster.ac.uk

Yours sincerely,



Dr Diane Hopkins
Research Integrity and Governance Officer, Secretary to FHMREC.

Appendix O: Codebook: initial coding

Affecting patient and family
eases pt worry when SPC and GPC collaborate
effect on family
negative effect on SPC.pt relationship with poor transitions
negative pt family emotions with poor transitions
patient fear and panic
patient feeling abandoned at transition
patient sense of relief
patient sense of SPC.GPC teams working together
patients getting mixed messages
patients navigating unknown experience
pt family uncertainty at transition
SPC perception. patient frustration at lack of GPC understanding
Barriers
Competency barriers
generalists' independence
GPC perceptions that SPC see them as incompetent
PCP not willing to provide PC. sending back to SPC
primary PC provision dependent on providers skill, comfort
PCP not believing SPC appropriate when suggested by RN
Relational barriers
barrier. GPC knowing who to call in SPC
hospitalist model affecting PCP involvement with PC
lack of trust
questioning longevity of PCP relationship as affect on perceptions of pt
SPC not understanding PCP team roles
tensions between SPC and primary care
Resource barriers
EMR usability to make PCP aware of SPC
fragmented IDT in GPC
limited resources
scheduling barrier
temporal barriers
GPC takes time
SPC time constraints
time lapse between SPC inpatient and GPC follow up
Being cautious
caution about self-importance, indispensable
caution in own role

Believing
acknowledging everyone wants to do the right thing
believing good intent
believing in a bigger picture
bidirectional transition
Bridging
bridging the gap between SPC and PPC
bridging to ensure care didn't change during transition
preventing SPC consultation from falling thru the cracks after dc
Building on
building on inpatient SPC consult
inpatient PC consult lays the foundation for primary PC followup
inpatient SPC may open PCPs eyes to holistic needs
preventing SPC consultation from falling thru the cracks after dc
seeds planted by inpatient SPC
setting the stage
SPC acknowledging importance of continuing GOC conversations after transition
SPC consult easing primary PC process
SPC helping PCP relationship with pt
SPC increasing PCP comfort with PC conversation
SPC inpatient changes the outpatient GPC conversation
Communicating
communicating effectively
communicating done well
communicating proactively. SPC to GPC
communicating pt goals and plans of care ease transtiion
Communicating thoroughly
communication KEY to good transition
crisis avoided with good transitional communication
direct vs. indirect communication
face to face handoff
SPC finding the right receiver
SPC reaching out directly to GPC DURING hospitalization allowed generalist involvement throughout course
SPC reaching out multiple times to GPC. not just at dc
SPC RN contacting GPC MD
Communicating ineffectively
communication between SPC and GPC attempted without success
following institutional norms for communication
lack of communication with inpatient PC team
lack of feedback generalist to specialist
lack of institutional processes

patient perception of communication between SPC and GPC inaccurate
SPC worry that GPC doesn't know HOW to reach out to SPC
Communicating non-intentionally
accidental communication between inpatient SPC and primary care SW
communication between inpatient and primary care not deliberate
communication between SPC and generalist dependent on provider
importance of knowing the inpatient PC consult has occurred
Primary care SW only contacted by SPC with major problems
uncertainty about communication
wanting generalists to initiate follow up with specialist
Communicating.deterrents
SPC worry that GPC doesn't know HOW to reach out to SPC
communicating.differences tertiary vs. community setting
geographic distance a factor in communication
lack of communication with GPC by tertiary SPC team
Primary care lack of awareness of inpatient SPC consult
uncertainty about communication
Communicating.facilitators
SPC knowing GPC increasing chance of communicating at transition
SPC knowing GPC team easing communication
warm handoff more effective
Communicating.means
Communicating electronically
depending on EMR notes for communication
means of communicating between teams
means of communicating between teams
written medical record inadequate for communication
communicating.outcomes
communicating pt goals and plans of care ease transtiion
communication KEY to good transition
crisis avoided with good transitional communication
face to face handoff
patient feeling heard with SPC.GPC teams communicating
PCP relationship with pt helped by SPC and GPC communicating
pts goals honored secondary to direct communication
communicating.provider dependent
communicating proactively. SPC to GPC
communication at transition limited by lack of PCP
communication between SPC and generalist dependent on provider
Cycling.cycles
cycle of patients inpatient

cyclical admissions
investing in new patients after transition
Differing understandings
continuing misconceptions of PC
differentiate hospice from generalist PC
differing perspectives in community vs. tertiary setting
GPC misconception that SPC takes over primary care
GPC RN conduit to clearing PC misconceptions
specialist worry that generalist may not share attitude about death
Emotions
acknowledging intensity of specialist work
difficulty talking about practice
Emotional attachment to pt and/or outcome
needing to dampen own emotions to do job
negative pt family emotions with poor transitions
over-investment
patient fear and panic
patient feeling abandoned at transition
patient sense of relief
patient with negative emotion rel to SPC
personal discomfort after transition
personal distress.burnout
primary care providers feeling relief that SPC started conversations
SPC feeling moral distress at transition without SPC follow up
SPC feeling parental
specialist inpatient PC intense
specialist sense of loss.control
specialist sense of loss.relationship
specialist sense of personal responsibility
specialist sense of relief at transition
tensions between SPC and primary care
very strong emotion at letting go of pt at transition
EMR
depending on EMR notes for communication
electronic communication beyond provider's visit note
electronic relationships
Facilitators
external influence on generalists provision of PC
facilitator. GPC knowing who to call in SPC
facilitator. patient family education.what follow up looks like
facilitator.SPC knowing who to call in GPC

family initiated GPC involvement inpatient
GPC more acceptable to some pts than SPC
GPC starts the referral process for inpatients
GPC team involved while inpatient
having the time to have conversations (GPC)
impacting brand new PCPs
individual clinician characteristics
primary PC provision dependent on providers skill, comfort
referring back to inpatient SPC consult in primary care
sentinel visit.turning point
some primary care providers skilled at hard conversations
SPC and primary PC can be in agreement vs. pt perspective
SPC inpatient consult helped GPC RN more than helped pt
SPC talking with pt about communicating with PCP
SPC understanding PCP team roles
specialized primary care visits to meet palliative needs
Formal processes
specialized primary care visits to meet palliative needs
supportive care model within primary care.what happens after transition
weekly primary care IDT huddle
Gaps
gaps between inpatient and outpatient teams
generalists getting lost in specialist care
GPC follow up focused on medications.physical needs
identifying the gap in society as a whole
lack of IDT In outpatient primary care setting
lack of institutional processes
lack of plan at transition
loss of good symptom management after transition
needing care not available at critical access site
not understanding generalist practice
patient desire to stay with PC.gaps of not being heard
patient doesn't want SPC follow up - pt choice to follow w GPC
PCP unlikely to have PC discussions
preventing SPC consultation from falling thru the cracks after dc
primary care SW left out of primary palliative care at transitions
primary care SW notes gaps in primary care addressing needs
Primary care SW only contacted by SPC with major problems
specialist unaware of final outcomes
specialist vs. generalist skill set
unmet needs

Hopes
GPC hoping for increased pt insight with SPC consult
Hoping for good outcomes for pts after transition
SPC hoping for good symptom mgmt by GPC
SPC hoping for pt.GPC rapport
SPC hoping for timely follow up with GPC
Ideal state
definition of successful transition
GPC team aware and involved DURING inpatient stay
idea to take the initiative in the transition
ideal state. collaboration
ideal state. SPC follow up calls after transition
ideal state.no hospitalization needed to get SPC involved
ideal state.SPC initiates direct contact with GPC every time
ideal state.SPC proactive
specialist goal for patient care
using full GPC IDT to full extent of abilities
wanting generalists to initiate follow up with specialist
In Vivo codes
bridging the gap
hammering
It's kind of like teeing it up
kick start
lays the foundation
opened the door
passing the baton. inadequate description
reconnecting the dots
seeds planted by inpatient SPC
setting the stage
Investing
investing in new patients after transition
over-investment
Judging
judging generalists' comfort with palliative care
judging generalists' desire to provide PC
judging generalists' skill with PC provision
judging generalists' tendency to actually provide PC
judging generalists' time to provide PC
judging patient's sense of loss at transition
judging PCP or subspecialists abandonment of pts
judging PCPs ability to have PC conversations

judging value of the PC consultation
judging value of the PC consultation (2)
ONLY generalist care
primary care providers who are confident in their pall care skills
SPC identifies needs beyond the ability of primary care team to manage
specialist vs. generalist skill set
Letting go
hard for PCP to let go of pt to IDT
Letting go at transition
paralleling to parenting and letting go of children
respecting boundaries after transition
very strong emotion at letting go of pt at transition
Negative attitudes
PC too aggressive
tensions between SPC and primary care
Observation of participants
Interviewer engaging with own thoughts
Out of scope for this study
differing understandings of comfort care
feeling frustrated.used by nonPC provider
handoffs within the primary care IDT
hospices ignoring inpatient PC recommendations
outside scope of this study
PCP roles within hospice care
Primary care backing off if SPC following
primary care RN wanting pt to follow our rules
providing end of life care without hospice
questioning patient's goals.decisions
responding to PCP referrers' expectations
specialist initiating contact with PCP to stay involved
symptom mgmt concerns when PCP is hospice attending
the surprise question in primary care
this is really outside scope of study perhaps
Owning
can't take the burden of owning pts
doesn't use ownership language
not owning patients
ownership
paralleling to parenting and letting go of children
PCP commitment thru the journey
Primary care owning patients

sharing ownership of patient between SPC and GPC
SPC feeling parental
specialist sense of personal responsibility
Patient autonomy affects followup
Perceptions
from GPC.GPC thinks they do PC better than they do
generalist perception that SPC sees them as incompetent
Generalists doing their own thing
GPC saw their PC provision as informal
GPC sees primary care as providing good Pall Care
GPC would be better provided if all IDT members were utilized fully
Lack of awareness of other teams' experience
patient perception of communication between SPC and GPC inaccurate
patient sense of SPC.GPC teams working together
perception of hospice as giving up
primary care team perception of SW role
Primary palliative care an extension of specialty PC inpatient
primary PC provision dependent on providers skill, comfort
questioning longevity of PCP relationship as affect on perceptions of pt
varying skills of PCP at PC conversation
Planning
caregiver distress when no plan
designing care plan around pt.family goals
developing a plan with pts hopes
having a good plan when leaving specialist PC
lack of plan at transition
not having a contingency plan in place
Population health.ACO
Pop health provides umbrella of care
population health integration
regulating integration of PC into primary care
Positive attitudes
communicating
GPC appreciating pt opportunity to express self with SPC
identifying benefit of SPC's ability to spend time
identifying SPC benefit of including whole family
judging value of the PC consultation
non-palliative care specialists embracing PC
Positive attitude
positive example of good transition
primary care providers who appreciate the SPC inpatient consult

reassurance
SPC consult taking burden off pt shoulders
purpose of the referral - planning, support
rare not to follow with SPC
Relating
acquaintance with primary team
disappointment in relationships with PCPs
familiarity in primary care can be blinding
having to earn trust with patient
informal connections
intermediary connection between specialist and generalists
knowing patient and family well
lack of ongoing SPC preserves GPC relationship w pt
lack of relationship with PCPs
lack of trust
minimal relationship between teams
negative effect on SPC.pt relationship with poor transitions
neutral effect on PCP relationship w pt
never practiced together with generalists
never practiced together with generalists (2)
not friends yet with some PCPs. gaps.hope for future
not friends yet with some PCPs. gaps.hope for future (2)
patient desire to stay with PC.gaps of not being heard
personal connections between PCP and pt
positive effect on PCP-pt relationship
pts' level of trust of PCP decreasing after SPC
pts not wanting to return to PCP after inpatient PC
relating electronically
relationships with PCPs key to good follow up
sense of team between GPC and SPC variable
SPC acknowledging valuing pts relationship with generalist
SPC and GPC a team
SPC feeling parental
SPC helping GPC RN relationship with pt
SPC helping PCP relationship with pt
SPC knowing GPC increasing chance of communicating at transition
SPC knowing GPC providers in community
SPC knowing GPC team easing communication
specialist sense of loss.relationship
Roles
caution in own role

collaborating with referrers
dual roles
GPC RN conduit to clearing PC misconceptions
GPC RN coordinator conduit to pt conversation with PCP
GPC RN coordinator has the time to have in depth conversations
GPC RN has ongoing pt relationship over time
GPC RN having follow up conversation
GPC RN preps the patient for PC conversation with PCP.teeing up
GPC RN speaks different language w pt than PCP
GPC would be better provided if all IDT members were utilized fully
hard for PCP to let go of pt to IDT
having specialized visits in primary care to address PC needs
IDT collaboration in primary PC
not being in charge
not replacing PCP
overlap of PC and primary care
PCP as PC recipient
Primary care NP vs. MD roles
Primary care RN coordinator GATEKEEPER
primary care RN coordinator misses opportunity for SW involvement
primary care RN coordinator seeing big picture
primary care RN coordinators increase management of pts need
Primary care RN focusing on pt's goals
primary care RN seeing SW as an ad hoc team member
primary care SW has different perspective - from team
primary care SW supports primary care RN coordinators
primary care SW tries to continue conversations from inpatient PC
primary care team perception of SW role
role of SPC in supporting GPC comfort in PC
SPC as mediator for pt.family conflict
SPC misunderstanding PCP role of NP vs. MD
SPC RN a conduit in transition
SPC RN contacting GPC MD
SPC worry about GPC not seeing SPC as a resource
specialist PC interdisciplinary team
specialist role to clarify GOC
specialist role to ease transition
SW ties up with a bow
wearing two hats in same case
Shifting
shifting focus in primary care to pts goals

Trusting
family trusts.values GPC RN coordinator
lack of trust
patient mistrust.uncertainty of all teams when inconsistent
Primary care distrusting SPC inpatient
pts' level of trust of PCP decreasing after SPC
transitioning from PCP distrust of SPC to need of SPC
trusting relationship between health care teams
trusting relationship with patient.specialist
Uncategorized thus far
adapting care to the individual pt's goals
adjusting to new prognosis
asking the surprise question
assumptions about what occurs in transition
blurriness of lines
brevity of PCP visits
calling out patient's responsibility in own care
changing culture of healthcare
changing culture of society
clarity
closing the loop
comanaging with primary team inpatient
complex SPC needs
complexity of patient needs
decreasing anxiety
depth
difficulty finding appropriate care
discomfort with the concept of PC.ethics
dying persons isolated
expected vs. unexpected illness matters
feeling scared by own response to clinical case
frequent experience for this participant
GPC generalizing own opinion to partners
healthy boundaries
hospice providing continuity
identifying family caregivers as resource seekers
identifying ideal time for SPC consult
identifying PC needs in primary care
identifying SPC benefit of including whole family
including whole family
increasing comfort with goals

inpatient practice with IDT
inpatient setting opens different possibilities
inpatient IDT following.not just SPC
integrity in practice
laughter - question discomfort with identifying distress
Length of stay.LOS potential factor in transitions
majority go to generalist SUBSPECIALTY care
majority of inpatient referrals not followed by specialist post dc
making self available outside normal parameters
minority go to generalist PRIMARY CARE
needing to see bigger picture
not ready
patient age matters
patient autonomy as a variable
patient needs priority over institutional rules
patient relying on healthcare team to meet needs
patients' decisions impact palliative plan of care
patients feeling safer to express self with SPC
patients seen frequently in ED.hospital
patients without social support
prescription issues at transitions
pushback from Prim Care re individual autonomy
questioning best way to follow up on PC needs
recognizing pt's autonomy
reverse transition
seeing referral as an invitation
separate healthcare systems
similar themes among cases
societal pressures affecting care
specialist team investment
suffering multifactorial
suffering.treatable and not treatable
symptom management
taking primary PC one step further
taking solace in doing some good
unexpected negative outcomes
Valuing
family valuing GPC RN coordinator input w inpatient SPC consult
GPC more aware of pt resources after inpatient SPC consult
GPC valuing SPC involving family
high value placed on direct communication SPC to GPC

identifying benefit of SPC's ability to spend time
SPC acknowledging valuing pts relationship with generalist
valuing contributions of SPC
valuing EMR notes as relationship
Valuing options SPC offers
valuing what the patient values.specialist
varying value placed on communicating with generalists by SPC providers
Worries
loss of good symptom management after transition
SPC worry about GPC not seeing SPC as a resource
SPC worry about GPC skill to manage symptoms
SPC worry about GPC time to manage symptoms
SPC worry that GPC doesn't know HOW to reach out to SPC
specialist worry about families without followup
specialist worry about plan not carried out
specialist worry that generalist may not share attitude about death
worries over premature hospice referrals
worry about losing what's been done
worry over patient suffering
written medical record inadequate for communication
maybe out of scope, a transition to hospice. but attended by PCP
palliative care values.one being connection to community
pt knowing who to call for what
recognizing consults that don't happen
recognizing importance of understanding pt's story
respecting pts goals and wishes
SPC serving as a surrogate for GPC team
surrogacy is about who is present, in the medical seat

Appendix P: Codebook: focused coding

Focused gerund categories	Focused non-gerund categories
Acting as one team across specialties and sites	Barriers to smooth transitions
Bridging	Bidirectional transitions
Building on	Facilitators to smooth transitions
Communicating	Gaps when transitions don't go well
Identifying transition of ISPC to OGPC as primary value of ISPC	Hopes related to the other team or transitions
Judging	Ideal state
Knowing	In Vivo codes
Letting go	Outcomes for teams, patient, families and plan of care
Owning	Palliative care value – connection to community
Relating	Population health – accountable care organisation
Trusting	Roles
Valuing	Worries related to the other team or transitions

Appendix Q: Codebook: theoretical coding

Name	Description
1. Acting independently	ISPC and OGPC teams are caring for the patient without collaborating in any way with the other team. <u>What does this look like?</u> relying on EMR notes alone (Andrea, Lacy, Rose); ISPC only getting follow up on outcomes from family (Zhiv); making assumptions about accountability (Linda); being inhibited in cone..... ; primary care reversing plan set in the hospital or refusing to return communication, not welcoming SPC involvement (Hill); acknowledges multiple services acting without “impact of the team”(JGG);
Contributing factors	
Attitudes and perceptions	
Perceptual factors	Factors related to how team members perceive one another or the other team, which can affect attitudes toward the other team and may inhibit connection between the teams
Relational factors	Factors related to relationships between individuals (e.g. SPC and GPC providers; having to do with trust, knowing each other, working in silos, etc)
Awareness and communication	
Communication factors	
Lack of awareness of other team	this is a broad lack of awareness - of the existence of the other team; of the consult happening; of what the other team does or contributes; of roles;
Time and space	barriers related to time or geography
Perceived outcomes of AI	
Fragmented care	Refers to operational aspects of care integration... Getting lost/falling through the cracks (Jean); lack of coordinated message with multiple specialists (Jean);
Negative clinical impact	Refers to direct impact on patients’ experience (vs. institutional impacts like readmissions) – closely tied to fragmented care. Patients receive

Name	Description
	less than optimal symptom management and may receive types of medical care or interventions that they may not desire. What does this look like? Pts “go without” (eg. Rxs) (Sally);
patient and family distress	What does this look like? Pt/fam panic (Sally); pts suffer (Rose);
positive outcome.despite AI	Examples: OGPC using the content of the ISPC consult note to trigger conversation with pt, even if no bridge (Lacey/SW, Lou/RNCC); or to guide future care, the “stage is set” (Sunshine);
professional distress or dissatisfaction	What does this look like? ISPC sense of loss (Zhiv, Duncan; Crash); anxiety (Zhiv); sense of wasted work (Jean); frustration in Primary Care (Andrea); moral distress (Crash); frustration and sadness in SPC (Zhiv); feels like disrespect (Hill); feels like non-valuing primary care (JGG);
2.Acting as one team across specialties and sites	SPC and GPC teams actively and visibly work collaboratively to meet the patient’s palliative care needs. Characterised by teams sharing responsibility to meet the patient’s needs, even if one team is not physically involved in the patient’s day to day care at a given moment in time or for an episode of care (e.g. Walter’s concept of surrogacy at the moment)
Barriers to AOT	
Contributors to AOT	
Definition.Properties.Characteristics	
Perceived outcomes of AOT	
3.Knowing each other	Why/when/how this happens: personal/non-professional relationship (Andrea); professional acquaintance (Andrea); searching EMR (Andrea); building relationship (JGG); being aware of a contact person (Kay, Sue); putting face to a name (Linda); understanding what the other team does/their expertise (or lack of) (Renee, Sally, Susan); Effects of: trust (JGG, Renee); more thought to the process when you have a face in mind (Linda); more likely to work together (Renee); may adapt approach of sharing information when the other team is known (Sally)

Name	Description
negative or contrasting examples - not knowing	Why/how/when does “not knowing” occur: no history in the organization (Andrea), rare interaction with team in another setting (inpatient vs outpatient) (Linda), lack of understanding the other team’s practice (Linda); not having a face to match to a name (Linda); lack of initiative to meet (Linda); can’t find contact name or info (Susan)
4.Communicating intentionally	Why/how/when does this happen? Copying/routing an EMR note(s) (Andrea, Hill); verbal/phone (Hill, Renee, Susan, Walter); e-message GPC to give “heads up” (Mae, Renee); SPC make first contact (Crash, Hill); SPC intentional contact w/GPC before consult (Hill) and before discharge (Hill, Walter); SPC contact to co-develop plan (Hill, Susan, Walter x2, Crash); GPC MD and RNCC continuing e-contact with ISPC after discharge (Hill); including IDT in communication (Hill/care coord; Linda/SW; Renee/SRN, Susan/SW);
Characteristics of communication	
negative or contrasting examples	Why/how/when does this not happen? Not owning the need/want to be connected (Andrea), not being a routine part of the process for every patient (Crash), specialists discounting GPC (JGG), trusting in the EMR note alone (JGG, Walter, Linda x2); SPC outreach not received (Susan); discounting of RN role (Susan) Effect of not happening: poorer patient care (Jane); unnecessary hospitalizations (Jane); unrealistic pt goals (Jane); oblivion to SPC consult (Linda); Contrast: communication b/w OGPC and OSPC easier (?)
Perceived outcome of CI	
5.Acknowledging role and value of other team	Why/when/how does this happen? Honouring the value pt places on other team (Crash, Walter); honouring GPC’s history with pt (Crash, JGG, Walter); seeing the pt together (Hill, Crash, Renee – extension thru OSPC); curiosity instead of judgment (JGG); explicitly talking to the patient about working together with the other team (Mae x2); SPC seeing oneself as GPC surrogate (Walt); viewing the pt’s care panoramically (Walt – ref#2) Effects of: patient sense of teamwork (Crash, Mae, Walter);

Name	Description
contrasting negative example	Why/how/when does this not happen? Judgment instead of curiosity (JGG, Walt); fears about the other team's competence (Zhiv); dismissal of the other team's input (Susan);

Appendix R: Database search terms for Medline, EmBase, PysInfo, and ProQuest

MEDLINE search terms:

Search ID#	search terms used
1	exp Palliative Care/
2	palliativ*.tw.
3	"advanced disease*".tw.
4	("end-stage disease*" or "end stage disease*" or "end-stage illness" or "end stage").tw.
5	Terminally Ill/
6	Terminal Care/
7	(terminal* adj6 care*).tw.
8	((terminal* adj6 ill*) or terminal-stage* or dying or (close adj6 death)).tw.
9	(terminal* adj6 disease*).tw.
10	(end adj6 life).tw.
11	hospice*.tw.
12	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11
13	(discharge and (plan* or service? or program* or intervention?)).ti.
14	*patient discharge/
15	(patient* adj2 discharge*).ab,ti.
16	(hospital adj2 discharge*).ab,ti.
17	(discharge adj2 plan*).ab,ti.
18	(discharge adj2 service?).ab,ti.
19	(discharge adj2 program*).ab,ti.
20	(discharge adj2 procedure*).ab,ti.
21	13 or 14 or 15 or 16 or 17 or 18 or 19 or 20
22	(shared care or collaborat\$ care).ab,ti.
23	(integrated care or coordinated care or co-ordinated care).ab,ti.
24	(specialist? and (primary adj2 (care or healthcare or health care))).ab,ti.
25	(specialist? adj4 (community or family doctor? or generalist? or family physician? or general practitioner? or family practice)).ab,ti.
26	(special* and generalist?).ab,ti.
27	(shared adj2 care).ab,ti.
28	(specialist* adj4 (community or family doctor? or generalist? or family physician? or general practitioner? or family practice)).ab,ti.
29	(specialist* adj4 (community or family doctor? or generalist? or family physician? or general practitioner? or family practice)).ab,ti.
30	((family doctor? or family physician? or general practitioner? or general practice?) adj13 team?).ab,ti.

31	((collaborat\$ or cooperativ\$ or co-operativ\$) adj3 (care or disease management or patient management or health care or healthcare or specialist?)).ab,ti.
32	(integrated adj4 (care or treatment or management)).ti. or (integrated adj2 (care or treatment or management)).ab.
33	(integrated adj3 (care or management or treatment)).ab,ti.
34	((collaborat\$ or cooperativ\$ or co-operativ\$) and (model? or practice?)).ti. or ((collaborative or cooperative or co-operative) adj2 (model? or practice)).ab.
35	((collaborat\$ or cooperativ\$ or co-operativ\$) adj12 (family practitioner? or family physician? or family doctor? or general practitioner? or primary care physician? or primary care doctor? or primary care practitioner?)).ab,ti.
36	((interdisciplin\$ or inter-disciplin\$) adj2 (assessment? or care or treatment or team? or primary care or specialist?)).ab,ti.
37	((coordinat\$ or co-ordinat\$ or team) adj9 care).ab,ti.
38	(integrated and (care or healthcare or management or treatment)).ab,ti.
39	(collaborat\$ adj3 care).ti. or (collaborat\$ adj2 (approach or approaches)).ab. or (collaborat\$ adj2 (approach or approaches)).ti.
40	(integrat\$ and (primary adj2 care)).ti.
41	Cooperative Behavior/
42	Interdisciplinary Communication/
43	Interprofessional Relations/
44	22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43
45	12 and 21 and 44
46	21 and 44
	reran above search with 3 additional terms (in d/c set, added "transitional care," "patient handoff OR patient hand off OR patient handover"; in teamwork set, added "patient care team") - exactly same results = 2225

EMBASE search terms:

Search ID#	search terms used
1	exp palliative care/
2	"palliat*".tw.
3	(terminal* adj6 care*).tw.

4	((terminal* adj6 ill*) or terminal-stage* or dying or (close adj6 death)).mp. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
5	(terminal* adj6 disease*).tw.
6	(end adj6 life).tw.
7	"hospice*".tw.
8	("end-stage disease*" or "end stage disease" or "end-stage illness" or "end stage").tw.
9	"advanced disease* ".tw.
10	1 or 2
11	9 or 10
12	terminally ill.ab,ti,tw.
13	terminal care.ab,ti,tw.
14	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13
15	(discharge and (plan* or service? or program* or intervention?)).ab,ti,tw.
16	*patient discharge/
17	hospital discharge/
18	(patient* adj2 discharge*).ab,ti.
19	(hospital adj2 discharge*).ab,ti.
20	(discharge adj2 plan*).ab,ti.
21	(discharge adj service*).ab,ti.
22	(discharge adj program*).ab,ti.
23	(discharge adj procedure*).ab,ti.
24	15 or 16 or 17 or 18 or 19 or 20 or 21 or 22 or 23
25	(shared care or collaborat\$ care).ab,ti.
26	(integrated care or coordinated care or co-coordinated care).ab,ti.
27	(specialist? and (primary adj2 (care or healthcare or health care))).ab,ti.
28	(specialist? adj4 (community or family doctor? or generalist? or family physician? or general practitioner? or family practice)).ab,ti.
29	(specialist? and generalist*).ab,ti.
30	(shared adj2 care).ab,ti.
31	(specialist? adj4 (continuity adj2 care)).ab,ti.

32	((family doctor? or family physician? or general practitioner? or general practice?) adj13 team?).af.
33	((collaborativ\$ or cooperativ\$ or co-operativ\$) adj3 (care or disease management or patient management or healthcare or health care or specialist?)).af.
34	(integrated adj4 (care or treatment or management)).ab,ti.
35	(collaborativ\$ or cooperativ\$ or co-operativ\$).mp. and (model? or practice?).ab,ti. [mp=title, abstract, heading word, drug trade name, original title, device manufacturer, drug manufacturer, device trade name, keyword, floating subheading word, candidate term word]
36	((collaborat\$ or cooperativ\$ or co-operativ\$) adj12 (family practitioner? or family physician? or family doctor? or general practitioner? or primary care physician? or primary care doctor? or primary care practitioner?)).ab,ti.
37	((interdisciplin\$ or inter-disciplin\$) adj2 (assessment? or care or treatment or team? or primary care or specialist?)).ab,ti.
38	((coordinat\$ or co-ordinat\$ or team) adj9 care).ab,ti.
39	(integrated and (care or healthcare or management or treatment)).ab,ti.
40	(collaborat\$ adj3 (care or approach or approaches)).ab,ti.
41	(integrat\$ and (primary adj2 care)).ab,ti.
42	*cooperation/
43	*Interdisciplinary communication/
44	*teamwork/
45	(partnership and (health care or care)).ab,ti.
46	25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45
47	14 and 24 and 46
48	24 and 46

PsycINFO search terms:

Search ID #	search terms used
	exp Palliative Care/
2	"palliat*".tw.
3	exp Terminally Ill Patients/
4	(terminal* adj6 care*).tw.
5	((terminal* adj6 ill) or terminal-stage* or dying or (close adj6 death)).tw.
6	(terminal* adj6 disease*).tw.
7	(end adj6 life).tw.
8	hospice*.tw.
9	("end-stage disease*" or "end stage disease*" or "end-stage illness" or "end stage").tw.
10	"advanced disease*".tw.
11	1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10
12	(discharge and (plan* or service? or program* or intervention?)).ti.
13	exp Discharge Planning/
14	*Hospital discharge/
15	(patient* adj2 discharge*).ab,ti.
16	(hospital adj2 discharge*).ab,ti.
17	(discharge adj procedure*).ab,ti.
18	(discharge adj service*).ab,ti.
19	(discharge adj program*).ab,ti.
20	(discharge adj2 plan*).ab,ti.
21	13 or 14 or 15 or 16 or 17 or 18 or 19 or 20
22	(shared care or collaborat\$ care).ab,ti.
23	(integrated care or coordinated care or co-coordinated care).ab,ti.
24	(specialist? and (primary adj2 (care or healthcare or health care))).ab,ti.
25	(specialist? adj4 (community or family doctor? or generalist? or family physician? or general practitioner? or family practice)).ab,ti.
26	22 or 23 or 24
27	(shared adj2 care).ab,ti.
28	(specialist? adj4 (continuity adj2 care)).ab,ti.
29	(special* and generalist*).ab,ti.
30	((family doctor? or family physician? or general practitioner? or general practice?) adj13 team?).ab,ti.

31	((collaborativ\$ or cooperativ\$ or co-operativ\$) adj3 (care or disease management or patient management or healthcare or health care or specialist?)).ab,ti.
32	(integrated adj4 (care or treatment or management)).ab,ti.
33	((collaborat\$ or cooperativ\$ or co-operativ\$) and (model? or practice?)).ti. or ((collaborative or cooperative or co-operative) adj2 (model? or practice)).ab.
34	((collaborat\$ or cooperativ\$ or co-operativ\$) adj12 (family practitioner? or family physician? or family doctor? or general practitioner? or primary care physician? or primary care doctor? or primary care practitioner?)).ab,ti.
35	((interdisciplin\$ or inter-disciplin\$) adj2 (assessment? or care or treatment or team? or primary care or specialist?)).ab,ti.
36	((coordinat\$ or co-ordinat\$ or team) adj9 care).ab,ti.
37	(integrated and (care or healthcare or management or treatment)).ab,ti.
38	(collaborat\$ adj3 (care or approach or approaches)).ab,ti.
39	(integrat\$ and (primary adj2 care)).ab,ti.
40	*cooperation/
41	**"Interdisciplinary communication".ab,ti.
42	**"teamwork".ab,ti.
43	(partnership and (health care or care)).ab,ti.
44	25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37 or 38 or 39 or 40 or 41 or 42 or 43
45	11 and 21 and 44
46	21 and 44

ProQuest search terms:

ab(("Palliative nursing" OR "Inpatient palliative care" OR "Inpatient Palliative Care Consultations" OR "Palliative care integration" OR "Palliative Care" OR "Palliative treatment" OR "palliative care" OR "Palliative services" OR "Specialist palliative care service" OR "Specialized palliative care services" OR "Palliative medicine" OR "Palliative care consultations" OR "Primary and specialty palliative care" OR "Palliative care" OR "Palliative care coordination" OR "Palliative care program")) AND ab(("Hospital discharge" OR "Hospital discharges" OR "Post-hospital discharge" OR "Hospital discharge planning")) AND (ab(("Organizational teamwork" OR "Interdisciplinary teamwork" OR "Interprofessional teamwork" OR "Teamwork Process" OR "Communication and teamwork" OR "Teamwork attitude" OR "Teamwork satisfaction" OR "Collaboration and teamwork" OR "teamwork behaviors" OR "Teamwork experience" OR "Teamwork behavior" OR "Teamwork processes" OR "Teamwork Uncertainty Principle" OR "Effective teamwork" OR "Teamwork schema" OR "Interprofessional collaboration and teamwork" OR "Relationships and teamwork" OR "Teamwork process" OR "Preference for teamwork" OR "Teamwork and collaboration" OR "Teamwork behaviors" OR "Perception of teamwork" OR "Medical teamwork" OR "Teamworks" OR "Teamwork quality" OR "Teamworking" OR "Collaborative Teamwork" OR "Teamwork Receptiveness Inventory" OR "Teamwork skills" OR "teamwork" OR "Collaborative teamwork" OR "Proactive teamwork" OR "Teamwork developmental process" OR "Transformational teamwork" OR "Teamwork activity recognition" OR "Teamwork" OR "Clinical teamwork" OR "Healthcare teamwork" OR "Teamwork effectiveness")) AND diskw(E))

Appendix S: Quality criteria review for included literature

Author, year, abbrev title	Journal	Type of paper (QT = quantitative; QL = qualitative; GT = grounded theory)	Are the aims & objectives of the research clearly stated?	Is the research design clearly specified & appropriate for aims & objs of the research?	Do the researchers provide a clear account of the process by which their findings were produced?	Do the researchers display enough data to support their interpretations & conclusions?	Is the method of analysis appropriate & adequately explained?
Abu et al (2018). Are we "missing the big picture" in transitions of care? Perspectives of healthcare providers managing patients with unplanned hospitalization	Applied Nsg Research	QL.other	Yes	Yes	Yes	Yes	Yes
Acosta et al (2018). Nurse's activities in care transition: realities and challenges	Journal of Nursing UFPE	QT.other	Yes	Yes	Yes	Yes	Yes
Balla & Jamieson (1994). Improving the continuity of care between general practitioners and public hospitals	Med Jl of Australia	QL.other	Yes	yes	Yes	Yes	Yes
Bell, C.M., Schnipper, J.L. et al. (2009). Association of	Journal of General Internal Med	QT.other	Yes	Yes	Yes	Yes	Yes

communication between hospital-based physicians and primary care providers with patient outcomes. J Gen Intern Med							
Blackford & Street (2001) The role of the PC nurse consultant in promoting continuity of end-of-life care	Internatl JI of Pall Nursing	QL.other	Yes	Yes	Yes	Yes	Yes
Bull & Roberts (2001). Components of a proper hospital discharge for elders.	Jl of Adv Nsg	QL.other	Yes	Yes	Yes	Yes	Yes
Canary & Wilkins (2017). Beyond hospital discharge mechanics: managing the discharge paradox and bridging the care chasm	Qualitative Health Research	QL.other	Yes	Yes	Yes	Yes	Yes
Gobel, et al (2012). Stakeholder perspectives on handovers between hospital staff and general practitioners: an evaluation through the microsystems lens	BMJ Quality & Safety	QL.other	Yes	Yes	Yes	Yes	Yes
Groene et al (2012) "It's like two worlds	BMJ Quality & Safety	QL.other	Yes	Yes	Yes	Yes	Yes

apart": an analysis of vulnerable patient handover practices at discharge from hospital							
Hesselink et al. (2013). Quality and safety of hospital discharge: a study on experiences and perceptions of patients, relatives and care providers	International Journal of Quality in Health Care	Mixed methods	Yes	Yes	Yes	Yes	Yes
Hesselink, G., Vernooij-Dassen, M. et al (2013). Organizational culture: an important context for addressing and improving hospital to community patient discharge	Medical Care	QL.GT	Yes	Yes	Yes	Yes	Yes
Huby et al (1997). The chief scientist reports... co-ordination of care on discharge from the hospital into the community for patients with HIV/AIDS in Lothian	Health Bulletin	Mixed methods	Yes	Yes	Yes	Yes	Yes
Johnson et al (2012). Searching for the missing pieces	BMJ Quality & Safety	QL.other	Yes	Yes	Yes	Yes	Yes

between the hospital and primary care: mapping the patient process during care transitions							
Jones et al (2015). A failure to communicate: a qualitative exploration of care coordination between hospitalists and primary care providers around patient hospitalizations	Journal of General Internal Med	QL.other	Yes	Yes	Yes	Yes	Yes
Keane et al (2017). General practice and specialist palliative care teams: an exploration of their working relationship from the perspective of clinical staff working in New Zealand	Health Soc Care Community	QL.other	Yes	Yes	Yes	Yes	Yes
Marks et al (1999). Asthma: communication between hospital and general practitioners	Jl Paediatric Child Health	Mixed methods	Yes	Yes	Yes	Yes	Yes
Mason et al. (2013). Coordination of care for individuals with	British Journal of General Practice	Mixed methods	Yes	Yes	Yes	Yes	Yes

advanced progressive conditions: a multi-site ethnographic and serial interview study							
Nguyen, O.K., Kruger, J., et al (2014). Understanding how to improve collaboration between hospitals and primary care in post discharge care transitions...	Journal of Hospital Medicine	QL.other	Yes	Yes	Yes	Yes	Yes
Pantilat et al. (2001). Primary care physician attitudes regarding communication with hospitalists.	Am J Med	QT.other	Yes	Yes	Yes	Yes	Yes
Ruth et al (2011). Evaluating communication between pediatric PCPs and hospitalists.	Clin Pediatrics	QT.other	Yes	Yes	Yes	Yes	Yes
Rydeman & Tornkvist (2006). The patient's vulnerability, dependence and exposed situation in the discharge process: experience of district nurses, geriatric nurses and social workers	Jl of Clinical Nsg	QL.other	Yes	Yes	Yes	Yes	Yes

Sampson et al (2016) The relationship between GPs and hospital consultants and the implications for patient care: a qualitative study	BMC Family Practice	QL.other	Yes	Yes	Yes	Yes	Yes
Sheu, L, Fung, K, et al (2015). We need to talk: PCP communication at discharge in era of a shared EMR	Jl of Hospital Medicine	QT.other	Yes	Yes	Yes	Yes	Yes
Tandjung et al (2011). Gaps in continuity of care at the interface between primary care and specialized care: general practitioners' experiences and expectations	Intl Jl of General Medicine	QL.other	Yes	Yes	Yes	Yes	Yes

Criteria taken from Dixon-Woods et al (2006). Conducting a critical interpretive synthesis of the literature on access to healthcare by vulnerable groups. *BMC Medical Research Methodology*, 6:35. doi:10.1186/1471-2288-6-35

Appendix T: Codebook: literature coding

Name	Description
Literature review coding	
<p>1.Knowing each other</p>	<p>This refers to the condition in which relationships exist between the inpatient specialist and outpatient generalist teams, and includes:</p> <ul style="list-style-type: none"> • Knowing each other personally; having met F2F or worked together in past; interpersonal networking • Understanding the needs and complexities of other team’s practice • Understanding roles and expectations b/w and within disciplines (handcoded – Blackford & Street, p. 278) • Trust and “mutual expectation”; good will; “shared mission” • Valuing the other’s contribution • Contact outside protocolized communication (e.g. discharge letters) and EHR <p>Seen as an aspiration – to know each other</p>
<p>1.Knowing each other.BARRIERS</p>	<p>This refers to factors that inhibit teams knowing each other, including:</p> <ul style="list-style-type: none"> • Lack of information about GP in the medical record (handcoded – Balla and Jamison, p. 657) • Lack of understanding/valuing the other’s contribution • Lack of understanding of the other’s practice/way of working (NVivo and Balla & Jamieson, p. 658) • Changes in the culture of healthcare (busier practices, increased workload, complexity of care and more subspecialties, constant change in staff) • Focus on own setting, goals, tasks, responsibilities • Ambiguity in healthcare system roles • Professional hierarchies (NVivo and Blackford & Street, p. 276)
<p>1.Knowing each other.OUTCOMES</p>	<p>This refers to what the literature described as results from teams knowing each other:</p> <ul style="list-style-type: none"> • Better mutual support of patient care • More direct and positive communication between teams • Smoother patient transitions • Wanting to help each other – contact wasn’t a burden
<p>2.Communicating intentionally</p>	<p>This refers to a condition in which one of the teams takes deliberate action to communicate with the other team across the discharge transition, not passively relying on the other to access and read clinical documentation, such as:</p>

Name	Description
	<ul style="list-style-type: none"> • Making direct phone calls (required having access to direct phone numbers) – preferred by GPs (NVivo and Balla & Jamieson, p. 658, Blackford & Street, p. 276-7) • Using EHR capabilities such as direct messaging with shared EHRs, auto-alerts re: hospitalizations • Sending a direct email • Sometimes happening face to face (joint meetings) • Including multiple “circles of communication” / “handover microsystem” • Listening and communicating with respect, honesty, timeliness • Bidirectionally interacting • Utilizing a particular role to facilitate (bridge) (handcoded – Blackford & Street, p. 273, 278) <p>Seen as necessary for coordinated, quality patient care across discharge transition, and is desired by primary care.</p>
2.Communicating intentionally.MORE THAN information transfer	This refers to the idea that communicating intentionally entails true communication, an <i>exchange</i> , not just a transfer of information
2.Communicating intentionally.OUTCOMES	<p>This refers to what the literature described as results from teams communicating intentionally:</p> <ul style="list-style-type: none"> • Maintaining trust • Increasing flexibility and willingness to cover for each other • Improved GP satisfaction with communication with hospital • More effective discharge plans (handcoded – Blackford & Street, p. 278) • Creation of better communication networks (Blackford & Street, p. 273)
2.Communicating intentionally.FACILITATORS	<p>This refers to conditions that contribute to teams communicating intentionally with one another around discharge transitions</p> <ul style="list-style-type: none"> • Designated role to coordinate communication (PCNC) (Blackford & Street, p.273, 278) • Dedicated role (MD, RN, in charge of communication (Johnson) • Integrated EHRs (Johnson)
2.Communicating intentionally.BARRIERS	<p>This refers to factors that inhibit teams communicating intentionally, including:</p> <ul style="list-style-type: none"> • Lack of time / daily work pressures (NVivo & Blackford & Street, p. 276) • Difficulty reaching the other team by phone (NVivo & handcoded, Balla & Jamison, p. 657) • Lack of feedback whether communication received • Lack of access to, or use of, shared HER

Name	Description
	<ul style="list-style-type: none"> • Lack of understanding/awareness of other’s practice • Lack of integration of communication into workflow • Lack of shared goals • Lack of respect/relationship • Reliance on non-individualized, default mechanism (handcoded, Blackfd & Street, p275) • Professional/disciplinary territorialism (handcoded, Blackford & Street, p. 276, 278) • Getting past gatekeepers (Blackford & Street, p. 276-7)
<p>3.Acknowledging role and value of other team</p>	<p>This refers to a condition of appreciating and expressing appreciation for the contributions of the other team, including:</p> <ul style="list-style-type: none"> • Defending colleagues from other team when disregarded • Acknowledging the other has a unique contribution (ie PCPs knowledge of person as a whole) • Relying on the other team for their expertise <ul style="list-style-type: none"> ○ In knowledge ○ In carrying out their part of the patient’s care <p>This state often develops over time, with experience with each other</p>
<p>3.Acknowledging role and value.BARRIERS</p>	<p>This refers to factors that inhibit teams from acknowledging the role and value of the other, including:</p> <ul style="list-style-type: none"> • Making assumptions about the other’s decision making • “Cool” relationships – distant and formal • Lack of respect and negative attitudesT • Poor past interactions
<p>3.ARV.negative example</p>	<p>This describes when the role and value of the other team is not acknowledged, which exhibits as:</p> <ul style="list-style-type: none"> • Outright disrespect • GP feeling subservient to specialists • Sense that the other isn’t fulfilling their responsibilities • Hospitalists not believing it’s important that GPs are kept informed
<p>4.Acting independently</p>	<p>This refers to a state of operating as separate teams to meet the patient’s needs, evidenced by:</p> <ul style="list-style-type: none"> • Relying on EHR process to communicate, but lacking confidence it works • Primary care lacking knowledge of patient’s hospitalization or relevant details of it • Ambiguity about roles and responsibilities

Name	Description
	<ul style="list-style-type: none"> • Perception of a “care chasm” by patients/families and professionals • Primary care perceptions of being excluded from discharge transition (NVivo, and Huby, p. 346) • Each team trying to provide best care possible but in isolation (NVivo and Huby, p. 347) • Rare contact between GPs and inpatient physicians with HIV pts at/after discharge (Huby, p 346, 347) • Perceived more by primary care than by inpatient specialists (Balla & Jamieson, p. 657)
4.Acting independently.CONTRIBUTORS	<p>This refers to conditions that contribute to teams acting independently:</p> <ul style="list-style-type: none"> • Lack of trust in GP (handcoded, Balla & Jamieson, p.657) • No process or procedure for working together • Lack of awareness to needs, skills, work patterns of colleagues in other setting (NVivo and Balla & Jamieson, p. 658) • Lack of collaborative attitude or relationship (NVivo and handcoded, Balla & Jamison, p 657) • Focus on own setting’s needs (NVivo and handcoded, Balla & Jamison w/inpatient specialists, p. 657, 658) • Incompatible/differing values, beliefs and priorities between groups (NVivo and handcoded, Balla & Jamison, p. 657, 658)
4.Acting independently.OUTCOMES	<p>This refers to what the literature described as results from teams acting independently, including</p> <ul style="list-style-type: none"> • Hospital care decisions made without knowledge of patient’s bigger story and values • Some patient care needs duplicated, some missed • Medication errors/patient harm • Emotional and mental distress for patient/family • Additional stress and work for primary care team • GP frustration – not getting what they need to carry out plan established in hospital (Balla & Jamieson, p. 657) • Pt perception: GP acting independently from hospital team led to more personal, less controlling care (Huby, p. 348)
4. Acting independently.DEFAULT PROCESS without intentional action	<p>This state of operating as separate teams happens by default, without intentional action taken by one or both teams (NVivo and Huby, p. 348)</p>

Name	Description
<p>6.acting as one team</p>	<p>This refers to a state of being in which the two teams operate in unison as a cross boundary team to meet the needs of the patient, as evidenced by:</p> <ul style="list-style-type: none"> • Building and maintaining relationships • Establishing accountability • Adapting skill sets • Perceiving selves as part of one team, “being in it together” • Valuing interdisciplinary teamwork (esp SPCT) • Dropping “turf” battles • A coordinator role as a link bringing the two together • Sharing patient management decisions/primary care playing an active role in inpatient management • Having joint care conferences/meetings • Blurring of disciplinary boundaries • Navigating intersections between multiple systems
<p>6.AOT.BARRIER</p>	<p>This refers to factors that inhibit teams from acting as one, including:</p> <ul style="list-style-type: none"> • Lack of detailed and timely information exchange (NVivo and handcoded, Balla & Jamison) • Lack of personal relationships • Lack of clarify regarding accountability • Inconsistencies in service coverage (primarily primary care) • Systemic pressures on teams • Systemic culture of organisations • Lack of sense of being an integral part of a bigger whole (NVivo and Balla & Jamieson, p. 657) • “professional tribes” – incompatible values • Professional hierarchies • Interdisciplinary barriers (RN/RN, MD/MD) (Blackford & Street) • Lack of formal guidelines for collaboration • Past negative experiences with collaboration
<p>6.AOT.FACILITATORS</p>	<p>This refers to conditions that contribute to teams acting as one, including:</p> <ul style="list-style-type: none"> • Having interpersonal relationships • Clarity of responsibilities • Relational and organisational alliances • Provision of quality care within one’s scope
<p>6.AOT.OUTCOMES</p>	<p>This refers to what the literature described as results of teams acting as one, including:</p> <ul style="list-style-type: none"> • Increased trust • Smooth transitions for patients
<p>Team-focused</p>	<p>1.Knowing each other</p>

Name	Description
<p>Changes/considerations:</p> <ul style="list-style-type: none"> 3/16/19: System-focused 3/16/19: Seeing and responding across boundaries (what I mean by seeing: not just observing, but having a world-view of one's own work that includes others in other disciplines, other settings – that sees oneself as a part of a bigger whole) – maybe “Seeing and belonging across boundaries” or “belonging to a cross-boundary team”? 	<ul style="list-style-type: none"> Knowing each others' roles – inter & intradisciplinary (handcoded, BBlackford & Street) GP perceptions (Balla & Jamison) <p>1.Knowing each other.OUTCOMES</p> <p>2.Communicating intentionally</p> <p>2.Communicating intentionally.MORE THAN information transfer</p> <p>2.Communicating intentionally.OUTCOMES</p> <p>3.Acknowledging role and value of other team</p> <p>6.acting as one team</p> <p>6.AOT.FACILITATORS</p> <p>6.AOT.OUTCOMES</p>
<p>Self-focused</p> <p>Changes:</p> <ul style="list-style-type: none"> 3/16/19: Within boundaries 3/16/19: Seeing within boundaries (seeing and responding??) – maybe “Working within boundaries” -- having a world-view of one's own work that is narrowly focused within a discipline or setting, excluding others.... 	<p>1.Knowing each other.BARRIERS</p> <ul style="list-style-type: none"> Hospital staff perceptions (handcoded, Balla & Jamison) <p>2.Communicating intentionally.BARRIERS</p> <p>3.Acknowledging role and value.BARRIERS</p> <p>3.ARV.negative example</p> <p>4.Acting independently</p> <p>4.Acting independently.CONTRIBUTORS</p> <p>4.Acting independently.OUTCOMES</p> <p>4. Acting independently.DEFAULT PROCESS without intentional action</p> <p>6.Acting as one team.BARRIER</p>

Appendix U: Sample of memos from literature analysis

2/10/19: Thoughts on literature review and theorizing: Now that I have done a chunk of the literature review, and I go back and review Charmaz, things make more and more sense. I get a better understanding of what she is talking about as she talks through various approaches to theorizing and theory, now that I've worked with my own data and that of some of the literature.

For example, as I started to look at the literature results that I have so far, my initial thought was "almost all of this literature is about communicating - and communicating in a transactional way - ways of transmitting information back and forth in order to provide coordinated care for patients" (with transactional contrasted to relational - where the focus is on how the individuals or teams relate to each other within that communication). So I was starting to think about communicating and how that impacted teams working together, etc. This seemed sort of mundane - of course, communicating impacts how teams work together - we've known this for years, etc. However, when I started playing with the main ideas that I had put on post-its from the included papers so far, and started physically sorting them on a white board, groupings of "self-focused," "patient-focused," and "team-focused" (all related to communication between inpt and outpt teams, and handovers at hospital discharge) ... Then as I went to try to draw this out graphically in a concept map, the idea arose that for teams to truly function collaboratively, that have to be able to SEE and VALUE more than themselves -- not just physically, but to be aware of the other, their practice, their skills, the value they bring, etc.

As I was reviewing Charmaz's chapter on reconstructing theory this afternoon, I read where she writes about the approach of social constructionism that "emphasizes practices and actions. Rather than explaining reality, social constructionists see multiple realities and therefore ask: What do people assume is real? How do they construct and act on their views of reality? Knowledge and theories are situated and located in particular positions, perspectives, and experiences" (Charmaz, 2014, p. 231). As I read this, I thought, this is what happened as I was looking at the post-its... I saw these practices or data that show teams acting in a self-focused way, some showing a patient-focus, and some that are team-focused. It would be easy to leave it as that simple. But what was the difference here? The examples of self-focused teams were seeing reality as what was right in front of them - our needs, our tasks, our concerns, not "seeing" their counterparts on the other end of the discharge process (even when they were acting in a patient-centred way). That view of reality resulted in a certain way of communicating (or not). This way of conceptualizing what's going on (the phenomenon) brings in a relational aspect to the interaction.

Similarly, when I look at the literature that demonstrates team-focus (shared goals, good will, systems mindset), these groups are viewing reality as acting, functioning, working as part of something bigger than their own immediate concerns, which in turn impacts how they function and relate to other professionals and teams, and care for the patient/family. I have had a couple of "flashes" of insight that pass through my mind that this is bigger than just methods of communication, or social "procedures" - but it is still simmering some, not completely in words yet.

3/9/2019: On my drawing, the key groupings of findings were under drawings of "self-focused" (teams who don't know/understand the other team, who are focused on their own needs and processes), "Patient-focused" (each team focused on the needs of the patient, but working in parallel, not unison - words from the literature to describe this include "separate professional tribes," "separate actors") and "team-focused" (the teams see and know each other, have shared values, respect, good will, and a "systems mindset" as they work for the best interest of the patient together - essentially working as a "cross-boundary team" -- words from the literature include "blurring of disciplinary lines," "handover microsystem").

Today I'm realizing that "self-focused" and "patient focused" are not necessarily two separate states, but that "self-focused" is one lens with which teams focus on meeting patient needs, just as "team-focused" is another lens with which teams focus on meeting patient needs. Both are "patient focused" (i.e. I didn't find any evidence in the literature that there were teams that were primarily self-focused - just caring about their own needs, to the detriment of the patient. Patient focus is a given...)

It seems (though I still need to go through the rest of my literature coding to confirm, but seems to be developing) that self-focused and team-focused may be alternative ways to describe "acting independently" and "acting as one team" - both focus on meeting the patient's needs.

It may bring in a dimension that was hinted at in my data - that what differentiates teams that act in one of these ways at any given time may be more of a relational mindset - is the team seeing and valuing the other - instead of a transactional mindset - that this is just an exchange of information, a passing of the baton from one team to the other.

And perhaps, not "self-focused" and "team-focused" but.... How can I say "self-focused" meaning the specific team (inpatient or outpatient) is focused on their own needs?.... Could "within boundaries focus" and "cross boundary focus"? Brainstorm..... +
Keep thinking... Something to do with systems?

Appendix V: Photos of literature data analysis exercises

