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Benefit or Burden? Exploring Experiences of the Acute Hospital as a Place of Care Amongst People
with Palliative Care Needs

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*A thesis submitted in fulfilment of the requirements for the degree of Doctor of Philosophy in
Nursing, The University of Auckland, 2017.*

Acknowledgements

To the participants and their families who so willingly gave of their precious time to tell their stories, I thank you. It is you who bring this research to life.

Doing a PhD has been a journey of discovery. A discovery about the research process and a discovery about myself. Someone told me at the start that doing a PhD is not about intelligence, it's about learning how to never give up. I knew I would never give up but I wasn't so sure that the people around me would survive, but they did.

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Preface

Using a mixed methods design this study explores patient experiences of benefits and burdens of hospital admissions in palliative care and their influence on preferences to return to hospital. This thesis includes seven publications, of which six have been published/accepted for publication and one is currently under review.

Chapter 1 provides an introduction to the study topic with an overview of relevant key issues including place of care and place of death and hospital admissions in palliative care. In addition, an overview of the New Zealand context specific to this research is provided.

Chapter 2 provides the findings from a national policy (publication 1) review (Robinson, Gott, Gardiner, & Ingleton, 2016), which reveals how the Western model of a “good death” positions palliative care and death in hospital as a problem to be solved. The policy review is followed by an overview of the good death concept and its relevance to palliative care in the hospital setting.

Chapter 3 outlines the role of reflexivity in this research. I summarise my own world view and outline the assumptions and beliefs I bring to this research, having worked in palliative care for many years. A critical discussion exploring the art and science of specialist palliative care nursing and how this reflects my own nursing practice (Robinson, Gardiner, Gott, & Ingleton, 2017) is included (publication 2).

Chapter 4 presents a published integrative review of the literature related to patient and family experience of palliative care in an acute hospital setting (Robinson, Gott, & Ingleton, 2014) (publication 3). The review sets the scene, providing a context for the study by identifying gaps in current international evidence regarding patient and family experience. The findings from the review reveal that what is known is limited to the negative aspects of palliative care in hospital, with little attention paid to the benefits of hospitalisation from the patient’s perspective.

Chapter 5 describes mixed methods as the chosen methodology for this study and outlines the typologies associated with this approach. I identify how quality in this mixed methods study was assured and discuss critical realism, the philosophical framework of the study.

Chapter 6 introduces the study design: a sequential two-phased mixed methods design. An overview of the study setting and screening tool used to identify participants eligible for the study is

provided. In addition, the approach adopted for sampling, recruitment and data analysis is described. Finally, the chapter ends with an overview of the ethical issues related to the study and how these were addressed throughout the study process.

Chapter 7 begins with the aims and objectives of the first phase (qualitative) of this mixed methods study and includes two publications (publications 4 and 5). The first article focuses on the benefits of hospitalisation from the perspectives of patients with palliative care needs (Robinson, Gott, Gardiner and Ingleton, 2015a). Participants identified benefits that extended beyond the treatment they received including factors such as getting/feeling better, feeling safe, relief for family and receiving help to manage at home. The cultural milieu of the hospital environment was identified by participants as a significant burden of being in hospital and provides a focus for the second published article (Robinson, Gott, Gardiner and Ingleton, 2015b).

Chapter 8 provides details of the quantitative element of this mixed methods study. The chapter provides an overview of the aim and objectives of Phase 2. In addition the chapter provides an overview of the questionnaire development and details regarding reliability and validity and how data quality was achieved. Two articles were published from the quantitative findings (publications 6 and 7). The first publication focused on the circumstances surrounding hospital admissions for patient with palliative care needs (Robinson, Gott, Frey, Gardiner, & Ingleton, 2017a) and is currently under review. The second publication identified the predictors associated with perceived benefits, burdens, and “feeling safe” in relation to hospitalisation (Robinson, Gott, Frey, Gardiner, & Ingleton, 2017b). A significant predictor for a preference to return to hospital was the experiences of feeling safe in hospital.

Chapter 9 is the final chapter which integrates the findings from all elements of the study. An overview of the strengths and limitations is provided along with implications for research, policy and practice.

Abstract

Background

The concept of a “good death” has informed the philosophy of palliative care. Supporting preferences for place of care and enabling death at home surrounded by family and friends remains the pinnacle of good palliative care. Evidence suggests that home remains the preferred place of care and place of death for most people. Yet, many people will spend a significant amount of time in hospital during the last year of their life and, in many countries, a majority will die in a hospital setting. With pressure on health funding, the way in which hospitals are being used in the last year of life is being increasingly scrutinised by leaders, clinicians and policy makers. “Inappropriate” or “potentially avoidable” hospital admissions are seen as opportunities for cost savings. However, there is a paucity of evidence regarding the experiences of people with palliative care needs, which focuses on both the positive and negative aspects of being in hospital. In addition, little is known about how these experiences influence a preference to return to hospital.

Aim

To explore the benefits and burdens of hospital admissions for people with palliative care needs and examine how these experiences influence a preference to return to hospital.

Methods

A two-phase, sequential mixed methods study.

Findings

Patients experience of benefit extended beyond the treatment they received to include: getting/feeling better, relief for family, getting help to manage at home, and feeling safe. Those living in high deprivation and those with cancer experienced more benefit being in hospital. Significantly more burden related to being in hospital was experienced by Chinese and Pacific participants. Most participants expressed a preference to be in hospital rather than remain at home even if the care they had received in hospital could have been provided at home. In addition, feeling safe was a significant predictor of a preference to return to hospital. Despite most being involved with community-based services at the time of admissions, participants did not perceive services such as the general practitioner and community hospice as enablers to remain at home.

Conclusion

This study confirms that people with palliative care needs view acute hospitals as playing an important role in their care, contrary to policy assumptions. These findings have significant implications for practice and policy internationally, notably in relation to which models of care are developed and funded. In particular, the findings indicate that in many countries there is currently a risk of developing a model of care that is not in line with the preferences and experiences of people with palliative care needs and that could result in them being unable to access hospital care when needed. The findings also demonstrate that if people with palliative care needs are to be cared for at home, more research is needed to understand what they require to feel safe at home during a period of acute illness or deterioration, rather than assuming that what is required is more access to community services.

Finally, further investigation is required to gain an understanding of what feeling safe in hospital means for patients from different socio-demographic groups across multiple care settings.

Publications and Presentations.

Published Papers.

Robinson, J., Gott, M. & Ingleton, C. (2013). Patient and family experiences of palliative care in hospital: What do we know? *Palliative Medicine*, 28(1),18–33. doi: 10.1177/0269216313487568

Robinson, J., Gott, M., Gardiner, C., & Ingleton, C. (2015). A qualitative study exploring the benefits of hospital admissions from the perspectives of patients with palliative care needs. *Palliative Medicine*, 29(8),703–710. doi: 10.1177/0269216315575841

Robinson, J., Gott, M., Gardiner, C., & Ingleton, C. (2015). Impact of the hospital environment on patient experiences of palliative care. *BMJ Supportive and Palliative Care*. Epub ahead of print: 25 September. doi: 10.1136/bmjspcare-2015-000891

Robinson, J., Gott, M., Gardiner, C., & Ingleton, C. (2016). The “problematization” of palliative care in hospital: An international review of palliative care policy from five countries. *BMC Palliative Care*. Epub Ahead of Print: 25 July. doi: 10.1186/s12904-0137-0

Robinson, J., Gott, M., Gardiner, C., & Ingleton, C. (2017). Specialist palliative care nursing and the philosophy of palliative care: A critical discussion. *International Journal of Palliative Care Nursing*, 23(7): 352–358. doi: 10.12968/ijpn.2017.23.7.352.

Robinson, J., Gott, M., Gardiner, C., Frey, R., & Ingleton, C. (2017). Predictors of patient related benefit, burden and feeling safe in relation to hospital admissions in palliative care: A cross sectional survey. *Palliative Medicine*. Epub Ahead of Print. doi: 10.1177/0269216317731991.

Robinson, J., Gott, M., Frey, R., & Ingleton, C. (2017). Circumstances of hospital admissions in palliative care: A cross sectional survey of patients admitted to hospital with palliative care needs. *Palliative Medicine (Under Review)*.

Conference Presentations.

Robinson, J. (2013, May). *Patient and family experiences of palliative care in a hospital setting: An integrative review*. Poster presented at the 13th World Congress of the European Association of

Palliative Care, Prague, Czech Republic. (Chosen by the scientific committee for the quick-fire round of verbal presentations).

Robinson, J. (2013, September). *Patient and family experiences of palliative care in a hospital setting: An integrative review*. Verbal presentation at the 12th Australian Palliative Care Conference, Canberra, Australia.

Robinson, J. (2015, September). *A qualitative study exploring the benefits of hospital admissions from the perspectives of patients with palliative care needs*. Poster presented at the 13th Australian Palliative Care Conference, Melbourne, Australia.

Robinson, J. (2014, May). *A qualitative study exploring the benefits of hospital admissions from the perspectives of patients with palliative care needs*. Poster presented at the 8th World Research Congress of the European Association for Palliative Care, Barcelona, Spain.

Robinson, J. (2015, November). *The “problematization” of palliative care in the hospital setting: A policy review from five countries*. Keynote speaker at the 4th Palliative Care Nurses NZ Conference, Wellington, New Zealand.

Robinson, J. (2017, May). *The benefits and burdens of hospital admissions and their influence on preferences for place of care during a period of acute illness for patients with palliative care needs: A cross sectional survey study*. A poster presentation at the 15th World Congress of the European Association of Palliative Care, Madrid, Spain.

Other.

(2015, September). *A qualitative study exploring the benefits of hospital admissions from the perspectives of patients with palliative care needs*. European Association of Palliative Care, Editor’s choice of Palliative Medicine.

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List of Abbreviations

ADHB – Auckland District Health Board

ACH – Auckland City Hospital

GP – General Practitioner

GPT – general practice teams

GSF-PIG – Gold Standards Framework Prognostic Indicator Guide

HPCT – hospital palliative care team

NP – Nurse Practitioner

JR – Jackie Robinson

MG – Merryn Gott

CG – Claire Gadinier

CI – Christine Ingleton

Glossary of Terms

Palliative care – care for people of all ages with a life limiting or life-threatening condition which aims to optimise an individual’s quality of life until death by addressing the person’s physical, psychosocial, spiritual and cultural needs while supporting the individual’s family, whānau, and other caregivers where needed, through the illness and after death.

Generalist palliative care/primary palliative care – is provided by all individuals and organisations who deliver palliative care as a component of their service, and who are not part of a specialist palliative care team.

Specialist palliative care – a team or organisation whose core work focuses on delivering palliative care, for example a hospice or hospital palliative care team.

Family carers – those closest to the person who provide care during a period of illness. They may include biological family, family of acquisition, family of choice and friends.

Hospice – is a philosophy of care, not only a building. The goal of hospice care is to help people with life limiting and life-threatening conditions make the most of their lives by providing high quality palliative care.

Life limiting illness – a condition for which there is no reasonable hope of cure and from which the person is expected to die.

Māori – the indigenous people of New Zealand.

Whānau – a Māori term for extended family/family group. In the modern New Zealand context the term is sometimes used to include friends who may not have any kinship ties to other members.

Structure of Thesis

The manuscripts included in each chapter are presented exactly as published and follow the University of Auckland's 2011 PhD Statute and the *Guidelines for Including Publications in a Thesis* (2014). In view of the word limitations associated with publications, further discussion is included where relevant in order to provide more breadth and depth of information relevant to the thesis as a whole. All pages, tables and figures have been numbered consecutively throughout the thesis for continuity. References have been collated and included at the end of the thesis.

Appendices provide supporting documents that may or may not have been included in the final publications but add clarity to the study thesis. These include documents such as ethical approvals, participant information and consent forms, examples of data collection forms, and screening tools.

Co-Authorship Form

This form is to accompany the submission of any PhD that contains research reported in published or unpublished co-authored work. **Please include one copy of this form for each co-authored work.** Completed forms should be included in all copies of your thesis submitted for examination and library deposit (including digital deposit), following your thesis Acknowledgements.

Please indicate the chapter/section/pages of this thesis that are extracted from a co-authored work and give the title and publication details or details of submission of the co-authored work.

Chapter 2, section 2.1: The "problematization" of palliative care in hospital: an exploratory review of international policy in five countries

Nature of contribution by PhD candidate: Responsible for article concept; manuscript preparation and submission; managing the review of the manuscript and response to reviewers comments

Extent of contribution by PhD candidate (%): 85

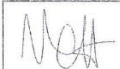

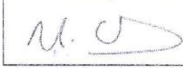
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Name	Nature of Contribution
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Christine Ingleton	Provided advice regarding content and manuscript preparation

Certification by Co-Authors

The undersigned hereby certify that:

- ❖ the above statement correctly reflects the nature and extent of the PhD candidate's contribution to this work, and the nature of the contribution of each of the co-authors; and
- ❖ in cases where the PhD candidate was the lead author of the work that the candidate wrote the text.

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Chapter 1: Introduction.

This chapter introduces the philosophy of palliative care and discusses place of death and preferences for place of care at the end of life to provide context for the study topic. Furthermore, the chapter provides an overview of how hospitals are used in palliative care and the way in which palliative care has evolved in New Zealand.

Palliative care has been defined by the World Health Organisation as an approach to care that “improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual” (WHO 2015). The principles that underpin this definition are outlined in Table 1-1.

Table 1-1 Definition of Palliative Care (WHO, 2015)

- Relief from pain and other distressing symptoms.
- Affirms life and regards dying as a normal process.
- Intends neither to hasten or postpone death.
- Integrates the psychological and spiritual aspects of patient care.
- Offers a support system to help patients live as actively as possible until death.
- Offers a support system to help the family cope during the patient’s illness and in their own bereavement.
- Uses a team approach to address the needs of patients and their families, including bereavement counselling.
- Will enhance quality of life, and may also positively influence the course of illness.
- Applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life.

Historically palliative care has been provided by hospice services. Indeed, the nineteenth century hospice founders were a key source of inspiration for Cicely Saunders whose work leading the development of the modern hospice movement set the foundation for the hospice and palliative care services we know today. It was during the 1950s that the “modern death”, usually from cancer and in hospital, was described as the “outcome of heroic and scientific struggles against the forces of illness and disease” (Clark, 1998, p. 45). In response, Saunders recognised a need to develop a unique philosophy of care for patients dying with advanced cancer (Clark, 2008a). In 1967, St Christopher’s Hospice, the first modern hospice, was opened in London, England. Deliberately set up outside the hospital setting, the early modern hospices focused primarily on supporting patients through the “terminal phase” of a cancer diagnosis. Hospices later developed to include community-

based services providing palliative care across different care settings, including for those with a non-malignant illness. There are now hospices in over 115 countries around the world (Clark, 2008a). Over the past 20 years, there has also been an international growth in consult-based services providing specialist palliative care support for those with palliative care needs in acute hospital settings (Clark, 2008a).

Along with these changes in service delivery there has also been a significant practice change, with palliative care now being recognised as a medical specialty in many countries (Clark, 2008a). In most high income countries, this change has resulted in a model of care that now acknowledges palliative care as being integral to all health professionals' practice with support from specialist palliative care services as needed (Department of Health, 2008, 2010; Ministry of Health, 2012). However, in many less developed countries the development of services is still insufficient to meet the palliative care needs of the population (Centeno et al., 2016).

In 2002, the definition of palliative care was extended by the World Health Organisation to include people with any life limiting illness, not just those with cancer, and it is also now considered to be applicable from early in the course of the illness trajectory (Llamas, Pickhaver, & Piller, 2001). However, this mainstreaming and upstreaming of palliative care continues to be informed by the early principles of palliative care, including those which underpin the "good death" (Clark, 2002).

Indeed, it has been long recognised that this concept of a good death is embedded within the practice philosophy of palliative care (Cottrell & Duggleby, 2016). Elements of a good death in modern Western culture have been defined as: "a pain free death; open acknowledgement of the imminence of death; death at home surrounded by family and friends; an aware death, in which personal conflicts and unfinished business are resolved; death as personal growth; and death according to personal preference and in a manner that resonates with the person's individuality" (Clark, 2002, p. 907). One aspect of supporting personal preference, which is prioritised in palliative care practice and policy, relates to the place where palliative care is delivered and death occurs (Clark, 2002). It is widely argued that home remains the preferred place of care and place of death for most people (Bell, Somogyi-Zalud, & Masaki, 2009) yet in high income countries most people will spend a significant amount of time in hospital during the last year of their life and the majority will die in an institutional setting – either an acute hospital or a residential aged care facility (Broad et al., 2013). With globally constrained health budgets and mounting healthcare costs, the way in which hospitals are being used in the last year of life is being increasingly scrutinised by policy makers, clinicians,

and academic researchers. In particular, “inappropriate” or “potentially avoidable” hospital admissions are being seen as providing opportunities for cost savings (Gardiner, Ward, Gott, & Ingleton, 2014; Robinson, Boyd, O’Callaghan, Laking et al., 2014). It is therefore unsurprising that there is increasing international interest in the role of the acute hospital for people with palliative care needs.

1.2 Preference for place of care and place of death.

Studies surveying patients, carers and the lay public consistently report that home is the preferred place of death (Gomes et al., 2011). What is also clear is that preferences for place of death do not remain static during the illness trajectory. Studies have shown that preferences for place of care and place of death decline as the illness progresses and patients increasingly choose inpatient care as they become less well (Thomas, Morris, & Clark, 2004). Furthermore, it is important to recognise that quantitative survey data conceals nuances in beliefs about preferred place of death, particularly for certain groups of people. For example, a study by Gott et al. (2008) found that whilst dying at home was considered to be ideal, older people indicated a preference to die in an inpatient setting such as a hospice, hospital or residential aged care facility. Factors such as being a burden on family, reluctance for adult children to provide personal care, and fear of dying alone informed this preference.

With an increasing emphasis on supporting patient choice in healthcare (Borgstrom, 2015), eliciting patient preferences for place of care and place of death, and achieving congruence between these, has become seen as an essential component of good palliative care (Ahearn, Nidh, Kallat, Adenwala, & Varman, 2013; Broad et al., 2013; De Roo et al., 2014). However, there is evidence to suggest that the preferred place of death is not often achieved, but that this is not necessarily viewed negatively (Tang & McCorkle, 2003). For example, a Canadian study found that 92% of family caregivers surveyed felt that where their family member died was the appropriate place, even though most had not died in their preferred place (Brazil, Howell, Bedard, Krueger, & Heidebrecht, 2005). Furthermore, the recent UK Views of Informal Carers Evaluation Study identified that over 70% of bereaved relatives whose family member had died in hospital felt that this was the most appropriate place of death, despite only 3% of respondents stating that hospital was the preferred place of death (*National survey of bereaved people (VOICES): England, 2015, 2016*).

1.3 Hospital admissions in palliative care.

As the management of life limiting illnesses such as cancer and chronic non-malignant disease has changed, so too has the way in which hospitals are used in palliative care. Hospitals are where treatment complications are managed and where illness exacerbations are treated. It is during these periods of acute illness that death may occur. Unsurprisingly therefore, death in hospital continues to be common-place in developed countries (Broad et al., 2013).

Most people with a life limiting illness will spend some time in hospital during the last year of their life (Pivodic et al., 2015). Furthermore, research has identified that between 20–36% of hospital inpatients are likely to have palliative care needs (Clark et al., 2014; Gardiner et al., 2012; Gott et al., 2012; To, Greene, Agar, & Currow, 2011). As noted above, policy makers and leaders in palliative care have become increasingly interested in the way in which hospitals are used by those with palliative care needs. Hospital care makes up the largest expense associated with end of life care in developed countries (Dumont et al., 2009). Service developments to increase the proportion of people who die at home (Gomes, Calanzani, & Higginson, 2011) are supported by arguments regarding the potential cost saving of reducing hospital admissions at the end of life (Gott et al., 2013). Furthermore, some commentators have suggested that during hospital admissions, resources are wasted with investigations, tests and treatments being offered to patients at the end of life with little benefit (Langton et al., 2014). Indeed, the focus of hospital care is on saving and prolonging life, which some may argue to be incompatible with the philosophy of palliative care.

1.4 The New Zealand context.

The development of palliative care in New Zealand has been largely influenced by the modern hospice movement and the development of palliative care in the United Kingdom (McCabe, 2004). In 1979, Mary Potter Hospice in Wellington was the first hospice to open in New Zealand. There are now 31 hospice services and 14 hospital palliative care services nationally, including one specialist paediatric palliative care service (Ministry of Health, 2013).

In terms of place of death, in New Zealand the largest proportion of people die in the hospital setting (34.2%) with 30.7% dying in residential care and 22.3% dying at home. Those with cancer are more likely to die at home while women and those in older age are more likely to die in a residential care facility (McLeod, 2016a).

Similar to other high-income countries, New Zealand is experiencing population changes that are predicted to dramatically impact how palliative and end of life care is provided. For example, deaths in New Zealand are predicted to rise from around 30,000 a year to 45,000 a year by 2038 and 55,500 a year by 2068 (Mcleod, 2016b). Comorbid deaths will also be increasingly more common, due to advances in the management of chronic disease (Ministry of Health, 2016).

Whilst the New Zealand definition of palliative care is inclusive of the principles outlined by the 2002 World Health Organisation (WHO, 2015), the NZ definition developed in 2007 (Ministry of Health, 2007) also takes into account the unique needs of Māori (the indigenous people of New Zealand), the cultural diversity of the population, and the guiding document regarding health consumer rights in New Zealand by acknowledging:

1. The fundamental place of the Treaty of Waitangi and the principles of Partnership, Participation and Protection and the importance of the He Korowai Oranga (the Māori Health Strategy, 2002). Furthermore, acknowledgement of a holistic Māori philosophy/model, such as Te Whare Tapa Wha (four-sided house) towards health/well-being is appropriate when applied to palliative care: Te Taha Tinana (physical health), Te Taha Hinengaro (psychological health), Te Taha Wairua (spiritual health) and Te Taha Whānau (family health).
2. Palliative care recognises and respects the rights of patients as detailed in the New Zealand Code of Health and Disability Services Consumers' Rights (*Code of Health and Disability Services Consumers' Rights Regulations 1996*, 2014).
3. Palliative care services will acknowledge the diverse cultural beliefs, values and practices of patients and their families or whānau in contemporary New Zealand.

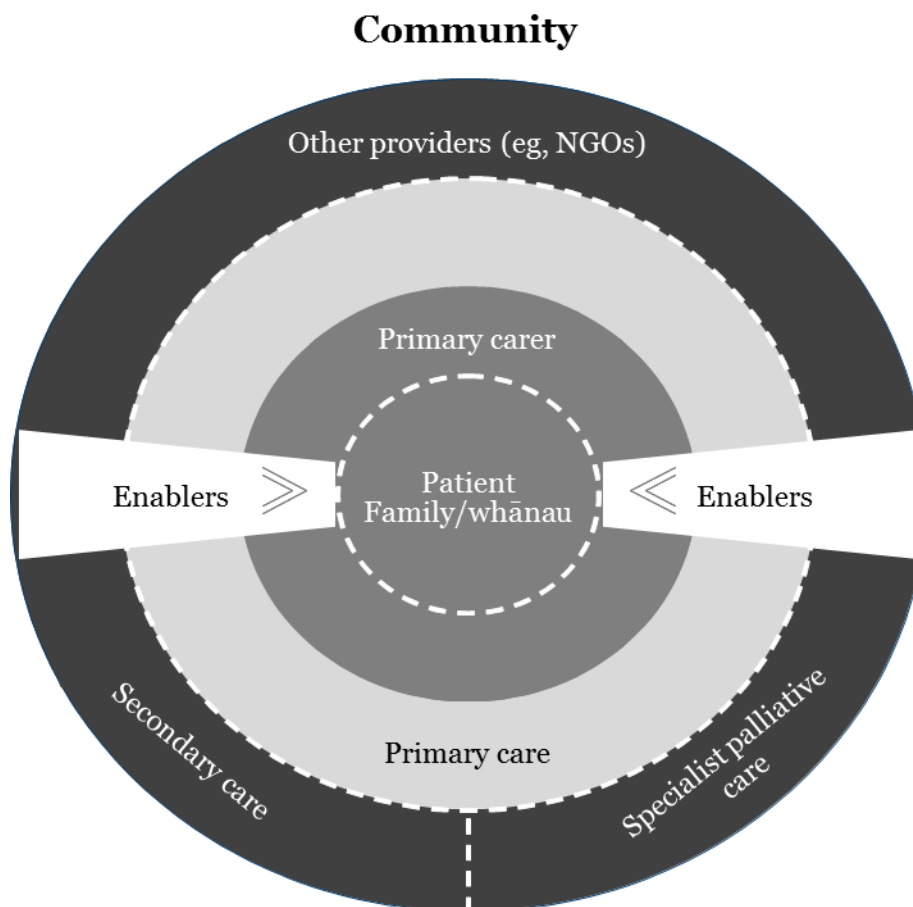
The New Zealand definition (Ministry of Health, 2007) of palliative care acknowledges that “primary palliative care” should meet the palliative care needs of the majority of people with a life limiting illness. “Primary palliative care” is provided by all individuals and organisations who deliver palliative care as a component of their service, and who are not part of a specialist palliative care team (Ministry of Health, 2015). A primary palliative care provider has an ongoing role in the care of people with a life limiting illness in the community and includes general practice teams, Māori health providers, allied health teams, district nurses and residential care staff. Primary palliative care is provided in the hospital by general ward staff, as well as disease specific teams (Ministry of Health, 2015).

Specialist providers, comprising hospice teams and hospital-based consult services, provide direct patient care for those with the most complex needs, whilst at the same time providing education and consultation with primary palliative care providers. Involvement of specialist teams is understood to be either episodic or continuous, depending on the needs of the patient and family and the capacity and capability of the “primary provider” (Ministry of Health, 2015).

Hospices in New Zealand are non-government organisations contracted by local District Health Boards (DHB) to provide palliative care for a particular geographical population. Most hospices provide a combination of inpatient and community-based care using an interdisciplinary model of care that includes nursing, medicine and allied health services. The proportion of government contributions towards the running costs of hospices in New Zealand is fixed at around 70% (Groeneveld et al., 2017). Hospital palliative care consult services are funded through general hospital funding. A small number of provincial hospitals contract hospice services to provide a consult service for their hospital inpatients.

In response to concerns regarding a lack of understanding about what constitutes both “specialist” and “primary” (or “generalist”) palliative care, the NZ Ministry of Health commissioned a document in 2013 that would inform strategic planning and purchasing of “accessible and equitable palliative care services” in the nation (Ministry of Health, 2012). This document outlined a model of care that placed the patient, family and whānau at the centre, with the primary provider represented in the first level of care (see Figure 1-1). Enablers to achieving an integrated model were identified, including a shared clinical record, clinical pathways, a purchasing framework and education for primary care providers. Second level care is provided by specialist palliative care including hospital-based consult services and hospices. The principles that underpin the Framework reflected the principles outlined in the WHO and NZ definitions of palliative care. In terms of implementation, the Framework recommended a regional approach to care planning, development of nationally agreed referral criteria to specialist palliative care and 24 hour access to primary and specialist palliative care.

Figure 1-1 Framework for adult integrated palliative care services (Ministry of Health, 2012)



However, despite the development of the Framework, there has been slow progress towards a truly integrated model of palliative care that encompasses the whole care continuum. In 2016, a review of adult palliative care services was undertaken by the NZ Ministry of Health to identify current and projected need for palliative care services and identify gaps and barriers to achieving high quality, equitable palliative care for all New Zealanders. The review culminated in a 3–5 year action plan, which provides District Health Boards guidance and strategic direction on service innovation across the primary and specialist palliative care continuum (Ministry of Health, 2017).

Given that my study is situated in New Zealand, it has been appropriate to provide this overview of palliative care in this country. However, it is also important to highlight that the New Zealand situation is similar to that of most other resource rich countries and our difficulties associated with a

full integration of palliative care across the health care continuum are not unique. Therefore, this study and its findings have relevance to other high income countries around the world.

1.4 Chapter summary.

This chapter provides a background for the research reported in this thesis by presenting an overview of the evolving model of palliative care from a predominantly “terminal care” model in a hospice setting, to a more contemporary model integrating palliative care within mainstream health care. In addition, the chapter has also presented an overview of the New Zealand context as it relates to palliative care.

The following chapter presents a review of international policy that was undertaken to explore how the role of the acute hospital is perceived by policy makers and leaders in palliative care. The problematisation of hospitals as a place of care for those with a life limiting illness within policy is highlighted.

Overall Study Aims and Objectives

The overall aim of this study was to explore the benefits and burdens of hospital admission for people with palliative care needs and explore how these influence preferences to return to hospital.

Using a two phase, mixed methods approach the objectives of this study were:

1. To understand how the acute hospital is positioned in health policy in the provision of palliative and end of life care.
2. To explore what is currently known about patient and family experiences of palliative care in the hospital setting.
3. To explore the benefits and burdens of hospital admissions from the perspectives of patients with palliative care needs.
4. To identify the factors associated with experiences of benefits and burdens of hospital admission for people with palliative care needs and how these influence preferences to return to hospital.

These objectives were achieved by undertaking:

- Objective 1: An international policy review. (Published in *BMC Palliative Care*).
- Objective 2: A systematic integrative review of the literature. (Published in *Palliative Medicine*).
- Objective 3: A qualitative study. (Two publications: one published in *Palliative Medicine* and the other in *BMJ Supportive and Palliative Care*).
- Objective 4: A quantitative study. (Two publications: one published in *Palliative Medicine* and the other under review in *Palliative Medicine*).

Chapter 2: The Acute Hospital in Palliative Care Policy.

National policy is influential in the development of services to improve the provision of palliative care in developed countries. How, when and where palliative care is provided is an essential component in the development of these policies. Yet the role of the acute hospital as a provider of palliative and end of life care is not well understood. The review that follows explores the role of hospitals within palliative care as described in government policy across five countries and discusses how this may impact on the role of hospitals as providers of palliative and end of life care.

The policy review addresses the first objective of this study: to understand how the acute hospital is positioned in health policy in the provision of palliative and end of life care.

Robinson, J., Gott, M., Gardiner, C., & Ingleton, C. (2016). The problematisation of palliative care in hospital: An exploratory review of international policy in five countries. *BMC Palliative Care*, 15(64). doi: 10.1186/s12904-016-0137-0.

Available from <https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-016-0137-0>

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2.1 Article: The “Problematisation” of Palliative Care in Hospital: An Exploratory Review of International Policy in Five Countries.

2.1.2 Background.

A recommendation from the World Health Organisation to recognise palliative care as a basic human right by adopting a public health approach to service development (Stjernsward, Foley, & Ferris, 2007) has seen many developed countries move towards developing national policy in palliative and end of life care (*Global Atlas of Palliative Care at the End of Life*, 2014). Furthermore, in response to the demands of an ageing population and the impact of people living longer with chronic disease, governments have focused on developing health care policy that seeks to identify ways to meet the predicted increase in demand for palliative and end of life care services (May et al., 2014). At the same time, practices in health and social care with older people and those

with complex needs are increasingly under the spotlight (Hall, Petkova, Tsouros, Costantini, & Higginson, 2010). However, the development of palliative care policy has occurred within the context of a global recession, which has seen increasing pressure to reduce public health spending while seeking ways to increase service capacity to meet future demand.

Whilst palliative care has developed into an established specialty area of clinical practice (Quill & Abernethy, 2013) it is more than just a technical skill; rather, it is predicated upon a specific philosophical approach to care. The ideology of a good death (McNamara, 2004) and the World Health Organisation's definition of palliative care is said to encapsulate a philosophy of palliative care (Randall & Downie, 2010) that is in line with that which has informed the development of the modern hospice movement. This philosophy continues to inform and guide palliative care policy and practice. According to Clark (2002) the philosophy of a good death incorporates the following elements: pain free death, open acknowledgement of the imminence of death, an "aware" death in which personal conflicts are resolved, death as personal growth, death according to personal preference and death at home, surrounded by family and friends. Drawing on this framework, achieving a natural death free from medical technology at home became a major focus during the early period of the modern hospice movement (Clark, 2008a). Some have suggested that this way of conceptualising a good death, particularly outside the acute hospital, set palliative care and hospice up in opposition to mainstream healthcare (McNamara, 2004).

However, the way in which hospitals are used in palliative care has changed dramatically since the start of the modern hospice movement. Early definitions of palliative care were limited to those with terminal cancer when life prolonging treatments had been exhausted (Pastrana, Junger, Ostgathe, Elsner, & Radbruch, 2008). However, it became apparent that those dying from non-cancer illnesses, such as heart failure and chronic obstructive respiratory disease, received little or no palliative care and died with significant unmet need (Barnes et al., 2006; Gardiner et al., 2009). In 2002 the World Health Organisation (WHO, 2015) provided the impetus to move palliative care further upstream in the illness trajectory, thereby seeking integration with curative and rehabilitation therapies and shifting the focus beyond the final stages of life. In addition, the diagnostic remit of palliative care expanded to include patients with a non-cancer diagnosis for whom prognosis might be many months or even years away and this has seen a change in the way palliative care is provided (Quill & Abernethy, 2013). For example, life limiting illnesses such as chronic obstructive respiratory disease and heart failure are characterised by exacerbations of illness requiring hospitalisation during which death may occur (Murray, Kendall, Boyd, & Sheikh, 2005). Moreover,

an increase in the use of hospital-based technology in palliative care, much of which can only be offered in an acute hospital setting, is also impacting on the way in which hospitals are being used.

It has been suggested that government policy is a fundamental component of initiating change to improve the provision of palliative and end of life care (*Global Atlas of Palliative Care*, 2014). With an increasing emphasis on the development of national policy it is therefore timely to explore how hospitals are positioned as settings for palliative care. Therefore, the aim of this exploratory study is to identify how the role of the hospital is envisaged within national policy on palliative and end of life care.

Data sources.

In 2014 the World Palliative Care Alliance and the World Health Organisation developed a Global Atlas of Palliative Care (*Global Atlas of Palliative Care*, 2014), which quantified the need for and availability of palliative care worldwide. At the time of the report, 20 countries had attained the “advanced integration” level of palliative care development indicating that palliative care was well integrated within mainstream health care providers and had substantial impact upon policy. It was from this group of countries that the policies included in this review were identified. Policy was defined as any government-led document written with the aim to identify gaps and inequities in service delivery and provide recommendations for service development in order to improve palliative and end of life care.

Table 2-1

Countries with Advanced Integration (Adapted from GAPC, 2014)

Advanced integration (n=20)	Australia, Austria, Belgium, Canada, France, Germany, Hong Kong, Iceland, Ireland, Italy, Japan, Norway, Poland, Romania, Singapore, Sweden, Switzerland, Uganda, United Kingdom, United States of America.
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Those in bold are countries with government policy in palliative and end of life care

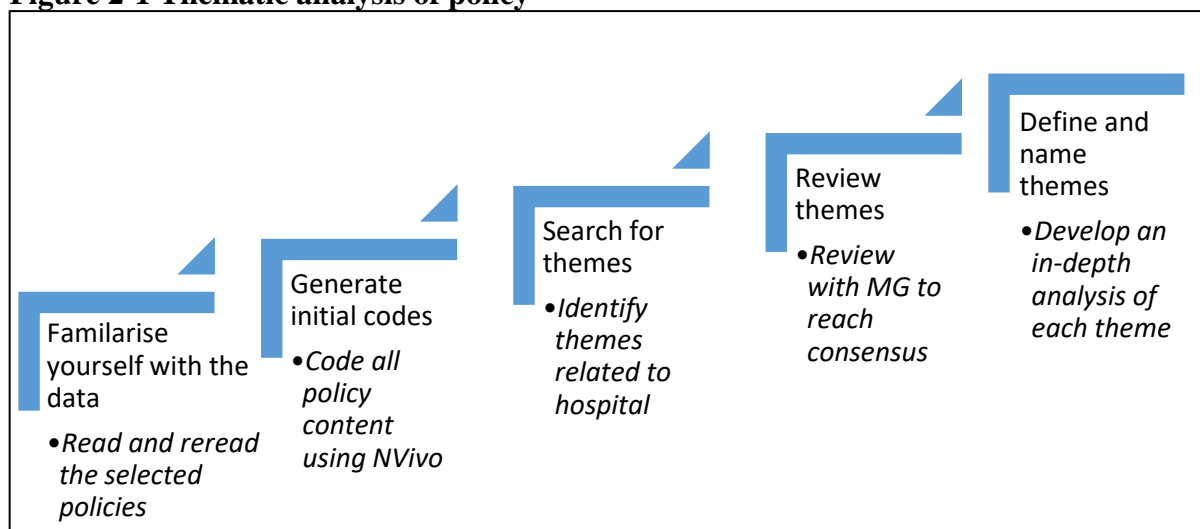
Policies were accessed through internet searching of government websites between October–December 2014. Whilst some countries such as Germany and Belgium had palliative care regulations or legislations in place, in order to be included in the review countries had to have a government-led national palliative care strategy or policy (see Table 2-1). Due to the cost of translation, those documents not available in English were excluded from the review. Therefore, Sweden, Norway, France and Austria were excluded. Although referred to as a “strategy” the Canadian (Health Canada, 2007) document was largely a report on the progress of community-based

workgroups implementing recommendations from a government report. For this reason, it was subsequently excluded from the final analysis. The United States was not included in the review as they do not have a federal-based policy in palliative care. Therefore policy documents from the United Kingdom, Australia, Switzerland, Ireland and Singapore were included in the review.

2.1.3 Methods.

An approach to thematic analysis as described by Braun and Clark (2006) was used to explore policy content. This involved firstly familiarisation with the data through a process of reading and re-reading the policy documents; secondly, a process of coding across the entire data set was completed using the software program *NVivo*. A general inductive approach was used to identify themes from those codes that were related to care and death in hospital. There was no predetermined coding frame; instead, this was developed as the data was coded. All coding was done by JR. The final steps in the analysis process involved the development of key themes, which was achieved through a cyclical process of review and re-review of the relevant codes with consensus reached during regular meetings with MG. Finally, an in-depth analysis of each key theme was undertaken (see Figure 2-1).

Figure 2-1 Thematic analysis of policy



2.1.4 Findings.

Policies included in the review were published over a 10-year period with the earliest released in 2001 (Department of Health and Children, 2001; Ministry of Health, 2001) and the most recent in 2011 (Lien Centre for Palliative Care, 2011). All policies adopted the WHO definition (WHO, 2015) as a framework to guide discussion. Furthermore, all used evidence from research to support the

need to improve palliative care across multiple care settings, including the hospital. Policies acknowledged a need for palliative care to be integrated into mainstream health care. There was minimal evidence of consumer consultation in the development of policies with all countries appointing a combination of government employed policy analysts/makers, expert clinicians and leaders in palliative care to develop policy. A summary of the key points made in each policy document can be found in Appendix 1.1.

Through a process of thematic analysis as outlined by Braun and Clark (2006) three key themes relating to palliative care and death in hospital were identified:

- Preferences for place of care and place of death outside the hospital setting.
- Unnecessary or avoidable hospital admissions.
- Quality of care in hospital.

Preferences for place of care and place of death outside the hospital setting.

Most policies focused on achieving patient preference for end of life care, particularly in relation to setting of care. All made reference to the large numbers of people dying in public hospitals, and also cited research evidence that concludes that home is the preferred place of death for most people. The English policy referred to surveys of the general public and those with a life limiting illness to argue that “. . . given the opportunity and right support, most people would prefer to die at home” (Department of Health, 2008, p. 7). They go on to say that only a small number of patients manage to die at home and most will die in an acute hospital, which is not their preferred place of death.

Two policies (Department of Health and Children, 2001; Department of Health, 2008) referred to the fluctuation of patient preferences over the course of the illness with a tendency for patient preference to move to an inpatient setting as the illness progressed. However, these policies noted that the evidence indicated a preference for hospice rather than hospital or aged residential care. This conclusion was derived from studies (Salisbury et al., 2009; Wilkinson et al., 1999) demonstrating that patient and family satisfaction is greater in hospice compared to the hospital setting; the Irish policy stated that “Hospice inpatients reported lower levels of pain compared to their hospital counterparts in some studies. Surveys found comparatively higher levels of satisfaction with inpatient hospice care, compared to conventional, non-specialised forms of care” (Department of Health and Children, p. 53). Two policies (Department of Health and Children, 2001; Department of Health, 2008) acknowledged the evidence that some groups, such as older people, may prefer to die in an inpatient setting to avoid being on their own or becoming a burden to family.

Unnecessary hospital admissions.

A focus on cost savings was evident throughout the reviewed policies and death in hospital was considered to be a significant cost burden to some health care systems. The Australian policy (Department of Health, 2010) stated “Twenty percent of people die in hospices and 10% in nursing homes. The rest die in hospitals. This results in a high cost burden for the health system and potentially a poorer quality of death” (Department of Health, 2010, p. 1).

Identifying and avoiding unnecessary hospital admissions was a focus for four countries to varying degrees (Department of Health, 2008, 2010; Federal Office of Public Health, 2009; Lien Centre for Palliative Care, 2011). Reducing hospital admissions was seen as an opportunity to save hospital-based spending and divert these savings to community-based services in order to support patient choice with their preferred place of care which, based on the preferences for place of care and place of death studies, was presumed to be outside the hospital setting and preferably at home.

Assumptions about cost savings were not evidence-based nor did they consider family carer costs. The Swiss policy referred to the range of palliative care services as a “support network” that would ensure that the preferred place of care and place of death is achieved whilst unnecessary hospital admissions avoided (Federal Office of Public Health, 2009, p. 5).

Policies identified a number of factors contributing to “unnecessary” hospital admissions at the end of life, including a failure of community services to meet patient needs and difficulties in identifying those who would benefit from palliative care services. Timeliness of referral to palliative care services was seen as key to achieving a reduction in unnecessary hospital admissions, with the Singapore policy stating that “Patients who are identified late in the course of the illness usually have poorer outcomes of care and unnecessary hospital admissions” (Lien Centre for Palliative Care, 2011, p. 32).

Cost savings associated with a reduction in hospital admission was considered an opportunity to increase funding for community sources (Department of Health, 2008, 2010). The English policy (Department of Health, 2008) suggests that the cost savings achieved through reducing hospital admissions could be used to improve the community-based provision of palliative care stating that “It is likely, for example, that at least part of the additional costs of providing improved care in the community and in care homes will be offset by reductions in hospital admissions and length of stay” (Department of Health, 2008, p. 16). However, costs incurred by family caregivers were not

considered.

Quality of care in hospital.

Research findings outlining poor quality palliative care provided in hospital settings were drawn upon throughout the reviewed policies (Higginson, Wade, & McCarthy, 1990; Seale & Kelly, 1997). Four (Department of Health and Children, 2001; Department of Health, 2008, 2010; Ministry of Health, 2001) policies made mention of strategies to improve palliative care in the hospital setting, most of which were centred around implementation of hospital-based specialist palliative care teams. Other strategies, such as programs to support patient preferences, choice at the end of life, or facilitating discharge, emphasised a need to avoid or reduce hospital admissions. All policies acknowledged the role of hospital-based palliative care teams and their influence in improving care in this setting and reducing length of stay. Furthermore, the role that hospital-based palliative care teams have in supporting clinicians to provide quality palliative and end of life care was highlighted in all policies. However, involvement of specialist palliative care teams were also seen as an opportunity for cost savings. For example, the Irish policy (Department of Health and Children, 2001) cited studies that suggest specialist hospital palliative care teams have an impact on reducing hospital inpatient bed days, increase patient time spent at home, and have equal or lower costs. Furthermore, they argue that hospices (in comparison) use fewer interventional therapies and diagnostic tests whilst suggesting a further opportunity for cost savings through avoidance of hospital care.

Some policies acknowledged that the quality of palliative care across all care settings needed to improve, with the English policy stating that “High quality care should be available wherever the person may be: at home, in a care home, in hospital, in a hospice or elsewhere” (Department of Health, England, p. 10). The hospital setting in particular was criticised as being inadequate in providing palliative care. The Irish policy cited a number of studies that demonstrated significant issues with hospital based-care stating that “the care provided by hospitals was more subject to criticism than any other type of care. It found a wide range of problems with inpatient hospital care. These included an uncaring attitude, poor symptom control, and difficulty in extracting information from doctors. Poor communication was reported as the most prominent criticism. . . .” (Department of Health and Children, 2001, p. 53).

2.1.5 Discussion.

Some authors suggest that government policy is developed in response to a “social problem” that needs fixing (Bacchi, 2012; Webb, 2014). Indeed, the way in which policy is typically written implies that something needs to change, yet the problem being addressed is often not made explicit (Robinson et al., 2016). It has been argued that identifying and interrogating the problem underpinning policy development is important because it helps to increase our understanding of the assumptions that inform governing practices (Robinson et al., 2016). The themes identified in this review suggest a “problematisation” of palliative care and death in the hospital setting. This is perhaps unsurprising as it is in line with the idea of a “good death”, which forms the philosophical underpinnings of palliative care and advocates for a “natural death” at home surrounded by friends and family. Emulating the ideology of a good death as currently defined may be difficult to achieve in a hospital setting.

Supporting patient preferences for place of care and place of death outside the hospital setting is a major focus across all the reviewed policies. However, the belief that place of care and place of death is an over-riding priority for patients at the end of life has been challenged. For example, a UK-based study exploring the relative importance of place of death to patients with advanced cancer to achieving what they considered to be a good death found that for some patients a home death is either unimportant or should be avoided (Waghorn, Young, & Davies, 2011). The authors found that factors such as “control of pain” and “not being a burden to family” ranked higher than being able to “die at home” for many participants. Preference for place of care and place of death has also been shown to vary with age, gender and ethnicity and is influenced by previous experience and concerns about being a burden (Cox et al., 2001).

Prioritising patient choice assumes a preference for individualised autonomous decision making; however, this approach does not fit with all cultures. End of life decision making requires a level of complexity in relation to choice, which can be difficult for some people when they are facing an uncertain and limited future (Borgstrom, 2015). Moreover, whilst the individualised approach to decision making dominates the Western model of healthcare, some non-Western cultures have been shown to demonstrate a preference for a more collective decision making approach, acknowledging that decisions made by one individual will have implications for their wider family or community (McLaughlin & Braun, 1998). In addition, in order to elicit people’s preferences for place of care and place of death there needs to be a willingness to talk openly about death and dying so that preparation can be made to fulfil their wishes at the end of life. Open acknowledgement of the

imminence of death is considered to be one of the elements of a good death (Clark, 2002). Yet for many cultures, openly talking about death may be considered detrimental to patient care, which has implications for conversations regarding diagnosis and prognosis (Seale & van der Geest, 2004).

There is an implicit assumption throughout the reviewed policies that preferences regarding place of care and place of death remain stable throughout the illness trajectory. However, there is clear evidence indicating that preferences may change as a person's circumstances evolve. Indeed, the closer to death people come, the less likely they will be to choose death at home and in fact many will choose a hospital setting (Gerrard et al., 2011; Robinson et al., 2015a). Moreover, while "home" is commonly understood to be a fixed geographical location, research has shown that home is in fact a malleable concept (Collier, Phillips, & Iedema, 2015b; Gott, Small, Barnes, Payne and Seamark, 2008). Indeed, studies have shown that as care needs increase the home environment changes in a way that it may no longer feel like the home patients remember. For example, an increasing need for medical equipment such as hospital beds and oxygen concentrators, along with health professionals visiting frequently, changes the nature of the home environment for some people (Gott, Seymour, Ingleton, & Bellamy, 2004).

Moreover, whilst people rarely choose the hospital as their preferred place of care at the end of life (Gomes et al., 2011), the hospital may become an attractive refuge during periods of acute illness. For example, patients with palliative care needs admitted to hospital during a period of acute illness have described feeling safe and cared for while being monitored and observed by health professionals with knowledge and expertise about their illness (Robinson et al., 2015a). This suggests that when care needs are changing home may feel less safe than inpatient settings.

A focus on identifying and avoiding unnecessary hospital admissions, particularly in the more recently published policies, suggests that hospitalisation for those with palliative care needs is regarded as a problem (Department of Health, 2008, 2010). Whilst it might seem logical to consider a hospital admission in the context of an incurable illness to be unnecessary, particularly when the hospital is seen as an environment where life prolonging interventions take place, a Dutch study found that the most common reasons for hospital admissions in the last three months of life is symptom control (Pringle, Johnston, & Buchanan, 2015). Furthermore, half these admissions were initiated by General Practitioners, suggesting that what was occurring could not be managed in the community. In the future, the need for hospital support to initiate and monitor some palliative care

interventions is likely to require more access to hospital level care (Seymour & Gott, 2011). However, this was not acknowledged in the reviewed policies.

Policies suggest that identifying unnecessary hospital admissions provides opportunities to save money and support patient preferences to be at home. However, there is neither an agreed definition of what an unnecessary admission is within the literature nor any validated tools to identify potentially avoidable admissions in a palliative care context. Indeed, differing approaches have been adopted in the literature. For example, a study by Robinson, Boyd, O'Callaghan et al. (2014) defined a potentially avoidable admission as one that occurred as a result of a predictable deterioration in the patient's condition, which could have been managed by community providers. In contrast, the study by Abel, Rich, Griffin and Purdy (2009) considered a hospital admission to be avoidable if the patient could have stayed at home if services as described in England's End of Life Care Strategy were available. These differences in methodology make it difficult to support the straightforward assumption implicit in the policies reviewed that avoidable hospital admissions for those with palliative care needs can be identified; the infiltration of the "rescue culture" of modern medicine also challenges the assumption that hospital admissions can be easily prevented (Gott, 2014).

Research describing poor quality of palliative care in the hospital setting was cited throughout the reviewed policies, reinforcing the argument that these are not settings where people with palliative care needs should receive care. However, findings from a recent integrative review showed that, largely due to inadequacies in study design, what is known about patient and family experiences of palliative care in a hospital setting is limited to discrete aspects of care (Robinson, Gott and Ingleton, 2014). Moreover, a study published subsequent to the review found that patients with palliative care needs experience a range of benefits associated with being in hospital that extend beyond the treatment they receive and almost all participants expressed a preference to be in hospital during a period of acute illness (Robinson et al., 2015a).

Overall the findings from this exploratory study suggest that Western understandings of a good death, which prioritises end of life care at home and death outside the hospital setting, have informed the development of palliative care policy in countries where palliative care is integrated into mainstream health care. An emphasis on inadequate end of life care in hospitals and a focus on avoidable admissions has "problematized" palliative care in the hospital setting. This policy focus has real implications for palliative care practice and ultimately patient and family experience. There is an urgent need to adopt a co-design approach to policy development to ensure that

recommendations for service development meet the needs and wants of patients with palliative care requirements and their family. In particular, given mounting evidence regarding patient preference for hospital admission, coupled with the increasing medicalisation of palliative care itself, future policy needs to consider what role hospitals should have at end of life, rather than assume they have none.

2.1.6 Conclusion.

Findings from this review suggest a problematisation of palliative and end of life care in acute hospital settings. This approach to policy development influences service recommendations, many of which are designed to solve the “problem” of people being cared for and dying in hospital. However, little is known about patient preferences for place of care during periods of acute illness or the benefits they experience from being in hospital. It has been suggested that without a better understanding of a patient’s priorities and preferences at the end of life, there is a risk that the model of palliative care outlined in policy will be applied “blanket-fashion” and prove to be ineffective and inequitable (Lloyd, 2011).

2.2 Additional information.

A key finding from the policy review was that, in countries where palliative care is integrated into mainstream health care, the Western understanding of the good death, which prioritises care at home and death outside the hospital setting, influences how the role of the hospital in palliative care is perceived (Robinson et al., 2016). Indeed, the benchmark for excellent palliative care continues to be care that is delivered at home. In this section, I discuss the evolution of the good death and challenge its relevance as a benchmark for good palliative care, with particular attention to implications for hospital settings. The following information was not included in the published manuscript due to word limit restrictions. However, the concept requires further exploration due to my finding that the way in which place of care and death is understood as part of Western conceptions of a good death, with resultant implications for attitudes towards palliative care delivery in the hospital setting (Robinson et al., 2016).

2.2.1 The “good death”.

The “good death” was first described by French historian Phillipe Aries in his work on changing Western attitudes to death and dying. Aries referred to the good death as one that took place hidden away in secret and death in hospital as “inhumane and solitary”. He argued that this contributed to the belief that death was a social taboo, invisible to society (Aries, 1981).

The work of Glasser and Strauss (1965) has also been argued as being influential in the development of the hospice model of a good death (McNamara, 2004). They describe the good death as a series of social events that culminated in an awareness of impending death. Kubler-Ross's (1969) work with dying people built on these foundations to introduce the idea that "acceptance" of impending death is important, as it allows the dying person to begin to prepare for the end of their life (Kubler-Ross, 1969). Kellehear (1990) further developed the concept of a good death in his study of dying people in a modern industrial world (Kellehear, 1990). He incorporated five key factors into his concept of a good death, which were located within the social life of the dying person: awareness of dying, adjustments to and preparations for death, giving up roles and responsibilities, and making arrangements for the farewell. He argued that dying patients had an essential role in the management of their lives as they prepared for death.

It was during the 1950s that the modern hospice movement developed, underpinned by specific understandings of a good death. This was a time of significant progress in disease modifying therapies and hospitals were regarded as places where lives could be saved and death could be delayed or deferred (Clark, 2008a). A good death at that time was considered a "well managed death" (Kellehear, 2007) and when death finally came it was seen as a failure of modern medicine rather than a naturally occurring life event (Walters, 2004). Hospitals were considered inadequate in caring for the dying patient with stories of "consultants writing off dying patients, unable to cure so unable to care" while death in hospice was seen as "an achievement; to accept death when it was inevitable, was not a negative thing to do" (Du Boulay, 1984). However, in most developed countries, times have changed and hospitals are now providing care and treatment for those with a life limiting illness in ways that were not anticipated 70 years ago when the modern hospice movement first began. It could therefore be argued that the way in which the good death concept continues to position hospitals as not having a positive role to play in palliative care delivery needs further investigation.

2.2.2 "Good death" in hospital.

Current conceptualisations of a "good death" in Western culture, which builds on the ideas described previously, have been described using six elements: a pain free death, open acknowledgement of the imminence of death, death at home surrounded by family and friends, an "aware" death in which personal conflicts and unfinished business are resolved, death as personal growth, death according to personal preference and in a manner that resonates with the person's

individuality (Clark, 2002). It is argued that, collectively, these elements constitute a “cultural script”, which the dying person and those caring for them are expected to adhere to. Indeed, it has been suggested that the good death is a form of social control, directing attitudes and behaviours in line with what is considered to be a socially acceptable way to die (Broom & Cavenagh, 2010). Yet, the “good death” as a concept was developed at a time when hospitals were being criticised as over medicalising death and dying. In response, the hospice positioned itself away from mainstream healthcare moving dying out of the hospital environment.

However, when describing the short period of time when hospice first developed, Dame Cicely Saunders, the founder of the modern hospice movement, stated that “. . . our determination to move out of earlier charities and our British National Health Service had already shown that the demonstration of basic hospice principles would enable ideas to move back into mainstream medicine” (Saunders, 1993).

Despite attempts to integrate what has been learnt back into mainstream health care, the policy review described in this chapter confirms that hospitals are still largely seen as being ill prepared to care for those with palliative care needs. This finding is consistent with other evidence as to how death in hospital is currently considered within research and practice, namely as a poor quality marker of palliative care (Barbera, Paszat, & Chartier, 2006). This may be because, with the exception of a pain-free death, the elements that make up the good death in Western culture are not easily achieved in the hospital setting.

Open acknowledgement of the imminence of death.

Providing the dying person time to acknowledge the “imminence of death” is an important element of the good death (Clark, 2002). However, not all deaths occur in this way. Death can be sudden and unexpected and may be characterised, for example, by a prolonged period of resuscitation. Deaths such as these are more likely to occur in a hospital setting.

The predicted trajectory of an illness influences our ability to openly acknowledge the imminence of death. At the time that the good death as a concept was being developed, hospice care was primarily focused on those with cancer (Seale, 1998). The illness trajectory associated with cancer is known to be relatively predictable (Murray et al., 2005) providing opportunities for the patient and those involved in their care to acknowledge and prepare for impending death. However, palliative care has evolved to include those with a non-malignant illness, such as chronic obstructive pulmonary

disease, heart failure, and dementia (WHO, 2015). The illness trajectory of these chronic diseases makes prognostication difficult and death unpredictable (Murray et al., 2005). Life threatening exacerbations of non-malignant diseases require hospitalisation where death may occur and appear to be sudden. This prognostic uncertainty makes an “acknowledgement of the imminence of death” for those with a non-malignant illness difficult to achieve.

Death at home surrounded by family and friends.

Death at home is considered to be a key element to achieving a good death (Clark, 2002) enabling the patient and family to take back control from the medical system (Gott, et., al, 2008). However, this ideal is not considered achievable for all and certain groups may prefer, or be more likely to, die in an institution rather than at home. For example, this includes people living alone (Morrow, 2005), people living in poverty (Macfarlane & Carduff, 2016), people from certain cultures (Seymour, Payne, Chapman, & Holloway, 2007) and older people (Gott et al., 2008).

Achieving a home death requires a level of direct care and support that, for some, cannot be provided. For example, a meta analysis of the key factors influencing death at home in patients with cancer found that availability of home care, its relative intensity, and the extent of family support were key in enabling patients to die at home (Gomes & Higginson, 2006). Therefore, those who live alone, experience long trajectories of illness characterised by poor levels of function, or live in areas where home care services are scarce, may be unable to achieve death at home.

For those who live alone, receiving palliative care at home may also increase the risk of dying alone. A hospital admission in palliative care has been described as a “placement beyond accompaniment” from family and friends; however dying alone at home may, for some, be worse with its “fantasy of abandonment that is difficult to repair” (Seale, 1995).

Over the past decade, there has been a relaxation in hospital visiting hours enabling those dying in hospitals, to die “surrounded by family and friends” (Nelson et al., 2010). However, the congruence between death at home and being with family is unclear. For example, does the person surrounded by family and friends dying in hospital experience less of a good death than the person who is dying alone at home? The relative importance of each good death element makes the concept as a whole difficult to use as an assessment of good dying.

2.3 Chapter summary.

This chapter has presented an international policy review that has revealed how palliative care, and death in a hospital setting, is considered a problem to be solved. Indeed, a major focus in palliative care policy is to reduce hospital admissions and achieve a patient's preference for place of care and death outside the hospital setting. However, although not made explicit, what constitutes "good dying" in hospital is judged on the traditional Western culture of a good death with little attention paid to how this could be achieved in a hospital setting. Moreover, policy makes little mention of patient experience of, and preferences in relation to, hospital admissions in palliative care.

The following chapter introduces my world view, providing an overview of my clinical and professional background as a Nurse Practitioner working in a hospital-based palliative care service.

Chapter 3: Reflexivity.

The following chapter provides an overview of the reflexive stance I adopted throughout the study. This became a core component to my research design and was important given the depth of my past and current experience as a Nurse Practitioner providing palliative care in a hospital setting. In addition, due to the study being carried out in my workplace, being open and reflective about how my clinical role might impact on the research process was essential. Philosophically, taking a reflexive stance to my research aligns well with the way I approach my clinical practice, integrating personal and professional reflection into the development of my skills and knowledge and delivery of patient care.

Reflexivity has been defined as “the process of a continual internal dialogue and critical self-evaluation of researcher’s positionality as well as active acknowledgement and explicit recognition that this position may affect the research process and outcome” (Berger, 2015). Reflexivity requires a process of reflection and interpretation of that reflection by the researcher on their role throughout the research process and its impact on the research outcome. Interpretation of the reflection creates a reality which is generated by the researcher. It is therefore important for researchers to be transparent about their background, credentials and interest in the topic being studied and how these influence every stage of the research process (Tong, Sainsbury, & Craig, 2007).

I am currently employed as a Nurse Practitioner in the Auckland City Hospital Palliative Care Team. I also have a joint appointment at the School of Nursing as a Professional Teaching Fellow involved in the development of palliative care in the undergraduate and postgraduate programmes. The following section provides details of how these professional experiences, and particularly my background in palliative care nursing, have influenced my world view. Further evidence of reflexivity can also be found throughout the thesis, specifically in relation to formulation of the research topic (see Chapter 5), collection and analysis of data (Chapter 6), and the integration and discussion of findings (see Chapter 10).

3.1 Researcher’s world view.

My world view has been influenced significantly by the way I was trained as a nurse and what I have learnt as I developed my skills and knowledge in palliative care over the past 15 years. I have been a registered nurse for 26 years and during that time I have learnt to appreciate and combine the “science” and “art” of nursing (Carper, 1978). The science is entrenched in my knowledge of the

pathophysiology of illness and my skills in clinical assessment and diagnostic reasoning to manage the symptoms that occur as a result of a life limiting illness. The art of my nursing can be seen through how I acknowledge the uniqueness of each individual in my practice and support them through a period of suffering and uncertainty. I have watched people face their own mortality with fortitude and courage and I have learnt how resilient human beings can be. The way in which they respond to what is happening is unique; some fight to the very end never acknowledging that death is inevitable, while others embrace what is to come.

My choice of research topic – experiences of benefits and burdens of hospital admissions for people with palliative care needs and their influence on preferences to return to hospital – has been informed by my experience of working in palliative care, initially in the hospice and community settings and more recently in the acute hospital. Indeed, the majority of my career has been in the acute hospital setting, a place of end of life care that does not always fit comfortably with the principles of palliative care, and particularly those relating to a good death, as discussed in Chapter 3. I also remain passionate about supporting those who wish to die at home and always provide this as an option for patients and families. I feel a sense of satisfaction when I am able to facilitate a successful discharge home of an imminently dying patient. Interestingly, this sense of “doing a good job” is wholly dependent on “getting the patient home”, as I rarely get to hear whether the death was a good death or not. This demonstrates my ingrained belief that death at home surrounded by family and friends is a key principle of good palliative care, although in practice I know that a good death is not wholly contingent on the site of death. Furthermore, I have seen many people die in hospital and experience a good death from the perspective of patients, families and staff.

Despite the challenges of providing palliative care in a hospital setting, I believe that health professionals caring for those with palliative care needs are committed to providing a high standard of care. I have also found that many patients and families are glad to be in hospital. Although many express a preference to be at home, when they are feeling unwell hospital seems, for many patients, to be the right place of care. In my experience, many people leave hospital with trepidation and fear as they try to contemplate an uncertain future and the impact their illness will have on their family. I have seen medical interventions (that can only be offered in a hospital setting) improve symptoms and sometimes extend life. However, I am also aware that the timing of these interventions, and the way they are offered to the patient, are essential to achieving a positive outcome. Ultimately, I selected my research topic because I believe that for some people there is value in having been in hospital – we just don’t know what this value is.

Clearly my background in nursing and palliative care has influenced the values and beliefs I brought to my research, as well as informed my practice in caring for those with a life limiting illness. The following paper was an opportunity to reflect on the philosophy of nursing and palliative care and explore how this has informed the development of my advanced practice in specialist palliative care nursing. The paper also provided a platform to critically discuss the impact of medicalisation and specialisation in palliative care and how this has influenced the development of my values and beliefs working in palliative care.

The following article is cited as:

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3.2 Article: Specialist palliative care nursing and the philosophy of palliative care: A critical discussion.

3.2.1 Introduction.

Historically, palliative care nursing has been informed by a strong philosophy of care (Matzo, Sherman, & Metheny, 2015), which is soundly articulated in palliative care policy, research and practice. However, over the past decade there has been a change in the way in which palliative care is provided in developed countries (Clark, Graham, & Centeno, 2015). These changes have included the increasing medicalisation and specialisation of palliative care, as well as the integration of palliative care into “mainstream” health care services with a broadening of how, where and to whom palliative care is provided (Buck, 2012; Llamas et al., 2001).

Mainstream health care is arguably still dominated by a biomedical model that assumes that all illness is caused by a single pathology and removal or management of the pathology will result in an individual’s return to health (Wade & Halligan, 2004). Embedding palliative care into this model may lead to a fractional approach to patient care that fails to address the wider ramifications of

health and illness, namely the psychological, emotional and spiritual aspects of a person (Wade & Halligan, 2004). At the same time, definitional changes in terms of what constitutes “palliative care” (Pastrana et al., 2008) have resulted in a re-definition of the cohort of patients considered to have “palliative care needs”, from those with a “terminal” cancer who may be in the last few weeks of life, to those with life limiting illnesses (including those with a non-cancer diagnosis) with a range of prognoses (Seymour, 2012). Furthermore, changing patterns of disease and dying relating to improved treatment modalities and ageing populations are presenting new challenges not only to the technical aspects of palliative care nursing, but also to the organisational aspects of care provision (van der Steen et al., 2017). For example, expanding the remit of palliative care to include all life limiting illnesses has required services to be flexible and responsive to different illness trajectories, identifying new models of palliative care that will better meet the needs of patients with a non-malignant illness (Lewin & Schaefer, 2017). In addition, research has demonstrated the value of introducing palliative care earlier in the illness trajectory with significant improvements seen in a patient’s quality of life compared with patients receiving standard care (*Global Atlas of Palliative Care*, 2014; Temel et al., 2010). All of these recent changes have resulted in a significant broadened focus of activity in the practice of palliative care leading to a disconnect between policy and practice (Gott, Seymour, Ingleton and Bellamy, 2012) and confusion about the scope of palliative care internationally (Pastrana et al., 2008).

To understand contemporary trends, it is helpful to consider the history of palliative care development. Palliative care initially positioned itself as an alternative to the highly technological approach to dying that predominated in acute hospital care (Clark, 2008a). In response, through the work of Cicely Saunders and the modern hospice movement, a unique philosophy of care for the dying outside the hospital setting was developed (Clark, 2008b). However, in more recent times it has been argued that the dominance of the biomedical model has led to the overmedicalisation of death and dying and an erosion of this unique palliative care philosophy (Clark, 2002). In order to be accepted as an authentic area of medicine in mainstream healthcare, the development of specialisation in palliative medicine was inevitable, and this specialisation has been underpinned by a biomedical approach to health and illness (Clark, 2002). In a similar fashion, palliative care nursing has embraced a model of specialist practice and knowledge, which has become distinct from other areas of nursing (*A national professional development framework*, 2014; Canning, Yates and Rosenberg, 2005). However, the tension for both medicine and nursing remains that only a minority of people worldwide are in a position to access palliative care provided by a dedicated, specialist service (Rosenwax, Spilsbury, McNamara, & Semmens, 2016). Therefore, many resource rich

countries have adopted the World Health Organisation (2002) focus on the integration of palliative care principles into mainstream health care into their health policies (*Global Atlas of Palliative Care*, 2014), advocating that both medical and nursing clinicians should have the required skills and knowledge to provide a palliative care approach.

This has focused attention onto developing skills and knowledge in palliative care through undergraduate and postgraduate programs, although there is global variation in terms of palliative care content in these programs (Dickinson, Clark, & Sque, 2008; Wallace et al., 2009). However, in addition to formal education, guiding nurses in their practice is the strong philosophical framework, which articulates the assumptions and values that underpin the discipline. Moreover, in practice, nurses work within a professional hierarchy of disciplines and are challenged by professional boundaries seen within the medical hierarchy, which impact on patient care (Gott et al., 2011; Powell & Davies, 2012).

It is within this context that the aim of this paper is to explore the challenges for nursing as a result of the evolving model of palliative care. By highlighting these challenges, this theoretical critique will enable nurses to reflect on opportunities to provide care that best meets the needs of patients with a life limiting illness.

Data sources.

This discussion paper is based on a critical reflection my own experiences and is supported by literature and theory from seminal texts and contemporary academic, policy and clinical literature. An overview of both the philosophical influences on nursing knowledge and theory and the practice philosophy of palliative care will be provided. Finally, a discussion of how these two philosophical frameworks intersect will be provided in order to highlight the role of nursing and its contribution to patient care within a palliative care context.

3.2.2 Nursing knowledge and theory.

The development of nursing knowledge has been influenced by a number of different philosophical frameworks (Cull-Wilby & Pepin, 1987). Through the early part of the 20th century nursing borrowed from the mechanistic biomedical model of knowledge development. However some have argued that scientific knowledge, which focuses on ascertaining an “objective reality”, is insufficient to support the complexity of nursing practice (Rutty, 1998). In an attempt to move away from a nursing model based on bio-medically derived reductionist principles, nursing theorists

conceptualised what is referred to as the “aesthetics” or art of nursing (Carper, 1978). The use of intuition, personal knowing and tacit knowledge provided a foundation to understand the meaning of the illness for an individual patient in a social context (Kennedy, 1998). Nursing began to place value on the human experience of illness and the unique meaning placed on that experience by an individual. Furthermore, the acquisition of skills and knowledge integrating these concepts (Benner, 1984) also influenced the development of nursing.

Carper’s theory of the “Fundamental Patterns of Knowing in Nursing” aligns well to palliative care, which some may argue requires practitioners to encompass both the art and science of practice (Costello, 2015). Carper describes four ways of knowing in nursing: empirics, ethics, personal, and aesthetics (Carper, 1978). The pattern of empirical knowing includes verifiable knowledge derived from subjective and objective data and is considered to be the science of nursing. Ethical knowing describes the moral obligations and values of the discipline and personal knowing and interpersonal connection between nurse and patient. Finally, the aesthetics of knowing is the nurse’s perceptions of what is considered significant in a person’s behaviour, also known as the art of nursing. Carper’s work places equal importance on theoretical knowledge (science) and knowledge that is gained through clinical experience (art).

The philosophical framework in Carper’s work acknowledges the acquisition of knowledge as being both theoretical and experiential. In addition, value is placed on learning that occurs as a result of the patient–nurse relationship, thus adopting a more holistic view of knowledge development. This combination of evidence-based care and values-based practice provides a philosophical framework that guides nursing practice (Cody, 2013).

3.2.4 Palliative care philosophy.

The philosophy of palliative care has been largely defined by the modern hospice movement and more recently articulated in the World Health Organisation (2015) definition of palliative care. Palliative care adopts an holistic approach to care that is attentive to the “the suffering that encompasses all of a person’s physical, psychological, social, spiritual and practical struggles” (Ong, 2005). The overall aim of this approach to care is to achieve what has been described as the good death.

A good death in Western society is considered to be a death with dignity, awareness, peace, adjustment and acceptance (Hart, Sainsbury, & Short, 1998). However, the conceptualisation of

what constitutes a good or bad death is obviously influenced by a person's beliefs and values. For health professionals, these values and beliefs and their relationship to patient care are also influenced by the culture in which they work, which varies between care settings (Clark, 2012). For example, a study by Costello in 2006 found that nurses working in a hospital setting constructed good and bad death experiences around the death event itself rather than the dying process. For example, death that was unexpected or where there was a perceived lack of time for preparation and connection with family were considered "bad deaths". By contrast, a good death was one that was expected, families were aware and distressing symptoms were absent (Costello, 2006). In contrast, a good death in a hospice context is said to focus more on the "journey of dying" integrating an open awareness of dying, open communication, and eventually an acceptance of death and settling of personal business. In order for these to occur, a person's pain and suffering must be relieved (McNamara, 2004). Whilst the construction of a good or bad death continues to be used in health care and throughout society, the way in which death is viewed has been dominated by a Western model of health care which is dominated by individualism, secularism and medical sciences (Bradbury, 2000). This is not the case in many non-Western societies where faith, religion and a community-based approach to decision making at the end of life may dominate (McLaughlin & Braun, 1998). Indeed, these sociological and cultural factors are likely to influence not only the perception of a good death, but also the way in which patients are cared for at the end of their life, as we see an increasing diversity of ethnicity in the nursing workforce.

A strong philosophy of care that is embedded in the concept of a good death continues to inform the development and practice of palliative care nursing. However, nursing comes to this area of clinical practice with an equally strong discipline-based philosophy of care.

3.2.5 Nursing and palliative care: A critical reflection.

Nursing had a pivotal role in caring for dying patients in the early days of the modern hospice movement and was influential in supporting the development of the philosophy of care (Clark, 2008b). Unlike medicine, nursing responded enthusiastically to the early work of Cicely Saunders, expressing concerns about dying patients being "abandoned" by doctors and "ignored by society" (Clark, 2008b). The response to Saunders' work was thought to be as a result of nurses' perceptions of the "over medicalisation" of death in the hospital setting and the use of "futile" medical interventions to prolong life (Zimmerman & Rodin, 2004). Indeed, the medicalisation of death and dying proved a key driver for the development of modern hospices, which enabled patients to be taken out of mainstream health care in order to place them in an environment that maximised the

likelihood of a good end of life experience (Clark, 2008a). The less medicalised environment of the hospice, with a focus on “care” rather than “cure”, led hospice nurses to become central to the provision of hospice care. The notion of caring features strongly within a nursing philosophy and is considered by some to be the essence of nursing practice (Watson, 2003). A meta-synthesis on the process of caring concluded that caring is a “. . . context specific interpersonal process that is characterised by expert nursing practice, interpersonal sensitivity and intimate relationships” (Finfgeld-Connett, 2007). Some have suggested that this core value within nursing fits easily with the philosophy of palliative care (Floriani & Rolland, 2012). Therefore, it could be argued that the prioritisation of “caring” over medical interventions and a philosophical framework that places value on the human experience is the reason why nurses made such a significant contribution to the development of a strong philosophy of care in hospices.

The holistic approach to care that hospices adopted early on in their development, focusing on “integrating the psychological and spiritual aspects of patient care”, has become a key component to their practice philosophy (Clark, 1998). Indeed, addressing issues such as hope, meaning and spirituality are now considered to be essential in caring for those facing the end of their life (Edwards, Pang, Shiu, Chan, & De Casterle, 2010). Literature suggests that a relationship based on trust provides a foundation to address sensitively existential issues (Boston, Bruce, & Schrieber, 2011). This requires a therapeutic relationship between the patient and nurse, which is based on values such as compassion, respect, empathy and self-awareness. This philosophical approach to the caring relationship fits well with Watson’s theory of human caring (Watson, 1988). Watson (1988) describes the “transpersonal caring relationship”, which exists between the patient and the nurse. This relationship is used to foster faith and hope based on the patient’s belief systems. Furthermore, it facilitates the patient’s expression of emotion through authenticity, empathy and warmth. (Watson, 1988)

However, the routinization and medicalisation of hospice care has arguably resulted in a “surveillance and control of the process of dying” (Floriani & Rolland, 2012), which compromises the principles of holistic palliative care. A number of factors have influenced this paradigmatic shift. Firstly there have been increasing technological advances in medicine with more interventions available to relieve pain and suffering related to an end of life illness (Lagman, Rivera, Walsh, LeGrand, & Davis, 2007). Secondly, with an expansion of palliative care to include all those with a life limiting illness (not just those with cancer), there is an increasing complexity of the illness trajectory (Murray et al., 2005). Finally, integrating palliative care early in the illness trajectory and

extending it beyond just “terminal care” has required more integration with mainstream health services, many of which remain embedded in the biomedical model of service delivery (Floriani & Rolland, 2012). This integration into mainstream services may create some challenges. For example, in the hospital setting where a biomedical model dominates, maintaining an approach to care that recognises the value of nursing is known to be problematic (Gott et al., 2011). Secondly, the philosophy of care in hospital tends to focus on cure and prolonging life, which can result in tension between a more care-based approach seen in nursing and palliative care. Finally, the philosophical principles that underpin the medical model may not always align well with a nursing framework. For example, the reductionist approach to patient care that is inherent within the biomedical model (Beresford, 2010) has the potential to create tension between what has been described as the art and science of nursing (Costello, 2015). It could be argued that the art and science of palliative care nursing is particularly vulnerable to being eroded by this reductionist approach to patient care. For example, it has been suggested that whilst the “science” of symptom control has advanced significantly over the years, the “art” of nursing, such as communication skills based on compassion, empathy and genuine kindness, are less well developed in palliative care nursing (Costello, 2015). These skills are an essential component in the care relationship, however a recent report into complaints about end of life care in UK highlighted failings in communication in almost all care situations (*Dying without dignity*, 2015).

With increasing integration into mainstream healthcare, palliative care is now considered to be integral to all clinicians’ practice regardless of their clinical setting (*A national professional development framework*, 2014). However, the split between generalist and specialist palliative care can be problematic, with continuing debate about remit, roles and boundaries (Firn, Preston, & Walshe, 2016; Gardiner, Gott and Ingleton, 2012). Although specialists in palliative care may be well positioned to manage patients with the most complex needs, there is a risk in specialists being called upon to see all patients with palliative care needs. This risk includes the potential deskilling of the non-specialist workforce (Gott et al., 2011), inability to meet patient need as demand outstrips resources, and ultimately to fragmented care as yet another provider becomes involved in the patient’s care (Quill & Abernethy, 2013).

Specialisation in palliative care has also been influential in the development of specialist palliative care nursing roles that require a different set of skills and knowledge. For example, advanced clinical skills, diagnostic reasoning and prescribing skills are required for advance practice roles, such as the nurse specialist and the Nurse Practitioner. These roles have become embedded into the

delivery of palliative care in many countries (Sheer & Wong, 2008). For example, in the United Kingdom the Macmillan nurse role has been well established as a nurse specialist in palliative care having clinical, consultative, educational and research responsibilities (Ingleton & Larkin, 2015). A review of these roles in 2002 found that as a result of changing models of cancer care and the rapid introduction of new nursing roles, there was a need to clarify the scope of the role in order to use their expertise most effectively (Seymour et al., 2002). Over recent years there has been an increasing interest in developing advanced practice roles that focus more on clinical assessment, diagnostic reasoning and prescribing, traditionally the domain of medicine. Evidence has shown that advanced practice roles, such as Nurse Practitioners, have improved patient outcomes with greater satisfaction in care, improved patient health and better access to health care services (Charlton, Dearing, Berry, & Johnson, 2008; Horrocks, Anderson, & Salisbury, 2002). However, some have suggested that advanced practice roles in nursing are developing in such a way that they are more aligned with the biomedical model and are criticised by some as being a medicalisation of the nursing profession (Mantzoukas & Watkinson, 2006). Furthermore, one could argue that advanced practice nursing roles contribute to the criticism that palliative care is suffering from an “over specialisation” and “over medicalisation” approach to death and dying (Mantzoukas & Watkinson, 2006).

This reductionist approach to nursing practice suggests an ongoing focus on knowledge development that is still based largely on a biomedical framework. Reductionism is said to be the opposite of holism and has been described as a deconstruction of a complicated process into individual parts to enable better understanding (Beresford, 2010). Whilst acknowledged as a useful approach at times, reductionism has its risks. Beresford argues that reductionism oversimplifies a process reducing a phenomenon to its parts resulting in a disassociation from the phenomenon. Although the context of his argument is in the biological treatment of disease, the same could be true in palliative care. For example, ignoring emotional and psychosocial aspects of pain is known to cause a barrier to the treatment of physical pain; this is outlined well in Cicely Saunders’ concept of “total pain” (Mehta & Chan, 2008).

Whilst the over-emphasis on knowledge that is informed by a biomedical model does not always sit easily within the palliative care philosophy, the empirical knowledge required to understand the pathology of illness, while at the same time understand the impact of the illness on an individual, their family and society, in many ways reflects the true philosophy of palliative care. As Cicely Saunders (1981), “You matter because you are you. You matter until the end of your life”,

suggesting an emphasis on recognising the uniqueness of every individual. However, she also acknowledges the dichotomy of caring stating, “In the hospice movement we continue to be concerned both with the sophisticated science of our treatments and with the art of our caring, bringing competence alongside compassion” (Saunders, Summers, & Teller, 1981).

Nursing theory that is embedded in a strong nursing philosophy has positioned the discipline well to integrate both the art and science into practice. However, this creates a level of epistemological uncertainty and is thought by some to be a threat to the integrity of nursing knowledge (Pitre & Myrick, 2007). However, the division of polarised discourses, such as qualitative and quantitative, art and science, positivism and constructionism, fails to reflect the epistemological reality of nursing practise. Indeed, managing the science or certainty of death whilst responding to the multiple realities of patients and their families as they perceive, experience and interact with their own illness and death, requires clinicians to engage with multiple paradigms within their practice.

We would therefore argue that, in order to integrate both the “art and science” of nursing, an approach is needed that embraces multiple paradigms. “Reciprocal interdependence” is thought to be an alternative way of knowing in nursing that is able to integrate differing world views into a comprehensive whole (Pitre & Myrick, 2007). Pitrie and Myrick (2007) state that “the parts comprising the whole and the whole composed of parts interrelate to create growth and transformation within the realms of nursing practice, science, and philosophy rather than the division of polarized discourses” (p 81). Differing world views existing together through a reciprocal process of understanding contribute to a greater truth than each one alone (Pitrie and Myrick, 2007). This is the challenge moving forward for palliative care nursing.

3.2.6 Conclusion.

This critical discussion paper has explored nursing philosophy and discussed how this can align or conflict with a palliative care philosophy. The “art” of palliative care nursing can be seen in the value placed on the unique illness experience, which is clearly supported by nursing theory. Equally the “science” of nursing is evident in the knowledge required of pathophysiology and the skills required to critically assess patient needs across all domains of care: physical, psychosocial, emotional and spiritual. Nursing theory supports this mix of art and science in nursing knowledge and practice.

However, it could be argued that at times specialist palliative care nursing is in direct conflict with the changing environment of contemporary palliative and end of life care, which is now integrated into mainstream health care in many developed countries. Indeed, the philosophy of palliative care – which considers the person as a unique individual within a social context requiring a “total care” approach – may be at risk of being eroded by the over medicalisation and specialisation of palliative care. With increasing medical technology available to manage distressing symptoms, it could be argued that clinicians are at risk of becoming overly focused on the physical response of the body to the disease, to the detriment of psychosocial, emotional and spiritual aspects of care.

Nurses are in a pivotal position to strengthen partnership working between providers across range of care settings, with positive outcomes for patient (Firm et al., 2016). However, nursing needs to continue to adapt and respond to the changing needs of the patients and their families in a rapidly changing healthcare environment. Nursing is in a unique position to apply new advanced clinical skills and knowledge originating from a biomedical model of health and illness, within a holistic model of care. The challenge is to not view these as polarising practice paradigms, but as complementary approaches that when used together can achieve better outcomes for patients and families. Understanding how this may occur will ensure that nurses remain responsive to the changing environment of palliative care.

3.3 Chapter summary.

In this chapter, I have outlined my world view, the purpose of which was to inform the reader about my philosophical and practice background and begin to articulate how my world view influences the the research process. An outline is provided of my nursing practice in palliative care and the development of my advanced practice skills, including clinical assessment, diagnosis and prescribing. The mix of art and science in my nursing practice has been influenced by the biomedical mechanistic approach to patient care that dominates the hospital environment and does not always align well with my practice philosophy (the “art”). Being open and transparent about the factors that have influenced my values and beliefs promotes rigor and quality to the research process, and to my overall thesis.

The following chapter contains an integrative review of the literature pertaining to patient and family experiences of palliative care in an acute hospital setting and addresses the second objective of this study: to explore what is currently known about the experiences of palliative care in an acute hospital setting from the perspectives of patient and family.

Chapter 4: Literature Review.

Systematic literature reviews are designed to summarise the literature to provide a comprehensive understanding of a particular issue and to inform the research topic (Whittemore & Knafl, 2005). Systematic reviews consist of a specific question, explicit methodology and a comprehensive search strategy of primary sources (Whittemore & Knafl, 2005). Integrative reviews synthesise evidence from a diverse range of methodologies, which can make data analysis challenging. Therefore the use of guidelines, such as the PRISMA guidelines, to develop a protocol that describes the rationale, review question and planned methods for the review is required (Moher et al., 2015).

The following integrative review of the literature brings focus to the overall research topic by addressing the second objective of this study which is: to explore what is currently known about the experiences of palliative care in an acute hospital setting from the perspectives of patients and family.

The following article is cited as:

Robinson, J., Gott, M., & Ingleton, C. (2014). Patient and family experiences of palliative care in hospital: What do we know? An integrative review. *Palliative Medicine*, 28(1), 18–33. doi: 10.1177/0269216313487568

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4.1 Article: Patient and Family Experiences of Palliative Care in Hospital: What Do We Know? An Integrative Review.

4.1.2 Background.

In most developed countries, acute hospitals play a significant role in palliative care provision. Evidence shows that at any one time 13–36% of hospital inpatients meet the criteria for palliative care need (Gott, Ahmedzai, & Wood, 2001; Gott, Frey, Raphael, O’Callaghan and Robinson, 2012; Morize, Nguyen, Lorente, & Desfosses, 1999). Hospitals are often the setting where a life limiting diagnosis is made and where patients present when symptoms develop or when they are not well managed (Wallace, Walsh, Conroy, Cooney, & Twomey, 2012). Furthermore for people with

illnesses such as chronic obstructive pulmonary disease and congestive cardiac failure, hospitals provide episodic care over many years for illness exacerbations during which death could occur (Murray et al., 2005). In most developed countries, hospitals are also the setting in which most people will die. A recent comparison of institutional deaths across 45 countries concluded that, for half of those countries, more than 54% of deaths occur in hospital (Broad et al., 2013).

One factor that is impacting upon the role of the acute hospital in palliative care is the increasing use of technology. Widespread use of life supporting technologies that keep people alive who would otherwise die within a foreseeable, but usually uncertain period of time, has radically transformed the life expectancy of some people with a life limiting illness (Seymour & Gott, 2011). Like other areas of health care, palliative care has embraced the advancement of health technologies. It is now common place to offer, what some may consider as being invasive (McNamara, et al., 1994) interventions to achieve symptom control and improve quality of life whilst at the same time, in some instances, extending life. Many of these interventions can only be provided in a hospital environment and may impact on the way in which palliative care is delivered (Gillick, 2009; McCall & Johnston, 2007).

As a result of the 2009 global economic crisis, governments are searching for ways to make limited public health spending go further. Studies looking at inappropriate or avoidable admissions amongst patients with palliative care needs and economic analyses of hospital use in the last year of life are being carried out to ensure that health resources are being used wisely (Chan, Jackson, Winnard, & Anderson, 2011; Ward et al., 2012). In addition, patient and family preferences to be cared for at home or in a hospice rather than in a hospital setting have been well established in the literature (Higginson & Sen-Gupta, 2000; Thomas et al., 2004). A systematic review of the literature by Brereton et al. (2012) has demonstrated the inadequacies of the hospital environment in providing palliative care. These factors are becoming key drivers at a policy level to reduce acute hospital admissions amongst patients with a life limiting illness. However, what is missing in this debate is how patients and families experience palliative care in hospital.

Understanding the experiences of hospital admissions for patients with a life limiting illness and their families is essential in understanding the role acute hospitals have in providing palliative care. For the purpose of this review palliative care has been defined, in line with the Canadian Hospice Palliative Care Association definition, as an approach that “aims to relieve suffering and improve the quality of living and dying” and is “appropriate for any patient and/or family living with, or at

risk of developing, a life threatening illness due to any diagnosis, with any prognosis [and] regardless of age” (Health Canada, 2007).

The aim of this review is to synthesise existing international evidence regarding the experience of palliative care in an acute hospital setting from the perspectives of patient and family. Synthesising literature in this way helps to provide a more comprehensive understanding of a particular topic to inform future research, practice and policy initiatives (Whittemore & Knafl, 2005).

4.1.3 Design.

An integrative review was completed in keeping with the process outlined by Whittemore and Knafl (2005). A review of the literature was undertaken followed by a process of data extraction and synthesis. Quantitative and qualitative studies that provided data regarding the experiences of palliative care in a hospital setting from the perspectives of patients and families were included.

Search process.

Using pre-defined search terms (see Table 4-1), MEDLINE (EBSCO), CINAHL, EMBASE, Cochrane, and PsycINFO were searched for studies published between January 1990 and November 2011. The search was carried out by JR with assistance from a specialist librarian. Appropriate wildcards were inserted to search for word ending truncations where necessary. Reference lists from relevant articles were cross checked. The following journals were hand searched for relevant articles between 1990 and 2011: *Palliative Medicine*; *Journal of Palliative Medicine*; *BMJ Supportive and Palliative Care*; *Journal of Pain and Symptom Management*; *International Journal of Palliative Care Nursing*, and *BMC Palliative Care*. Details of the study identification and selection process are shown in the PRISMA flowchart (Figure 4-1).

Table 4-1
Search Terms Used in Electronic Search

	Search Terms
Palliative Care	Palliative care; supportive care; terminally ill; hospice care; end of life care
Hospital	Hospital admission; readmission; hospitaliz(s)ation; length of stay
Patient	Patient experience; patient perspective; patient satisfaction; patient preference
Family	Family experience; family perspective; family satisfaction; family preference

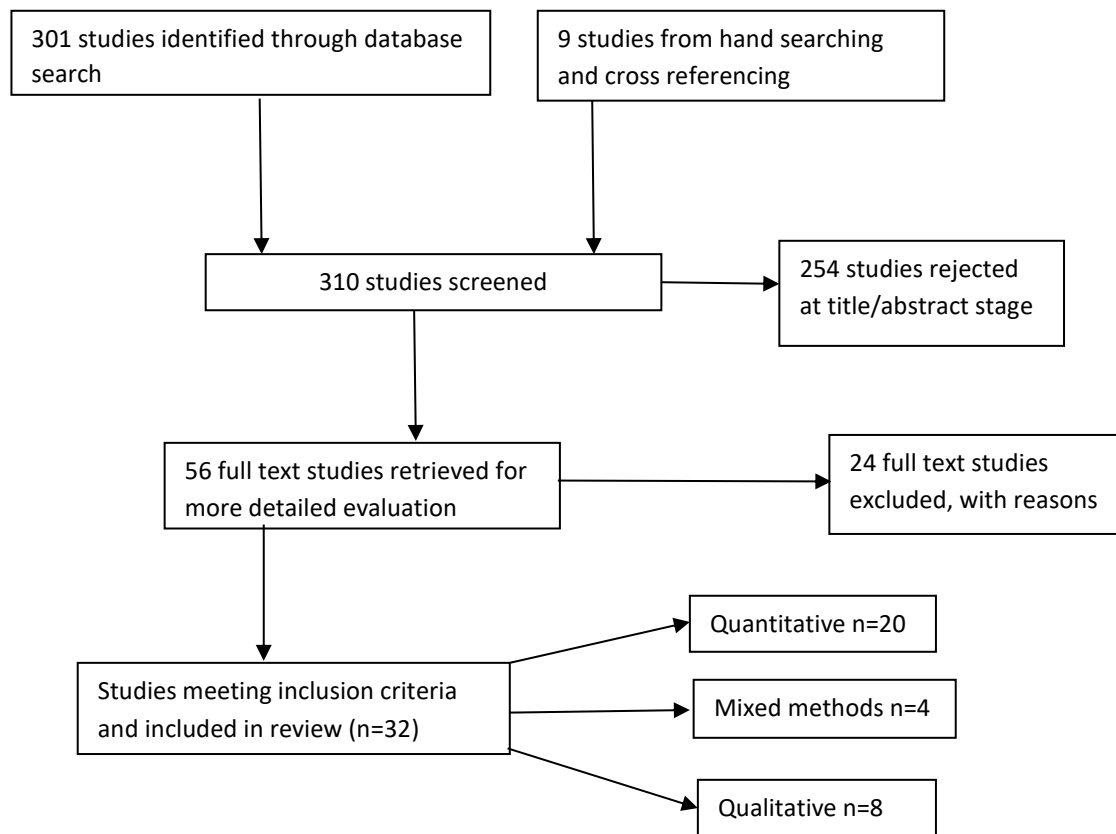
A rigorous approach to the search process identified 301 studies that were examined for relevance to the review topic. Studies had to refer to the experience of care in hospital amongst patients with palliative care needs and/or their family and include the views of patients and/or families. Studies also had to refer to an adult population over the age of 18-years-old and be available in English. Studies prior to 1990 were excluded as it was felt that palliative care as an integral component of care in an acute hospital setting was less well developed prior to that time (Clark, 2008a). In addition, studies conducted in the emergency department (ED) and intensive care unit (ICU) were also excluded because there are unique issues related to patient and family care that are specific to these clinical environments. A summary of inclusion and exclusion criteria can be found in Table 4-2.

Table 4-2
Inclusion and Exclusion Criteria for Literature Review

Inclusion	Exclusion
Written in English language	Written in languages other than English
Papers focusing on patient and family views	Papers focusing on health professionals' views and case reviews
Palliative care in hospital	Palliative care in ICU or ED
Palliative or end of life care	Not focusing on palliative care
Papers after 1990	Papers before 1990
All types of studies	

Study selection was conducted in a systematic sifting process over three stages: title, abstract, and full text. At each stage, studies were rejected that definitely did not meet the inclusion criteria. Using the title and abstract each paper was assessed by JR and rejected if they did not meet the inclusion criteria. Those that met the criteria were then independently assessed by JR and one of the other authors; in cases where there were disagreements of inclusion, consensus was reached by discussion. All literature was retained as background information. Overall, 32 studies satisfied the inclusion criteria (see Appendix 1).

Figure 4- 1 PRISMA flow chart



Data Evaluation.

Evaluating the quality of studies in a systematic review relies on a narrow sampling frame and similar research designs. In the case of integrative reviews, the inclusion of both qualitative and quantitative studies makes the process of data evaluation difficult (Whittemore & Knaf, 2005) and may provide little value. Furthermore, palliative care poses its own specific challenges to systematic review methods; the research base is relatively limited and the complexity of methodological and ethical issues results in an evidence base largely unsuitable for traditional forms of review and synthesis (Braun & Clarke, 2006). For these reasons, data evaluation was not undertaken in this review.

Data Extraction and Synthesis.

All data relevant to patient and family experiences of hospital admissions were examined using a four-step process to identify key themes (see Table 4-3). The data extraction process was reviewed by all authors and agreement sought on the identification of key themes.

Table 4-3

Process of Data Extraction and Synthesis (Adapted from Braun and Clark, 2006)

Step	Process
Familiarisation with the data	Immersion in the data by reviewing each study thoroughly, extracting and tabulating qualitative and quantitative data.
Generation of initial codes	Focusing on data related to the review question (patient and family experience) codes were manually attached to the data.
Searching for themes	Codes were sorted into overarching themes within the tabulated data.
Identifying themes	Potential themes were refined and discussed with MG and CI. Themes were discarded if there was not enough data or the data was too diverse.

4.1.4 Results.

Through a search of electronic databases, 301 studies were identified with a further nine found through hand searching of relevant journals. Of the 310 studies screened by title and abstract, a total of 56 full text studies were retrieved for further review. Twenty-four studies were excluded because they did not meet the inclusion criteria. A total of 32 studies satisfied the inclusion criteria. (See Appendix 1.2). They consisted of a mixture of qualitative (n=8), quantitative (n=20), and mixed methods studies (n=4).

Ten studies related to patients with cancer (Addington-Hall & O'Callaghan, 2009; Field & McGaughey, 1998; Herd, 1990; Rogers, Karlsen, & Addington-Hall, 2000; Seale & Kelly, 1997; Spichiger, 2008, 2009a, 2009b; Sykes, Pearson, & Chell Resea, 1992; Tanaka, Iwamoto, Kaneyasu, & Petrini, 1999), two related to patients with stroke (Payne, Burton, Addington-Hall, & Jones, 2010; Young, Rogers, Dent, & Addington-Hall, 2009), and one with chronic obstructive pulmonary disease (Rocker, Dodek, & Heyland, 2008). Four (Conner, Allport, Dixon, & Somerville, 2008; Costello, 2001; Dunne & Sullivan, 2000; Russ & Kaufman, 2005) studies did not state diagnosis. Two papers used two diagnostic groups in the same study; one compared patterns of care for

patients with non-small cell lung cancer with severe COPD (Claessens et al., 2000). The second study compared experiences of patients who died with end stage dementia to those who had died with congestive heart failure (Formiga et al., 2007). The remaining thirteen studies included patients from a variety of different diagnostic groups (Baker et al., 2000; Billings & Kolton, 1999; Borum, Lynn, & Zhong, 2000; Cantor, Blustein, Carlson, & Gould, 2003; Desbiens et al., 1996; Desbiens, Mueller-Rizner, Connors, Wenger, & Lynn, 1999; Dzul-Church, Cimino, Adler, Wong, & Anderson, 2010; Heyland et al., 2005; Jacobs, Bonuck, Burton, & Mulvihill, 2002; Koffman & Higginson, 2001; Lynn et al., 1997; Teno et al., 2004; The SUPPORT Principal Investigators, 1995).

Seven studies used data from the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) (Baker et al., 2000; Borum et al., 2000; Claessens et al., 2000; Desbiens et al., 1996; Desbiens et al., 1999; Lynn et al., 1997; The SUPPORT Principal Investigators, 1995). The objective of SUPPORT was to “improve end-of-life decision making and reduce the frequency of a mechanically supported, painful and prolonged process of dying” (The SUPPORT Principal Investigators, 1995). Data were collected across five teaching hospitals in the USA.

The perspectives of bereaved families were captured in 17 of the studies (Addington-Hall & O’Callaghan, 2009; Baker et al., 2000; Billings & Kolton, 1999; Cantor et al., 2003; Dunne & Sullivan, 2000; Field & McGaughey, 1998; Formiga et al., 2007; Herd, 1990; Jacobs et al., 2002; Koffman & Higginson, 2001; Lynn et al., 1997; Rogers et al., 2000; Russ & Kaufman, 2005; Seale & Kelly, 1997; Sykes et al., 1992; Young et al., 2009). The time from death to data collection ranged from four weeks to two years. Four studies included the views of both patients and families (Heyland et al., 2005; Payne et al., 2010; Spichiger, 2008, 2009a). Two studies sought the family’s perspectives to describe their experience of having a family member in hospital in relation to such things as decision making and communication with health professionals. In those studies that collected data directly from patients there was variation in how participants were identified as being “palliative” or near the end of their life. The majority based this on diagnoses rather than estimated prognosis.

Seven studies compared palliative care across a number of different care settings including the hospital (Conner, Allport, Dixon, Somerville, 2008; Field & McGaughey, 1998; Herd, 1990; Koffman & Higginson, 2001; Sykes et al., 1992; Teno et al., 2004; Young et al., 2009). Two studies specifically compared palliative care in a hospital setting with care provided in a hospice

(Addington-Hall & O’Callaghan, 2009; Sykes et al., 1992). One study compared patient and family experiences of care in hospital, at home, and in aged residential care (Teno et al., 2004).

Five recurring themes were identified from the synthesised data:

- a) Symptom control and burden.
- b) Communication with health professionals.
- c) Decision making related to patient care and management.
- d) Inadequate hospital environment.
- e) Interpersonal relationships with health professionals.

Symptom control and burden.

Of the papers identified, nineteen examined patient and family experiences of care in relation to symptom control and/or symptom burden in the acute hospital setting. Two papers concluded that both patients and families rank control of pain and other symptoms as extremely important, however yet identified it is an aspect of care they are consistently most dissatisfied with (Heyland et al., 2005; Rocker et al., 2008). Furthermore, two papers reported that both patients and families will prioritise relief of pain or maintaining comfort over prolonging life (Claessens et al., 2000; Jacobs et al., 2002).

Overall the reviewed evidence indicates that hospitalised patients with a serious life threatening illness report a high symptom burden. In a study by Desbiens et al. (1999) nearly half of patients interviewed reported having one or more symptoms of at least moderate severity occurring at least half the time or of extreme severity of any frequency. Pain, dyspnoea, anxiety and depression caused the greatest symptom burden. Families also reported a high level of symptom burden for patients who were dying in hospital. For example, in one study more than 80% of family participants reported that their family member frequently experienced serious pain, dyspnoea or affective distress (confusion, depression or emotional distress) during their final hospital admission (Cantor et al., 2003).

Two studies compared family experiences of their family member’s symptom control in hospital and hospice. Addington-Hall and O’Callaghan (2009) found that significantly more patients had pain controlled “all of the time” in hospice compared to hospital (81% c/t 39%). However, there were no differences found in the prevalence of pain or the distress it caused. By contrast Seale and Kelly

(1997) reported that relief of pain and other symptoms was achieved in the majority of patients in hospital with no significant differences in the effectiveness of treatments across the two settings.

Dissatisfaction with pain and symptom control from the perspective of both patients and families featured highly in the reviewed studies. Desbiens et al., (1996) found that 50% of seriously ill patients reported extreme or moderate severe pain at least half the time and 15% were dissatisfied with pain control. In the study by Lynn et al. (1997) almost 40% of conscious patients were reported by surrogates as having severe pain and dyspnoea in the last three days of life and three quarters of these families found this distressing. The impact of witnessing a patient in pain was significant for families and became a focus of distress when left uncontrolled (Dunne & Sullivan, 2000).

Communication with health professionals.

Patient and family experiences of communication with health professionals in the acute hospital setting was a dominant theme in the review, featuring in seventeen studies. The disciplinary background of the health professionals involved was not stated in the majority of studies reviewed. Most studies drew upon bereaved family experiences of interactions with health professionals (n=14). Although there were some reports of positive experiences, across the reviewed studies the overriding view from both patients and families was that the standard of communication with health professionals in the acute hospital setting was poor.

Patients and families criticised the quality and type of information received from health professionals with reports of difficulties in understanding the language used (Koffman & Higginson, 2001). This was particularly so for conversations involving prognosis. Families also felt that they were not always kept informed of the patient's condition. As a result, death was typically perceived as happening "suddenly". The amount and type of information provided by health professionals was reported in four studies to not be tailored to individual preferences. Doctors "talking over" unconscious patients was identified as being particularly concerning to families who feared that the patient was unable to express their preference for information about prognosis and might be told something they did not want to know (Payne et al., 2010).

A common theme related to the way in which information was communicated to patients and families in hospital; this was reported to often be done badly, particularly when health professionals were giving "bad news" (Field & McGaughey, 1998; Rogers et al., 2000; Seale & Kelly, 1997).

Furthermore, in one study participants felt that staff lacked the skills required to have these difficult conversations (Rogers et al., 2000).

Studies reported that patients and families perceived busy staff as being unavailable (Dunne & Sullivan, 2000). This sense of unavailability was exacerbated further when visiting families experienced difficulties finding a doctor or nurse who could provide an update on the patient's condition. Constantly having to seek out staff to get updated information about the patient, coupled with the fact that staff rarely approached them to ask if there was anything they needed to know, left the family feeling dissatisfied.

Decision making related to patient care and management.

In a study by Young et al. (2009), being involved in decision making about patient care and management was found to be a predictor of family satisfaction in the last three days of patient life. Both patients and families rated being “involved in decisions regarding treatment and care” as an important element of end of life care (Heyland et al., 2005).

According to the reviewed studies, the majority of patients and families felt that they were involved in decisions related to patient care and treatment as much as they wanted to be (Baker et al., 2000). Heyland et al. (2005) found that over 80% of participants, including both patients and families, were satisfied or highly satisfied with how they were involved in decision making during a hospital admission. Addington-Hall et al. (2009) found that families were more likely to report that they had been involved in decisions about the patients' care in hospice than in a hospital setting.

A number of factors were identified in the reviewed studies as impacting on a family's ability to contribute and participate effectively in end of life decision making within the hospital setting. This included a lack of information about care and treatment options, lack of knowledge about the patient's condition, uncertainty regarding prognosis, difficulties in obtaining information, and receiving insufficient explanations about what staff were doing and why (Payne et al., 2010).

Two studies reflected on how families had difficulties making decisions that they perceived to be a matter of “life or death” for the patient, even when death was inevitable (Payne et al., 2010; Russ & Kaufman, 2005). In these situations families felt that using health statistics related to the patient's chances of recovery was not helpful. Feeling rushed into making these decisions increased family distress. In a study on end of life issues in stroke situations, Payne et al. (2010) found that a family's

perception of what constitutes a good death influenced their level of comfort in making decisions about resuscitation and withdrawing treatment.

Inadequate environment.

In the papers reviewed, the hospital environment was criticised as being noisy and busy and an inappropriate place to die (Dunne & Sullivan, 2000; Herd, 1990; Seale & Kelly, 1997). The perception of busyness within the hospital resulted in patients and families feeling as if they were “lost in the numbers”, which left them feeling unvalued and uncared for (Conner et al., 2008).

In a study by Dunn and Sullivan (2000), families felt that a lack of privacy impacted on their ability to have conversations with patients at a time when they wanted to talk about personal issues. In addition, families commented on a lack of interview rooms to talk privately to staff. As a result, families felt self-conscious at expressing strong emotion in public places when having conversations about end of life.

The lack of single rooms for dying patients was a concern for families who worried about the dying patient being disturbed by agitated and confused patients in multi-bed rooms. Families also expressed concerns for recovering patients being distressed by watching someone dying in the same room (Payne et al., 2010).

In studies by Rogers et al. (2000) and Spichiger (2009b) hospital bureaucracy was seen as being a barrier to effective care. Admitting procedures did not accommodate the care required to keep a patient comfortable (Rogers et al., 2000) and visiting hours were inflexible, thus causing families to feel that they were in the way if they were present outside visiting hours. Patients were moved frequently within and between wards and at a time when families perceived them as being too ill to be moved (Dunne & Sullivan, 2000).

Interpersonal relationships with health professionals.

In the reviewed papers patients and families were more inclined to remember those health professionals who took the time to show empathy and kindness. Some families felt that nurses did not take the time to show empathy towards the patient and were insensitive to families who wanted to stay with the patient (Koffman & Higginson, 2004). This was particularly difficult for those families who were the patient’s main caregiver prior to hospital admission. In one study the lack of

integration of a family's caregiving role by hospital staff led to feelings of helplessness (Dunne & Sullivan, 2000).

Family perceived busy nurses as not having time to spend with patients to find out what was important to them. In a study by Spichiger (2008), this left patients and families feeling forgotten and not cared for. In contrast, when families felt cared for it was often in response to staff who were attentive to their needs, appeared approachable and friendly, and checked in frequently with family to make sure they had what they needed.

In a study by Young et al., (2009) there was a high correlation with patient satisfaction and being treated with respect and dignity.

4.1.5 Discussion.

This integrative review provides an overview of international evidence regarding patient and family experiences of palliative care in a hospital setting. The evidence suggests that patients experience a significant symptom burden with poor management of symptoms while in hospital. The hospital setting is considered to be an inappropriate environment for dying patients, being too busy and noisy and lacking privacy. Being involved in decision making related to patient care and management can be difficult for families and a number of factors impact on their ability to do this effectively. Furthermore, patient and family experiences of communicating with health professionals and establishing a positive relationship are challenging in the hospital setting.

Differences in patient and family experiences of palliative care with different diagnoses have been reported in previous research. Those with a non-cancer illness are more likely to experience repeated hospital admissions (Rosenwax et al., 2011) and less likely to receive input from hospice palliative care services compared to those with cancer (O'Leary & Tiernan, 2008; Skilbeck & Seymour, 2002), despite the fact that their palliative care needs can be significant (Solano, et al., 2006). The studies identified in the review included patients with a wide range of diagnoses and were at varying stages of the illness trajectory, although most studies did not report details of illness stage. This makes it difficult to come to any conclusion regarding differences in patient and family experiences of hospitalisations by diagnosis or prognosis.

Moreover, a number of design issues were identified in the reviewed studies and as a result we only have a limited understanding of the overall experiences of patient and family. Firstly, the use of

satisfaction-based studies limits our understanding of the overall experience of care in hospital for the patient and family. Whilst satisfaction surveys are widely employed to elicit the views of service users they often use closed questions addressing the priorities of the service provider or researcher rather than the service user. In addition, expectation is considered to be a major determinant of satisfaction and is largely related to an individual's perceptions of the benefits of care and the extent to which these meet their expectations (Sitzia & Wood, 1997). However, this was not addressed in any of the studies.

Secondly, using symptom prevalence as an indicator of a patient's overall experience of palliative care in hospital is limiting. It would not be unusual to find patients in a hospital setting with a high symptom burden during a period of acute illness, and in fact this is often what precipitates an admission to hospital (Wallace et al., 2012). In view of the fact that the hospital setting is often criticised as being poorly prepared to provide adequate symptom control at the end of life (Le & Watt, 2010; Walling et al., 2010) exploring the effectiveness of symptom management may be more useful.

Thirdly, using patient proxies provides a limited understanding of patient experience. Fifteen studies in the review used patient proxies to a varying degree as a way of understanding the patient's experience of care in hospital. This included information regarding the severity of symptoms such as pain and dyspnoea. Whilst data collected after death from proxies are a vital source of information in palliative care, the validity of reporting has been questioned. Factors such as the previous relationship with the patient, caregiver burden and an individual's beliefs and expectations of care can impact on the congruence between patient and proxy reporting. Proxies have been shown to be reliable reporters on the quality of services and on observable symptoms, however agreement is poorer for subjective symptoms such as pain, anxiety and depression (McPherson & Addington-Hall, 2003). Accuracy of recall is influenced by the period of time between the experience and the recollection of the experience. In those reviewed studies that used data collected from family, all but one study surveyed families who were bereaved. The time from death to the collection of data varied considerably and ranged between one month and two years. Retrospective data collection from families post-bereavement has been shown to change significantly over time, particularly in regards to symptoms such as pain and depression (McPherson & Addington-Hall, 2004).

Finally, comparing experiences of hospital care with that which is provided in other settings such as hospice may not be that useful. Some aspects of hospital care are unlikely to ever meet the same

standard as hospice care. For example, the homely environment provided by hospices is difficult to emulate in a hospital setting (Brereton et al., 2012). In the latter setting, multi-bedded rooms are commonplace and patient turnover is high. Providing an appropriate level of privacy, cleanliness and easy proximity to family and friends has been identified by patients, families and health professionals as being important in hospital end of life care (Brereton et al., 2012) and yet the hospital continues to be cited by patients and families as an inappropriate setting primarily because of its limitations in providing these aspects of care.

Limitations.

This integrative review synthesises the current international evidence base regarding patient and family experiences of palliative care in an acute hospital setting. Electronic search, retrieval, and review strategies were used; however, the search is subject to some limitations. Databases were limited to English, and due to resource limitations, a search of the “grey literature” was not carried out. As a result, some studies may have been missed.

4.1.6 Conclusion.

Despite the fact that people express a preference to be cared for and die at home or in a hospice, hospitals continue to play a significant role in providing palliative care. In many countries the majority of people still die in a hospital setting and many will be admitted to hospital during the last year of their life.

This review has identified that, largely as a result of study design, our knowledge of patient and family experiences of palliative care in an acute hospital remains limited to discrete aspects of care. Further research is required to explore the total patient and family experience taking into account all aspects of care, including the potential benefits of hospital admissions in the last year of life.

4.2 Chapter summary.

Most patients with a life limiting illness will spend some time in hospital in the last year of their life (Goldsbury et al., 2015). In the majority of resource rich countries, most people will also die in a hospital setting (Gomes & Higginson, 2008). This chapter has presented a systematic integrative review that identifies a key gap in the current international evidence regarding the experiences of hospital admissions for people with palliative care needs. In particular, the review found a lack of knowledge related to the benefits of being in hospital. Indeed, whilst the review findings suggest palliative care in hospital is largely a negative experience for patients and families, current evidence

is limited to very discrete aspects of care and does not reflect the total experience of care in a hospital setting for those with life limiting illnesses. It was this gap in the literature, combined with my experience of providing palliative care in the acute hospital setting (see Chapter 4), that provided the impetus for my doctoral research and confirmed the appropriateness of my research questions:

- What are the experiences of benefit and burden of hospital admissions in palliative care?
- How do the experiences of benefit and burden influence patient preferences to return to hospital?

Building on this chapter, the next chapter provides an overview of mixed methods and explains the rationale for choosing this particular methodology to address the questions posed.

Chapter 5: Methodology.

5.1 Preamble.

This chapter describes mixed methods as the chosen methodology for my study and outlines the typologies associated with this approach. The way in which data quality was achieved is described, along with a discussion of critical realism, the philosophical framework of this study.

The choice of methodology should be determined by the nature of the research topic or question (Creswell, 2009). My study addressed the questions:

- What are the experiences of benefit and burden of hospital admissions in palliative care?
- How do experiences of benefit and burden influence patient preferences to return to hospital?

Before embarking on the study itself, I wanted to address a number of key issues. Firstly, I needed to understand how hospitals were viewed within a contemporary Western palliative care context. Completing a policy review (see Chapter 2) revealed that hospitals continue to be benchmarked against the concept of the “good death”, a model of dying that has had a significant influence upon the modern hospice movement and now underpins palliative care philosophy. This has resulted in such policy continuing to focus largely on reducing or preventing patients from being admitted to hospital, with little attention paid to patient experience and, in particular, any benefits of hospitalisation. Secondly, I needed to determine the current state of evidence regarding patient experiences of palliative care in the hospital setting (see Chapter 4). Overall, the literature review revealed a gap in knowledge and understanding of patients experiences of being in hospital in a palliative care context. In addition the literature review identified that previous research had focused predominantly upon the negative aspects of care.

However, despite patients with palliative care needs having negative experiences of being in hospital, we know that patients spend a significant amount of time in hospital in the last year of their life (Bardsley, Goerghiou, Spence, & Billings, 2016). The policy and literature reviews therefore led me to refine my research topic and develop the central questions guiding my study as outlined above. I decided that a mixed approach was best suited to address my question and thus begin this chapter by describing this methodology.

5.2 Mixed methods research.

Mixed methods has been defined as “the class of research where the researcher mixes or combines quantitative and qualitative research techniques, methods, approaches, concepts or language into a single study” (Johnson & Onwuegbuzie, 2004). Integrating data at certain points in the research process is an important component of mixed methods research. A key issue for mixed methods researchers is deciding upon a unifying philosophical framework that supports the use of both quantitative and qualitative methods. In the following section I discuss the philosophical assumptions that underpinned my approach to mixed methods research.

5.2.1 Philosophical considerations.

In order to understand the philosophical assumptions that underpin a particular approach to research it is useful to reflect on the dominant paradigms associated with qualitative and quantitative research. Paradigms are defined as “systems of beliefs and practices that influence researchers to select both the questions they study and methods that they use to study them” (Morgan, 2007). In their broadest sense, paradigms can be considered as a “world view; being the way in which the researcher experiences and thinks about the world including their values, beliefs and morals” (Creswell, 2013). A world view is said to be influenced by the orientation of a discipline in terms of how knowledge is created (epistemology) and the nature by which an individual views reality (ontology). Thus, being clear about the researcher’s position in relation to a particular paradigm or world view (see Chapter 3) provides the reader with clarity regarding the philosophical assumptions researchers are bringing to their research.

Quantitative researchers are traditionally aligned with a post-positivist paradigm where outcomes are considered to be as a result of a complex array of causative factors that interact with each other (Giddings & Grant, 2006). A commitment to objectivity and a belief that there can only be one reality is a characteristic of quantitative methodology, with researchers striving to be free from “bias” and “remain objective” by separating themselves from participants as much as possible (Robson, 2011). In contrast, qualitative researchers typically align themselves with constructivism, a paradigm that embraces the notion of multiple realities and knowledge, which grows from understanding the subjective experience of individuals (Creswell, 2013). Table 5-1 outlines the ontological, epistemological, and axiological differences between quantitative and qualitative methodologies.

Table 5-1

Differences in Qualitative and Quantitative Methodologies (Robson, 2011)

	Quantitative	Qualitative
Ontology	Single reality	Multiple realities
Epistemology	Researcher and researched maintain separation	Researcher and researched are dependent on one another
Axiology	Value free	Values are influenced by the researcher

Mixed methods has been described as the third methodological approach, alongside qualitative and quantitative methodology (Johnson & Onwuegbuzie, 2004). However, the paradigms that underpin qualitative and quantitative approaches are considered to be polar opposites by some who argue that they should not be mixed because the epistemological positions of the methodologies are essentially incompatible (Sale, Lohfeld, & Brazil, 2002). This polarising discourse, which has previously dominated the research literature, evolved into what has been described as a “war of paradigms” where “one professing the superiority of deep, rich observational data and the other the virtues of hard, generalizable . . . data” (Sieber, 1973, p. 1335). However, more recently it has been argued that we should instead move beyond this polarisation to view these approaches as sitting on a continuum of philosophical views (Johnson & Onwuegbuzie, 2004). Indeed, it has been suggested that qualitative and quantitative researchers have similarities in the way they approach their research (Onwuegbuzie & Leech, 2005). For example, both use empirical observations to address their research questions and use strategies to strengthen their studies’ validity or trustworthiness.

In summary, while there has been some criticism of the “mixing” of two philosophically opposed paradigms (Greene, 2008), mixed methods is increasingly regarded as a useful approach to provide a more comprehensive understanding of complex phenomena (Creswell, 2013). The following section will discuss the evolving model of mixed methods as a research methodology.

5.2.2 The emergence of mixed methods.

Mixed methods research is still considered to be a relatively new research methodology (Doyle, Brady, & Byrne, 2009; Johnson et al., 2007), although this approach has been identified in the work of cultural anthropologists in the 1950s and 1960s. However, it was not until later, in response to the recognised limitations of using qualitative or quantitative approaches alone (Doyle et al., 2009), that mixed methods as a recognised approach began to find some acceptance in the research world. Until then, researchers were forced to choose between the dichotomy of qualitative and quantitative

paradigms. However, it has been argued that mixed methods is an approach that bridges the gap between qualitative and quantitative approaches (Johnson & Onwuegbuzie, 2004), providing researchers with a third methodological approach that may be more aligned with their philosophical position.

Mixed methods researchers traditionally align with pragmatism. Pragmatism has been defined as being a paradigm with no commitment to a particular system of reality or philosophy (Creswell et al., 2010). Pragmatists will choose whatever method or technique they feel best answers their research question, believing that “truth is what works at the time” (Creswell & Clark, 2010, p. 39). While many have regarded pragmatism as the most appropriate philosophical framework for mixed methods research (Biesta, 2010; Onwuegbuzie & Leech, 2005; Maxwell & Mittapalli, 2010) suggest that pragmatists fail to acknowledge the influence of the researcher’s philosophical assumptions on the research method, which is particularly important when mixing qualitative and quantitative methods. They argue that critical realism provides a philosophical perspective that “. . . validates and supports key aspects of both qualitative and quantitative approaches while identifying some specific limitations of each. . . .” (Maxwell and Mittapalli, 2010, p148). The following section will provide an overview of critical realism as the chosen philosophical framework for this study.

5.2.3 Critical realism and mixed methods.

The ontology of critical realism makes a distinction between three types of reality: the real, the actual, and the empirical (Schiller, 2016). The “real” domain consists of the differing structures that must occur in a certain combination for an event or outcome to manifest. These structures or causal mechanisms are considered by critical realists as being generative and cannot be observed, but can be inferred through a combination of empirical investigation and theory construction (McEvoy & Richards, 2006). The existence of these real underlying structures is said to not rely on individual perception or experience and instead exists outside the awareness of human beings (Schiller, 2016). Actual reality is one that can be experienced as a result of the interplay of differing structures, but it does not depend on this experience to exist. Finally, empirical reality is considered by critical realists as being reality that is constructed by human perceptions and experiences (Schiller, 2016). However, critical realists believe that human accounts of reality are potentially flawed because their account of reality fails to consider wider mechanisms, such as socio-cultural factors, that influence actual reality (Schiller, 2016).

For critical realists, the objective of research is not to identify one truth or to identify the lived experience of an individual, but to develop a greater depth and breadth of the understanding of a particular phenomenon (McEvoy & Richards, 2006). In doing so, critical realists believe that the choice of methods should be dependent on the type of question being asked; therefore, the mix of qualitative and quantitative methods is considered an appropriate method of knowledge development (Maxwell, 2012; McEvoy & Richards, 2006), thus providing opportunities for critical realist researchers to integrate all domains of reality.

The way in which I have developed my knowledge in both the “art” and “science” of nursing and palliative care (see Chapter 4) aligns well with the philosophical positioning of critical realism. For example, the philosopher Roy Bhaskar (1998), founder of critical realism, describes two types of knowledge – knowledge that does not depend on the activity of people, such as gravity or death, and knowledge that is developed by people, such as concepts, facts and theories. Critical realists view the nature of truth in different forms, combining a social constructionist epistemology (understanding the world is a construction from one’s own perspectives) with a realist ontology (the view that a real world exists independently of one’s perceptions, theories and constructions) (McEvoy & Richards, 2006).

5.3.1 Mixed methods design.

Mixed methods research can be carried out using a number of different designs. Outlining the chosen design of mixed methods research supports the credibility of the study by providing clarity on how, and at what stage of the research process, integration of data will occur (Bryman, 2006). It was Tashakkori and Teddlie (2010) who first described a mixed methods design using the term “typology”, in order to develop a common language to articulate the way in which a study is designed. Classification of typologies can be based on the number of phases of the research process, the way in which data is mixed and prioritised, and/or the stages in which the mixing of methods/data occurs.

5.3.1 Mixed methods typologies.

Mixed methods may use single or multiple phases. The mixing of data collection may be sequential, concurrent, or embedded, and the researcher may prioritise the qualitative phase over the quantitative phase or vice versa. Furthermore, the way in which the phases are mixed can vary, with some studies using only supplemental data from a particular phase, while others using the whole data set. The timing of data mixing may be partial or full and occur concurrently or sequentially.

Finally, the mixing of data may occur throughout the research process, including during sampling, data collection and/or data analysis. These factors contribute to the formation of a particular typology of mixed methods research.

Although a number of different mixed methods designs have been described (Creswell et al., 2010; Tashakkori & Teddlie, 2010) some have criticised the over emphasis on the specifics of study typology, suggesting that they have become almost “too refined” and are largely created in theoretical terms (Bryman, 2006). Nevertheless, outlining the chosen typology or design is recognised to be an important element in achieving rigor in mixed methods research. For example, Creswell (2014) argues that decisions such as the sequence of each strand (or phase), the emphasis paid to each strand, and the point in which integration or mixing will occur needs to be outlined in the study design. He outlines three specific mixed methods designs (Creswell, 2014).

Convergent parallel: in this approach the researcher combines the quantitative and qualitative data to provide a comprehensive analysis of the research topic. Data from both strands of the study are collected concurrently and are integrated into the findings.

Explanatory sequential: this approach is described as sequential with the researcher completing the quantitative strand first, followed by the qualitative strand. The findings from the qualitative strand are used to explain the quantitative results in more detail. The emphasis tends to be on the quantitative strand in this design.

Exploratory sequential: this approach is in reverse to the explanatory sequential design and the emphasis tends to be on the qualitative phase. The study starts with the qualitative strand, with these findings used to inform the subsequent quantitative phase. For example, the qualitative data may be used to inform the development of a survey or questionnaire, to identify appropriate data collection tools, or to identify variables that should be included in the quantitative phase.

My doctoral study adopted an exploratory sequential design using the findings from the qualitative phase (see Chapter 7) to inform the subsequent quantitative phase (Chapter 8). Specifically, the Phase 1 findings were used to inform the development of the Phase 2 questionnaire survey.

In addition to outlining the design of a mixed methods study, the researcher must also utilise techniques that will promote and demonstrate the quality of the research. The following section will outline a framework to assess quality throughout the research process.

5.3.2 Inference quality.

Some commentators have suggested that, in order to achieve quality in mixed methods research, one must evaluate the qualitative and quantitative phases separately prior to mixing data (Tashakkori & Teddlie, 2008). However, conversely, it has been argued that this siloed approach to demonstrating research quality supports the criticism that combining the two conflicting paradigms is not possible (Tashakkori & Teddlie, 2008).

An alternative approach to demonstrating the quality of mixed methods research is to use an integrated inference quality framework to assess the way in which the data is interpreted at the end of each strand (or phase) and again when the strands are mixed in order for the researcher to make “meta inferences” (Tashakkori & Teddlie, 2008). Inferences at each point need to be of good quality to be valid. I adopted this approach for the purposes of my study and recognised interpretative rigor as essential to achieving inference quality and, ultimately, credible findings. Inference quality for this study was achieved at various stages of the research process. Strategies used to achieve inference quality are included in Chapters 7 and 8 in relation to each phase of the study. In addition, inference quality is addressed during the discussion, where the mixing of data from both phases is presented.

5.5 Chapter summary.

Mixed methods research is thought to be particularly appropriate in palliative care research where “the majority of interventions are complex, and the process of evaluation and identification of certain outcomes is particularly challenging” (Farquhar, Ewing, & Booth, 2011). In this chapter, I have outlined why mixed methods was selected to address my particular research question, as well as provided information about the study’s philosophical underpinnings, namely critical realism. A discussion was provided regarding the various typologies or designs used in mixed methods, and strategies used to maximise inference quality. The next chapter will build on this discussion by providing details regarding the study context, including the study setting, sampling and recruitment, and ethical considerations.

Chapter 6: My Study Design.

In the previous chapter I provided an introduction to mixed methods and the various designs or typologies that can be used in this methodology. This chapter provides the rationale for selecting a mixed methods design for my study. In addition, I provide an overview of the study aims and objectives, the chosen typology, and details regarding the study setting, recruitment, sampling and methods of data collection. Finally, I will discuss ethical considerations, with a particular emphasis on those ethical issues unique to palliative care research. Further details regarding ethical issues specific to each phase of the study are included in Chapters 7 and 8.

6.1 Rationale for mixed methods.

There are a number of reasons why I chose mixed methods as the methodology for my study. Firstly, the research question: *What are the experiences of benefit and burden of hospital admissions in palliative care?* was directly related to patient experience. Adopting a qualitative approach would provide an opportunity for me to explore directly with patients their experiences of benefit and burden as a result of being in hospital. The second question: *How do experiences of benefit and burden influence patient preferences to return to hospital?* required an approach that would identify relationships between a patient's experiences and their preferences to return to hospital, and was thus best suited to a quantitative approach.

Secondly, using the findings from a qualitative approach I could be certain that the concepts used in the quantitative phase were directly related to patient experiences (of benefit and burden) rather than a theoretical, or professionally informed, understanding of what occurs during a hospital admission for people with palliative care needs.

Finally, combining qualitative and quantitative approaches provides a breadth and depth of understanding about the benefits and burdens of hospitalisation for those with palliative care needs, which could not have been achieved by using a single methodology (Creswell et al., 2010). In addition, mixing approaches provided an opportunity to use the knowledge gained from one strand to inform and develop subsequent strands, as described in the previous chapter.

In summary, this study used an exploratory, sequential mixed methods design, starting with a qualitative strand (Phase 1, described in Chapter 7). The findings from the qualitative strand were used to develop a questionnaire survey (Appendix 3.5) for Phase 2, described in Chapter 8).

6.2 Study Aims and Objectives.

The overall aim of this study was to explore the benefits and burdens of hospital admission for people with palliative care needs and explore how these influence preferences to return to hospital. Using a two phase, mixed methods approach the objectives of this study were:

1. To understand how the acute hospital is positioned in health policy in the provision of palliative and end of life care.
2. To explore what is currently known about patient and family experiences of palliative care in the hospital setting.
3. To explore the benefits and burdens of hospital admissions from the perspectives of patients with palliative care needs.
4. To identify the factors associated with experiences of benefits and burdens of hospital admission for people with palliative care needs and examine how these influence preferences to return to hospital.

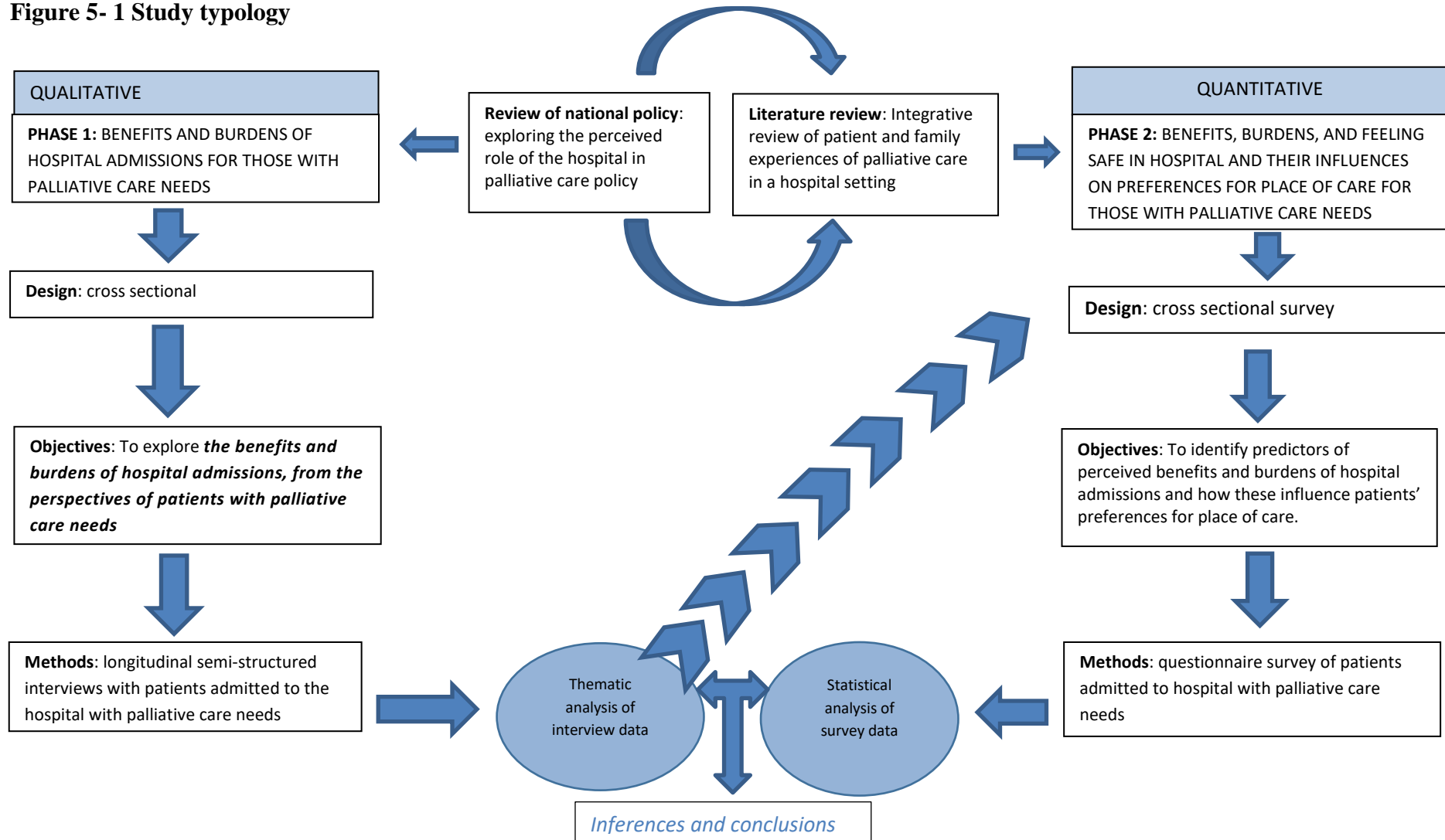
6.3 Study design.

A two-phase, mixed methods was conducted to address the study aim and objectives. The gap in research evidence identified in the existing literature, regarding patient experience of hospital within a palliative care context, meant that an exploratory qualitative study was important. Therefore, Phase 1 involved collecting data using semi-structured interviews from 14 people admitted to hospital who met the Gold Standards Framework Prognostic Indicator Guide criteria indicating presence of palliative care needs (see 6.6.1). Participants were interviewed twice: firstly, within 48 hours of being admitted to hospital, and again within one week of being discharged. Data from Phase 1 were used to inform the development of Phase 2, which comprised a questionnaire survey of 116 hospital inpatients who met the same criteria for palliative care need used in Phase 1. The questionnaire was used to collect data on the concepts related to benefit and burden, which had been identified in Phase 1 (see Chapter 8), as well as preferences to return to hospital. Using the Phase 1 findings ensured the questionnaire was relevant to the population being surveyed.

Mixing of data did not occur until after the analysis of each phase was completed. Inferences and conclusions were made by comparing and contrasting findings from the two study strands (see Figure 5-1). As outlined in the previous chapter, this sequential design used qualitative and quantitative methods in consecutive phases with each strand informing the development of questions

for subsequent strands. However, the two strands of inquiry remained independent of each other, including during data collection and analysis.

Figure 5- 1 Study typology



6.4 Study typology.

As discussed in the previous chapter, a two phase, sequential mixed methods typology was adopted for this study. The full details of each phase are provided in Chapters 7 and 8.

6.4.1 Phase 1.

Using a qualitative approach, the objective of Phase 1 was: *to explore the benefits and burdens of hospital admissions from the perspectives of patients with palliative care needs* (see Chapter 7).

Qualitative methodology provides the researcher with mechanisms to explore the meanings behind individual experiences of a particular phenomenon (Turner, 2010), from the choice of data collection to the strategies used in data analysis and interpretation of findings.

Semi-structured interviews were used as the method of data collection. Using prompts in the form of open-ended questions, semi-structured interviewing uses a facilitatory approach allowing the participant to discuss issues they feel are most relevant to the research topic.

The interviewer's role in semi-structured interviewing is to encourage and facilitate ongoing discussion while ensuring that the overall focus of the interview is maintained. A copy of the interview schedule used in this study can be found in Appendix 2.5. Details of how the interview schedule was developed are included in Chapter 7.3. Participants were identified on admission to hospital (see section 6.3) and were interviewed twice – at the start of hospital admission and again one week after the admission.

The choice of data analysis in this study was a form of thematic analysis as described by Braun and Clark (2006). This approach uses a coding of narrative taken directly from the transcribed interview. Reading and re-reading the interview transcript results in the emergence of common themes, which require a level of interpretation by the researcher. Further details of the thematic analysis process used in Phase 1 is provided in Chapter 7.3. Finally, Phase 1 was not only an opportunity to identify the elements related to experiences of benefit and burden, as identified by patients. It also identified key concepts that could be employed in the development of the questionnaire used in Phase 2 details, which can be found in Chapter 8.

6.4.2 Phase 2.

Using a questionnaire survey, Phase 2 adopted a quantitative approach surveying patients admitted to hospital with palliative care needs (see Chapter 8). The aim of Phase 2 was to *explore benefits and burdens of hospital admissions and examine how these influence preferences to return to hospital.*

A quantitative approach provided an opportunity to explore the relationships between study variables using a process of statistical testing. Participants were identified at the time of admission (see section 6.3) and were interviewed as they neared the end of their admission to hospital. Using the concepts identified in Phase 1, participants were asked to rate statements related to benefit, burden, and preferences to return to hospital. In addition, they were asked about the support they were receiving at home prior to the admission (see Appendix 3.3 for a copy of the questionnaire).

Techniques used in quantitative data analysis involve a range of statistical tests. This allows for relationships between variables (or concepts) to be identified. This was a major component of Phase 2.

Mixing of data did not occur until after the analysis of each phase was completed. Inferences and conclusions were made by comparing and contrasting findings from the two study strands (see Figure 5-1). A synthesis of the two strands occurred after completion of both phases (see Chapter 9).

6.5 Study setting.

Recruitment for both phases of this study took place at Auckland City Hospital (ACH). Auckland City Hospital (ACH) sits within the Auckland District Health Board (ADHB) and is the largest public hospital in New Zealand, experiencing over two million patient contacts per year. ACH has approximately 700 adult inpatient beds and experiences around 150,000 admissions every year. ACH provides care for a district population of 468,000 people and provides tertiary services for a regional population of approximately 1.3 million. In addition, ACH provides a number of national specialist services for New Zealand (Auckland District Health Board, 2014).

I have been a co-investigator on a number of recent studies to explore issues relevant to palliative care management at Auckland City Hospital. This work provided important context for the design and interpretation of my research. A prospective census conducted in 2013 of palliative care need amongst adult inpatients identified that 19.8% of the total census population met Gold Standards Framework Prognostic Indicator Guidance (GSF-PG)(Gold Standards Framework) for palliative care need. The sample was followed prospectively, with 67.7% having died within 12 months after the census date. The sensitivity and specificity of the GSF-PG at one year was 62.2% and 91.9% respectively and it was found to have a positive predictive value of 67.7% and a negative predictive value of 90%. This demonstrated that the GSF-PG is a suitable tool for identifying patients with palliative care need in the acute hospital setting (O’Callaghan et al., 2014). Almost one half (47%) of the sample we identified had a cancer diagnosis, with other diagnoses comprising heart disease (11.1%), renal disease (8.1%), chronic obstructive pulmonary disease (5.1%), and frailty (5.1%). Although most had evidence of a palliative approach documented in their clinical notes (78.8%), very few had any documentation about goals of care (Gott, Frey, Robinson, Boyd et al., 2012) and 22% were thought to have experienced a potentially avoidable admission (Robinson, Boyd, O’Callaghan, Laking et al., 2014).

A survey of clinical staff working at Auckland Hospital found that staff spent on average 19.3% of their time caring for patients at the end of life and rated this care as “good”. However, only 19% of the respondents reported having had received any formal education in palliative care and most would like to receive additional training (Frey et al., 2013). A further study, also carried out at Auckland City Hospital, exploring the attitudes of ward staff on the role of the hospital in palliative care, found that ward staff based their views on the “appropriateness” of an admission to hospital in relation to their beliefs about what constituted a “good death”. Their views of a “good death” typically involved being cared for in a homely environment. Participants identified a number of reasons for what they perceived to be “inappropriate hospital admissions in palliative care, including inadequate resourcing of community services, family carers being unable to cope, and the “rescue culture” of the hospital setting (Gott, Frey, Robinson, Boyd, et al., 2013).

Similar to other large, tertiary hospitals in high income countries (Clark et al., 2014; Gardiner et al., 2012), these studies demonstrate significant palliative care need in the adult inpatient population at Auckland City Hospital. Furthermore, they confirm the need to build palliative

care capacity within the hospital setting. Increasing capacity firstly requires a better understanding of how patients experience palliative care in hospital and how this influences their preferences to return. Therefore, given the nature of the research question for this study, Auckland City Hospital was considered an appropriate study site.

In summary, Auckland City Hospital was chosen as the study site because: 1) it has a large number of admissions across a variety of different medical specialties including some regional services; 2) previous research (as described above) has established the proportion (19.7%), and characteristics of patients with palliative care need experiencing a hospital admission (Gott, Frey, Robinson, Boyd et al., 2013), as well as other findings relevant to palliative care management in this setting; and 3) I am employed as a Nurse Practitioner with the Auckland City Hospital Palliative Care Team and have well established connections within the hospital and with community-based palliative care services (although this brought both advantages and disadvantages as described in Chapters 4 and 10).

6.6 Sampling and recruitment.

Although the sample characteristics were not pre-determined for this study, factors identified from the literature known to influence experiences of hospital admissions such as age, diagnosis, and ethnicity (Bowling, Illiffe, Kessel, & Higginson, 2010; Gardiner et al., 2010; Pinnock et al., 2011) were taken into account during participant recruitment. A purposeful approach to sampling as described by Coyne (1997) was adopted in both phases of the study. The reason for choosing this approach was two-fold. Firstly, I was familiar with the characteristics of the sampling frame in terms of age, gender, ethnicity, and diagnosis (Gott, Frey, Raphael, O'Callaghan et al., 2012), and secondly, purposeful sampling gave me an opportunity to select participants with certain characteristics to ensure that my sample was relatively representative of the hospital inpatient population.

Recruitment for both phases was limited to those patients admitted and discharged from ACH between Monday and Friday, which is when the majority of hospital discharges occur. The procedure for recruitment was also the same for both phases. Admissions were screened by myself using the Gold Standards Prognostic Indicator for palliative care need (see following section) using clinical information from the hospital patient management system. Those patients that met the inclusion criteria (see Table 6-1) were invited to participate in the study by the ward nurse who provided them with a copy of the Patient Information Sheet (see

Appendix 2.2 Participant Information and Consent Form (Patient). If the patient was interested in participating in the study, I would meet with them to discuss the study in more detail and obtain written consent.

Table 6-1
Inclusion Criteria

Inclusion criteria
Admitted < 48 hours prior to contact
Inpatient at ACH
Speaks English
Not referred to hospital palliative care team
Meets one or more of the GSF PIs
Aged >18-years-old
Patient not imminently dying
Cognitive capacity to be interviewed

6.6.1 Gold Standards Framework Prognostic Indicator Guide.

The Gold Standard Framework Prognostic Indicator Guide (GSF-PIG) was used as a screening tool to identify eligible participants (see Appendix 2.4 Gold Standards Framework Prognostic Indicator Guide). The GSF-PIG was developed as part of the Gold Standards Framework which is a care programme designed to support primary health practitioners to identify patients in the last year of life. The GSF-PIG is designed to assist clinicians in identifying patients who have palliative care needs by listing clinical indicators for several life limiting illnesses. Whilst primarily developed for the primary health care setting, the GSF-PIG has been shown in research to be effective in identifying patients who are likely to be in the last year of life (Gott Robinson, Frey, Raphael, O’Callaghan et al., 2013; Gardiner, Gott, Ingleton, Seymour, Cobb et. al, 2012). Furthermore, as noted above, the GSF-PIG has been shown to be highly specific and moderately sensitive screening tool within an acute hospital setting when used by experienced palliative care clinicians (O’Callaghan, Laking, Frey, Robinson et al., 2014).

In order to understand the size of the sampling frame available for my study, I undertook an analysis of Auckland Hospital admission data over a 12-month period (July 2011–June 2012). This revealed that there were 17,020 admissions for 10,208 patients with at least one of the GSF diagnoses during this period (although it is important to note that not all these patients would meet the additional prognostic criteria). The eligible population therefore consisted of all adult patients admitted to ACH with evidence of a GSF diagnosis in the

clinical records. Hospital admission data showed the top four admitting services for patients with a diagnosis listed on the GSF-PIG were General Medicine, Medical and Radiation Oncology, Urology, and General Surgery. Therefore, recruitment focused on admissions to these four areas of the hospital.

6.7 Ethical considerations.

Attention to research ethics is an essential component of research design and an important element to be considered throughout the research process to ensure that participants, non-researchers and researchers are protected. A recent critical review of the literature identified key arguments related to the ethics of palliative care research and has provided a framework for the following discussion (Duke & Bennett, 2010). Where the framework relates to ethical issues specific to each phase of the study, these are included in the preambles of Chapter 8 and Chapter 9.

Ethical approval.

Ethical approval for Phase 1 (see Chapter 8) was provided by the University of Auckland's Human Ethics Committee (UAHEC9499). Ethics approval for Phase 2 (see Chapter 9) was provided by the Health and Disability Ethics Committees (15/CEN/109). Documentation associated with the ethics application for each phase is included in Appendices 2.1 and 3.2.

Is the research morally appropriate?

In order for the research to be considered “morally appropriate” a number of issues need to be addressed. Firstly, the aim of the research must be to address an issue on which nothing is known about or there is some disagreement in the “expert community” (Duke & Bennett, 2010). The literature review (see Chapter 5) established a need to fully understand the experiences of hospital admissions for those with palliative care needs. Furthermore, the policy review highlighted how the hospital is positioned in policy and practice and the limitations of the evidence this is based upon.

Secondly, in order for the research to be morally appropriate, it must be aimed at producing new knowledge (Duke & Bennett, 2010) Given the argument discussed above, the moral imperative must be to produce new knowledge about patient experience, which is inclusive of not only the burden of being in hospital, but also the benefits. Indeed, how these experiences influence patient preferences to return to hospital throughout the illness trajectory, not just in

the last days of life, is an essential component of the “preferences for place of care” argument that views care at home as the ultimate achievement and supports the need to minimise or reduce hospital admissions in palliative care.

Thirdly, in gathering this new knowledge, the risk to participants must be balanced with the benefits of participating. Minimal risk is considered to be “that which does not expose people to harm or discomfort greater than which they would encounter in every day life or during an episode of care” (Karlawish, 2003). The ethical principle of beneficence is central to ethical research, protecting participants from any harm associated with participation in the research.

Maintaining confidentiality and/or anonymity can be key to this and was a central consideration for my study. Data were collected in such a way that individual participants could not be identified from within the data set. Storage of electronic data was on a password-protected computer and paper-based data was stored in a secure cabinet at the School of Nursing. Access to the data was limited to JR and her supervisors. All data will be destroyed after six years. Access to clinical information was limited to myself; as an ADHB employee, I was working under the ADHB Staff and Patient Confidentiality Agreement.

Are research participants likely to be vulnerable?

There has been substantial debate in the literature about the “vulnerable” nature of the study population for palliative care research (Duke & Bennett, 2010). Yet, there is little evidence to support concerns raised regarding the “vulnerability” of those with palliative care needs. Indeed, evidence has shown that patients value the opportunity to participate in research, basing their decision on altruistic reasons and knowing that what they contribute to the research findings may not specifically benefit themselves, but has the potential to benefit others (Bellamy et al., 2011). Others have argued that patients with palliative care needs cannot be considered a cohort of frail, dying patients (Mount, Cohen, MacDonald, Bruera, & Dudgeon, 1995). Indeed, with the mainstreaming and upstreaming of palliative care seen in the past decade (see Chapter 1) those with palliative care needs are being identified much earlier in the illness trajectory and many are still living active and full lives and would not consider themselves to be vulnerable. Classifying them as such therefore challenges their autonomy to make decisions for themselves.

All participants of research should be treated as autonomous decision makers (Judkins-Cohn, Kielwasser-Withrow, Owen, & Ward, 2014). Respecting a patient's autonomy is an important component of ethical research. Participants have a right to refuse to be involved in the research and can choose to withdraw at any time and without explanation. This process was highlighted during the consent process and detailed in the Participant Information Sheet used in both phases. At the start of the second interview (in Phase 2) an overview of the study was provided to participants and they were given the option to withdraw at that time. Furthermore, participants were reminded that the interview could be discontinued at any time with no impact on their care.

Informed consent is underpinned by the ethical principles of autonomy and beneficence (Judkins-Cohn et al., 2014). Obtaining informed consent requires each participant to understand the implications of participation. Due to the deterioration of physical health of the study population, a fluctuating level of cognition due to the effects of serious illness causing a delirium is not uncommon (Hosie, Davidson, Agar, Sanderson, & Phillips, 2012).

In this study, consent from eligible participants to meet with the researcher was obtained by the ward nurses. This was followed up again by myself as I introduced the study in more detail to participants. Written consent was obtained from all participants (see Appendix 2.2). Given the risk of fluctuating cognition in this population, a judgement of participants' cognitive state and their ability to answer the interview questions took place during recruitment, obtaining consent, and throughout the interview process.

Are researchers likely to be exposed to risk/harm?

Palliative care researchers are at risk from being repeatedly exposed to the distress and suffering associated with patients who are nearing the end of their life. Interviewing participants regarding their experiences can be stressful (Sivell et al., 2015). Furthermore, analysing interview data and repeatedly listening to distressing stories during the transcribing process can become an emotional burden, reminding the researcher of their own mortality or indeed bringing up their own previous experiences of death and dying (Clark et al., 2000).

Personal awareness and the emotional labour associated with working in palliative care is something I have become aware of in my professional work as a palliative care nurse. For many years, I have attended monthly personal supervision sessions, which provide me with an opportunity to process the emotional labour of my work. Supervision continued throughout the research period. Furthermore, I used regular meetings with my supervisors to debrief and explore strategies to manage the challenges of being a palliative care researcher alongside being a clinician.

Whilst being an experienced clinician in palliative care provided me with the necessary communication skills to provide a high level of emotional support to participants during the interview, at times I found myself using these skills in the same way I would during a clinical consultation. For example, using communication skills such as naming, understanding, and reflecting at times changed the focus of the interviews I conducted in Phase 1 to one which appeared to be influenced by therapeutic communication techniques. Whilst this approach may have resulted in participants talking openly and freely with a sense of trust between us, I felt concerned leaving the interview with no plan to follow up or offer ongoing support. Instead, I offered support to participants through other mechanisms, as is standard practice within palliative care research. For example, I offered to refer them back to their GP or hospice nurse. This sense of “unfinished business” and a continued concern for the well-being of the participant after the interview has finished has been highlighted as a concern for the researcher-clinician (Hay-Smith, Brown, Anderson, & Treharne, 2016).

I was aware that involvement in the research during both phases may have brought up issues for participants that felt unresolved at the end of the interview. Therefore, in Phase 1, after the audio-recorder had been turned off, I spent time with each participant providing them with an opportunity to reflect on the interview and identify any issues that they may need further support with. In addition, I followed up with a letter thanking them for their participation including details of where they can get further support if needed (see Appendix 2.7). Data collection during Phase 2 questionnaire surveys were administered by palliative care nurse specialists and myself. After the survey was completed, participants were given an opportunity to discuss any concerns that may have been raised during the survey with the person administering the survey, all of whom were experienced palliative care nurses with knowledge of the various support services. However, no participants requested further support post-interview (Phase 1) or post-survey (Phase 2).

Is there a potential conflict of interest?

An integral component of the nurse–patient relationship is trust, therefore acknowledging my dual role of nurse and researcher was an important aspect of conducting my research ethically. For this study, I was employed by the Auckland District Health Board as a Nurse Practitioner with the Auckland City Hospital Palliative Care Team (HPCT). I was aware that a conflict of interest may arise as a result of me having a dual role. For example, a patient may feel pressured into consenting for fear that their care may be compromised if they declined to participate. Furthermore, participants may have been worried about disclosing negative aspects of their experiences knowing that I am also a hospital-employed health professional. To address this, written information was provided that highlighted to participants that participating in the research would not impact on their care (see Appendix 2.2), and I noted clearly in the Participant Information Sheet that I was both a researcher and a clinician.

In addition to the written information, I also ensured no patients under my direct care were also invited to participate in the research. This was not a significant risk, given that only 10–12% of ACH inpatients with palliative care needs are referred to the Hospital Palliative Care Team (Gott, Frey, et al., 2012). The potential conflict of interest was also managed by the following:

1. Patients already referred to the hospital palliative care team (HPCT), at the time they were identified as being eligible to participate, were excluded from the study.
2. Patients referred to the HPCT who had already been recruited to the study were seen by other members of the team where possible.
3. In the unlikely event that I needed to become involved in the patient’s care, the participant was given the option of withdrawing from the study, however this did not occur at any time during the study period.

Beneficence, or “to do only good”, is a guiding principle in protecting a potentially vulnerable study population (Orb, Eisenhauer, & Wynaden, 2000), a principle that is also integral to nursing’s professional code of ethics (NZ Code of Conduct for Nurses, 2012). In view of deteriorating physical health, along with the presence of symptoms that may be causing some discomfort, I was aware that participating in this research could be a burden for participants.

I was very clear that the needs of participants would never be put before the objectives of the research (Duke & Bennett, 2010). I was also sensitive to the fact that participants may not be aware, or want to know, the palliative nature of their illness. Using terminology such as “palliative care” and “life threatening/limiting illness” in patient information was avoided for those reasons (Addington-Hall, 2002), (see Appendix 2.2). However, I am also aware that this approach, whilst commonplace in palliative care research and advocated by research ethics committees, is contentious, as participants need to be well informed about the specifics of the study in order to give informed consent.

Supporting non-research staff.

For many nurses, recruiting study participants is often in addition to an already busy workload, and the pressure to support a researcher with recruitment within the clinical environment can be an added stress. In order to overcome these challenges, using a participatory approach to engage and motivate people to create a sense of working as a team with colleagues to recruit patients can be useful (Duke & Bennett, 2010). For this study, I met with senior nurses very early on in the study design process. Using their expertise and knowledge of the service, we explored various ways in which we could maximise the identification and recruitment process. This created a sense of team work as we worked towards a common goal. During the recruitment period I visited the wards each morning, engaging with ward staff about the project and explaining the purpose of the study and what was required in terms of eligibility criteria. To save time, I reviewed the admissions that occurred overnight prior to the ward visit so the discussion with the ward nurses was limited to those who were potentially eligible. Ensuring that the identification and recruitment of participants is as time efficient as possible is another way of valuing the time pressures that many ward nurses experience daily in their clinical work.

Once an eligible patient had been identified, I approached the ward nurse to request their help in introducing the study to the patient. During this process, I balanced spending time explaining the study whilst at the same time valuing the limited time they had to engage in supporting me with recruitment. If they did not feel comfortable approaching patients to participate I went over the various strategies they could use to introduce the study in a way that would leave patients with no obligation to participate. This approach was used in both phases of the study.

Is gatekeeping a potential concern?

Gatekeeping is founded on the belief that potential participants need to be protected from any potential harm associated with being involved in research and is a risk to inclusivity (Duke & Bennett, 2010). Patients may be judged as being too frail, unwell, or distressed to participate and the decision to be involved is therefore taken by someone else despite the patient being capable of consenting. This may be a family member or a clinician involved in the patient's care.

Gatekeeping by clinicians is a real risk during the recruitment process, particularly for palliative care studies (Duke & Bennett, 2010). However, in relation to my study the nurses caring for potential participants were familiar with my practice as a palliative care nurse and this reduced the risk of gatekeeping as they were aware that I, too, did not want to burden patients by insisting they participate in the study.

6.8 Chapter summary.

This chapter has provided an overview of the study context, including details regarding the study setting, sampling, and recruitment for both study phases. In addition, a discussion has been provided about the ethical issues related to palliative care research and how these will be addressed throughout both phases of the study. The following chapter describes in detail the first phase of the study. Phase 1 is the qualitative strand of this mixed methods study and addresses the third objective of the study: To explore the benefits and burdens of hospital admissions from the perspectives of patients with palliative care needs.

Chapter 7: Phase 1: The Benefits and Burdens of Hospital Admissions for Patients with Palliative Care Needs.

7.1 Preamble.

In this chapter, I present the findings from the first phase of my study. Having demonstrated from the integrative review that the main focus of the literature regarding patient experiences of palliative care in the hospital setting is associated with the negative aspects of care, the first phase was an opportunity to explore not only the burdens of being in hospital, but also the perceived benefits from the patient's perspective. Collecting data prospectively as the admission occurred provided an opportunity to explore how patient preferences for place of care may be influenced during an acute episode of care in the context of an incurable illness.

7.2 Aims and objectives.

Aim: To explore the benefits and burdens of hospital admissions from the perspectives of patients with palliative care needs.

Objectives:

- Describe the precipitating factors that cause patients with palliative care needs to be admitted to hospital.
- Explore the anticipated and actual benefits and burdens of hospital admissions for patients with palliative care needs.
- Explore what is achieved during a hospital admission in relation to improved health status for patients with palliative care needs.
- Explore how patients with palliative care needs perceive the role of the acute hospital during a period of acute illness.

Preamble.

Two articles were published from the findings and have been reproduced in their entirety. Due to the required word limit set by the journals detailed information strategies used to achieve data quality was unable to be included in the manuscript; therefore, this information along with additional findings from the study have been included at the end of the chapter. The first paper focused on the benefits of hospital admissions and was cited as:

Robinson, J., Gott, M. Gardiner, C. & Ingleton, C. (2015). A qualitative study exploring the benefits of hospital admissions from the perspectives of patients with palliative care needs. *Palliative Medicine*, 29(8), 703–710. doi: 10.1177/0269216315575841

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7.3 Article: A Qualitative Study Exploring the Benefits of Hospital Admissions from the Perspectives of Patients with Palliative Care Needs.

7.3.1 Background.

Palliative care need in the hospital setting is well described in the literature. Indeed, studies have shown that up to 30% of inpatients are likely to be in the last year of their lives (Clark et al., 2014), and most people in developed countries will die in a hospital setting (Broad et al., 2013). Moreover, factors such as the global ageing population and the increasing use of hospital-based technology in palliative care are predicted to impact significantly on demand for hospital care in the short to medium term (Gomes & Higginson, 2008). This potential rise in hospital usage at the end of life, when viewed within the context of the global economic recession and a dominant societal view of a good death occurring at home, has resulted in policy recommendations to reduce hospitalisations at the end of life in a number of countries (Department of Health, 2008, 2010).

However, identifying avoidable hospital admissions for those with palliative care needs is difficult (Gott, Frey, Robinson, Boyd et al., 2013) and the factors that contribute to these admissions are not well understood. Studies showing that inadequate symptom management and unmet care needs at home may result in a hospital admission (Barbera et al., 2010; Gardiner et al., 2012) underpin the argument that increasing community-based resources could prevent a component of these admissions (Gott, Frey, Robinson, Boyd et al., 2013). However, there is also evidence that even when community-based services are involved and health care providers advise against a hospital admission, patients will still present to hospital (Gott, Frey, Robinson, Boyd et al., 2013).

Whilst studies of the general population have shown that the majority of people would prefer to be cared for and die at home rather than in hospital (Higginson & Sen-Gupta, 2000), preferences for place of care may change as the illness progresses (Agar et al., 2008). Moreover, evidence suggests that some patients would rather be cared for in a hospital or hospice setting (Gott et al., 2004; Seymour et al., 2007; Stajduhar et al., 2008). With the advent of specialist palliative care units, designed to care for those with the most complex needs, meeting patient preference is becoming less likely, indeed very few people die in a hospice setting in developed countries and most people die in hospital (Gomes & Higginson, 2008).

However, a recent review of the literature identified that little is known about patients' experience of using hospitals at the end of life (Robinson, Gott and Ingleton, 2014). Moreover, whilst the negative aspects associated with a hospital admission have been previously examined, no studies were identified that explored benefits associated with a hospitalisation from the patient perspective. Given a policy drive to reduce hospital admissions amongst patients with palliative care needs in many countries, it is important to fill this gap in the existing research literature. Understanding patient experience, including the benefits of hospitalisation, will contribute to a more balanced understanding of the role hospitals play in the provision of palliative care and why patients seek care in a hospital setting. The aim of this paper is to explore the benefits of hospitalisation for patients with palliative care needs from their perspective.

7.3.2 Design.

Given the exploratory nature of the research, a qualitative approach was adopted. Critical realism (McEvoy & Richards, 2006) was used as a theoretical framework to guide study design. Critical realism acknowledges “the empirical (that which is experienced and perceived), the actual events that occur (whether perceived or not), and the real underlying structures that can cause changes in those events” (Harwood & Clark, 2012, p31).

Longitudinal semi-structured face-to-face interviews were used to elicit the views of patients with palliative care needs admitted to one large urban hospital in New Zealand. Serial interviewing provides opportunities for rich and contextualised accounts of individual experiences over time (Murray et al., 2009). Auckland City Hospital (ACH) is the largest

public hospital in New Zealand and provides care for a socio-demographically diverse population. Ethics approval was obtained from the University of Auckland’s Human Ethics Committee (No: UAHPEC 9499). The sample comprised patients admitted between July 2013 and March 2014 who met one of the Gold Standard Framework Prognostic Indicators (GSF-PIG) for palliative care need (see Appendix 1.3). The GSF-PIG has been successfully used in research settings to identify hospital inpatients in the last year of life (Gott, Frey, Robinson, Boyd et al., 2012; O’Callaghan et al., 2014).

7.3.3 Sampling.

Participants were recruited from general medicine, oncology (medical and radiation), urology and surgery. According to ACH admission data, 30.8% of admissions were for patients with a GSF diagnoses (unpublished data, December 2012). A daily list of hospital admissions to these services was reviewed. Past and current clinical notes were screened to assess patients’ eligibility including whether they met one or more of the GSF prognostic indicators (see Table 7-2). The interviewer (JR) also worked as a nurse with the ACH palliative care team. To avoid a conflict of interest as a result of dual roles, any patients that had been referred to the palliative care team were excluded from the study. No participants recruited to the study were referred to the service.

Table 7-1
Phase 1 Participant Inclusion Criteria

Inclusion criteria
Admitted < 48 hours ago
Speaks English
Not referred to hospital palliative care team
Meets one or more of the GSF PIs
Aged >18-years-old

Eligible patients were approached by the ward nurse. JR was contacted directly by the nurse if the patient agreed to take part. Written consent was obtained from all participants and family who the participant requested to be present.

A purposeful approach to sampling was adopted (Coyne, 1997). Sample characteristics were not pre-determined; however, factors identified from the literature known to influence experiences of hospitalisation such as age, diagnosis and ethnicity (Bowling et al., 2010;

Gardiner et al., 2010; Pinnock et al., 2011) were taken into account during the recruitment phase. Participants were selected to ensure a range of ages, diagnoses and ethnic groups were achieved. As data were analysed, additional characteristics such as prognosis and current treatment were considered and guided the subsequent selection of participants.

7.3.4 Data collection.

Participants were interviewed twice. Interviews were conducted between July 2013 and March 2014. Expectation is considered to be a major determinant of satisfaction and is related to an individual's perceptions of the benefits of care and the extent to which these benefits are met (Sitzia & Wood, 1997). Therefore, the purpose of the first interview was to understand participant's expectations of hospitalisation and explore the circumstances that brought them into hospital. This interview occurred within 48 hours of admission, was conducted on the ward and lasted 20–30 minutes. The second interview occurred within one week of discharge and lasted 45–90 minutes. The purpose of the second interview was to explore the participant's experiences of having been in hospital.

A number of pre-determined open-ended questions were used to guide the interviews. Interview guides for both the first and second interview were informed by a systematic review of the relevant literature (Robinson, Gott & Ingleton, 2014). The interview guides were designed to elicit participant views regarding the expected and actual benefits associated with being in hospital. The interviewer (JR) used an unstructured approach to interviewing, which allowed for the emergence of themes that were relevant to the study aim (Kvale & Brinkmann, 2009). Two pilot interviews were carried out to test the questions for clarity and understanding. As no changes were required, data from these interviews were included in the final analysis.

7.3.5 Data Analysis.

All interviews were audio recorded and transcribed verbatim. The software programme *NVivo* was used to categorise data. A process of thematic analysis, as described by Braun and Clark, (2006) was used to analyse the interview data. This involved a process of coding across the entire data set and then collating the codes into themes. Themes from within the data were identified using an inductive approach. There was no predetermined coding frame; instead, this was developed as the data were coded and was subsequently applied to all transcripts. JR conducted and transcribed all interviews. CG and JR reviewed two transcripts independently

to ensure consistency in coding and to clarify coding decisions. All coding was done by JR with consensus regarding theme development reached during regular meetings with MG, CG, and JR.

7.3.6 Findings.

A total of 14 participants were recruited. See Table 7-2 for details regarding participant characteristics. Twelve participants completed both interviews; two died prior to the second interview. Family were allowed to be present during the interviews if requested by participants. During seven interviews, a participant's family were present; however, the extent of their participation was minimal.

Table 7-2
Participant information

Variable	Frequency (%)
Gender	
Male	59 (50.9)
Female	57 (49.1)
Age	
18-59 years	31 (26.7)
60-79 years	63 (54.3)
>80 years	22 (19.0)
Ethnicity	
NZ European	69 (59.5)
Māori	18 (15.5)
Pacifika	7 (6.0)
Asian	3 (2.6)
Other	19 (16.4)
Deprivation	
Index 1-2	23 (19.8)
Index 3-4	23 (19.8)
Index 5-6	21 (18.1)
Index 7-8	14 (12.1)
Index 9-10	33 (28.4)
Diagnosis	
Cancer	95 (81.9)
Lung	19 (16.4)
Breast	16 (13.8)
Upper GI	14 (12.1)
Colorectal	13 (11.2)
Prostate	12 (10.3)
Other	21 (18.1)
Non-cancer	21 (18.1)
Heart disease	10 (8.6)
COPD	8 (6.9)
Other	3 (1.8)
Karnofsky ^a	
80-100	37 (31.9)
50-70	67 (57.8)
<40	12 (10.3)
Lives alone	
Yes	28 (24.1)
No	88 (75.9)

^a Karnofsky 80-100 (Able to carry on normal activity; no special care is needed); 50-70 (Unable to work, able to live at home cares for most personal needs, a varying amount of assistance is needed); 40 (Unable to care for self, requires equivalent of institutional or hospital care, disease may be progressing rapidly).

Although participants were not directly questioned about their prognosis for ethical reasons, all appeared to understand that their illness was incurable and that over time it would progress. Participants were at varying stages of their illness and the reasons for admission

included symptom management, management of treatment side effects, investigations of new symptoms, and exacerbations of non-malignant conditions (see Table 7-3).

Table 7-3
Reasons for Admission

Reason	Number*
Side effects of cancer treatment	5
Symptom management	1
Investigations of new symptoms	5
Complications/exacerbations of illness	5

*multiple reasons selected

Participant expectations of the benefits of being in hospital were based on unmet need prior to the admission. Most participants had their expectations met during the hospital admission. However, many experienced additional benefits that had not been identified by participants during the first interview.

Participants described a range of benefits related to their hospital admission and reported on their preferences for place of care. The benefits of being in hospital were reported to extend beyond the treatments they received, and all but one participant reported a preference on this occasion for hospital care, even if they had been able to access the care they received in hospital at home.

Four themes related to the benefits of being in hospital were identified from data collected from both interviews:

- Being cared for and feeling safe.
- Getting help to manage at home.
- Relief for family.
- “Getting and/or feeling better”.

Being cared for and feeling safe.

Most participants reported they felt relieved about being admitted to hospital. Not knowing why they were feeling unwell or why new symptoms had developed contributed to a sense of

feeling unsafe at home. Furthermore, staying at home came with a risk of becoming more unwell:

You are sitting at home on the side of the bed huffing and puffing and coming here knowing that. I had the nebuliser and I was doing all this but I mean if I got to the stage where I was breathing my last at least here is somebody there to do whatever it is. (89-year-old woman with COPD)

Having knowledge about their symptoms, what was causing them, and how they could be managed, was reported by some participants as a relief. Understanding the cause of the symptoms required investigations that could only be accessed in a hospital setting:

I knew there was something wrong with me and I needed my stomach drained. I didn't know that I needed that but they couldn't have done that at home, but intuitively I knew because my own little health regime had broken down. (57-year-old NZ European woman with cancer)

Knowing that the hospital staff were doing everything they could to understand the cause of their symptoms was reassuring for participants and contributed to a sense of being cared for:

This is what she said: this time whilst you are here we can't let anything get past us, so either today or tomorrow or sometime I'm having a CT scan just of my head so they are going to look into that as well. (83-year-old NZ European woman with cancer)

Hospital staff were seen as the "experts" in managing illness. Some participants reported that coming to hospital provided them with an opportunity to access this expertise in a timely manner and to "solve the problems" they were experiencing:

I suppose I learn things like what type of treatment I have. So if the doctor is managing me, I don't have such knowledge to solve this problem to find out those questions, those answers so it is good, very good. Therefore the nurse and the doctor, they got more information about my sickness. (60-year-old man with cancer)

In addition, the ongoing observation and monitoring that are features of hospital care, as well as the expert help that is readily available, contributed to a feeling of being safe:

I feel safe here because I can press the buzzer three times and know that somebody is going to come running whereas I can't do that at home. (57-year-old NZ European woman with cancer)

Getting help to manage at home.

Many participants reported that they had received input from the multidisciplinary team including physiotherapists, occupational therapists, and dieticians. Access to equipment to maintain their independence at home was facilitated during their hospital stay:

The hospital have been marvellous – like in respect of helping me to stay at home. They have given me a hospital bed and they have helped me with things around the home to make my life easier like raise my chairs and rails. (77-year-old NZ European man with cardiac disease)

Participants reported that they received education and support from staff to manage their care needs at home. For some participants, improving their mobility and independence was considered an essential component in preparing to manage at home:

Before I was twisting around but now I can just pop my legs behind me and then stand up and there's no pain on my legs, no stress on my back. All those things that before I was twisting and turning. So they may seem like little things but I think even as you get more debilitated they become more important. Before it was the bigger things, now it is the little things that make my life more manageable. (57-year-old NZ European woman with cancer)

Another participant received input from the dietician who provided her with special foods and supplements that she felt would help her to remain physically strong. This advice was provided in conjunction with management of nausea and vomiting, which had left the participant feeling frail:

They did the job I was there for, which was to control the nausea and get me eating. They made very good suggestions for high health foods and to continue them at home – that was very good. Big leaflets and lots of ideas for high health foods and managing the nausea. I am getting stronger. I got very weak with not eating but I am getting stronger. (83-year-old NZ European woman with cancer)

Relief for family.

Participants reported that their families felt relieved when they were admitted to hospital. This was seen as relief from the responsibility of decision making associated with caring for someone with a serious illness. One participant reported that his family panicked when he became unwell at home:

Being in the hospital is the best place because that way you know you are going to get looked after properly and at home, like all my family, they don't know what to do and they just panic. (47-year-old Cook Island Māori man with cancer)

Some participants expressed concerns for their family and were aware of the strain their illness placed on them. The benefit of being in hospital was related to relieving the burden on family having to care for someone at home who was unwell:

I was absolutely relieved. I thought there was no good me going home to my daughter. My daughter has been marvellous, absolutely marvellous, looking after me but then she has started a big, new job today and she's working and got four children. (83-year-old NZ European woman with cancer)

Some family present during the interviews reported that they felt relieved when the decision was finally made for their family member to go to hospital:

It would have been on our conscience if we had . . . while she was at home not knowing what to do. We got her to hospital and she came out better. (Husband of 75-year-old Māori woman with cancer)

Participants also felt that their family were relieved when they saw them finally getting the treatment they needed, which was only accessible in the hospital setting:

She's relieved that I'm getting some treatment. She's hoping that I will get well enough to start eating and hoping that I will get well enough to put some weight on and get strong.
(83-year-old NZ European woman with cancer)

“Getting and/or feeling better”

Receiving care in the form of symptom management, investigations, and treatment resulted in most participants “feeling better”. Although some could not describe specifically what treatment they had received or how it had contributed to their improvement, all participants felt that they left hospital feeling better than when they had arrived:

I always feel like I'm really, really great when I come out of hospital and it makes me sort of feel like when I come out I know what I have got to do to make me feel better.
(69-year-old NZ European woman with cancer)

Moreover for some participants “getting better” was the only way they could describe the benefits of being in hospital. Going to hospital was simply something they did when they felt unwell, and if they didn't go to hospital, some participants believed there was a risk they might die:

What do you think might happen if you don't go to hospital? (Interviewer)
If I don't go to hospital something might happen. I might die. (79-year-old man with cardiac disease)

The fear of staying at home while unwell, combined with previous experiences of “feeling better” as a result of having been in hospital, influenced participants' preferences for care. Almost all participants reported a preference to return to hospital if they became unwell again:

They give me treatment and then I recover and they send me home and then I come [to hospital] again, ready for the challenge coming. (61-year-old man with cancer)

“Getting better” was measured using clinical indicators and body language cues by some participants. For example, one participant used laboratory results and the facial expressions of

her doctor to understand the seriousness of her illness and whether she was getting better or not:

They say that the creatinine was at 230, which apparently is excessive and then some from the expression on the man's face. It's now 200 and that's an improvement in the right direction, but he said, "I am not prepared to let you go until its further down".
(80-year-old NZ European woman with cardiac disease)

7.3.7 Discussion.

This is thought to be the first study to explore the benefits of hospitalisations from the perspective of patients with palliative care needs. Participants identified a number of benefits associated with the admission, including being cared for and feeling safe, receiving care to manage at home, relief for family, and "getting better and/or feeling better".

Whilst the concept of feeling safe has been defined for general hospital admissions (Mollon, 2014) within a palliative care context little is known about how feelings of safety influence preferences for place of care. Our findings suggest that a sense of feeling safe in hospital is associated with patients being cared for by staff who have expert knowledge and who are readily available should their condition change. Moreover, a sense that staff were monitoring their condition contributed to their sense of security. Most studies examining patient experiences of feeling safe in hospital have been conducted in intensive care or emergency settings where staff have specialised technical knowledge and the level of monitoring and observation of patients is high (Hawley, 2000; Wassenaar, Schouten, & Schoonhoven, 2014). Participants in this study were situated across the hospital, which suggests that patient perceptions of "expertise" are more pervasive and may relate to not just technical skill but also to a sense of competence and confidence patients feel in the staff caring for them.

If a consequence of being in hospital is that patients "feel safe", it may be logical to assume that being at home may feel "less safe" at certain times. This was supported in our study by participants expressing anxiety about remaining at home when symptoms occurred that were unexplained or worsening. Furthermore, the relief experienced by families when the hospital admission finally occurred indicated a level of anxiety for caregivers. Unexplained symptoms and sudden changes in the patient's condition can cause patients and families considerable fear and anxiety (Worth et al., 2006). Indeed, one study has described patients' experiences of

palliative care at home as “uncertain safety”. Anxieties about remaining at home when problems, such as unbearable pain, occur can leave patients feeling frightened and insecure (Worth et al., 2006) .

When patients’ needs are changing at home, community services are challenged to respond in a timely manner in order to ensure patients feel safe. Most participants in this study stated a preference to be in hospital rather than remain at home even if what had been provided in hospital could have been accessed at home. This suggests there is something unique about being in hospital that might be difficult to replicate in the home setting. A recent study by Beernaert et al. (2014) explored barriers and facilitators to the early identification by general practitioners of palliative care needs. They found that patients often viewed their hospital physicians as being more capable than their General Practitioner when dealing with specific manifestations of their illness. The authors found that General Practitioners are less likely to be involved in patient care when patients are receiving curative or life prolonging treatment and find it easier to identify palliative care needs in the last weeks of life when prognosis is clearer (Beernaert et al., 2014). These factors can make it difficult for General Practitioners to be involved in clinical decision making during a period of sudden deterioration or change in symptoms, particularly when there is uncertainty about prognosis.

Caring for someone at home with a life limiting illness can be challenging for family caregivers (Proot et al., 2003). The findings from our study suggested a level of burden for family that was associated with the responsibility of caregiving, particularly when the patient was becoming unwell at home. A study by Skilbeck (2005) found that carers were burdened not only by the physical work associated with caregiving but also the constant need to assess and monitor the patient for complications and changes in their condition. A study by Stajduhar et al. (2008) suggests carers feel frightened when unexpected changes in the patient’s condition occur, and rely on services being responsive with ready access to health professionals to feel secure in their role as caregiver. Our study supports these findings and indicates that the presence of such expertise in hospital may be an important factor in reducing carer burden.

A sense of “getting better” and “feeling better” as a result of having been in hospital was a common theme throughout this study. These concepts in relation to people with a life limiting illness are poorly understood in the literature. A study by Beaton et al. (2001) found that the

underlying meaning of “being better” for patients with musculoskeletal injuries reflected not just a resolution in the underlying disorder but were influenced by a person’s experience of the illness, their coping styles, and the comparators used to define health and illness, all of which can influence the experience of “being better” (Beaton et al., 2001). In our study some participants used the concept of “feeling better” as a way of articulating the benefits of having been in hospital. Similar to Beaton’s (2001) study, the factors that contributed to participants feeling better were not only associated with an improvement in the physiological parameters of their illness or a resolution of their symptoms.

7.3.8 Conclusions.

Perceptions of the appropriate role of the acute hospital in palliative care are predicated upon a number of factors including perceived preference for place of care, patient burden, and cost. By exploring the benefits associated with hospitalisation from the perspectives of patients with palliative care needs, this research provides a unique contribution to the literature. Findings suggest that the benefits associated with being in hospital extend beyond the treatment patients receive to encompass feelings of safety and “feeling and/or getting better”. Furthermore, hospitalisation enabled patients to access the help they needed to manage at home and relieved family of responsibilities of caregiving. These findings challenge current assumptions regarding the role of the acute hospital in palliative care provision in developed countries. Further research is needed to explore the apparent dissonance between the policy view of the appropriate role of hospitals within a palliative care context and the experiences and opinions of patients themselves.

Preamble.

A second paper was published using the findings of Phase 1. This paper focused on a major theme identified by participants in relation to experiences of burden and was cited as:

Robinson, J., Gott, M., Gardiner, C., & Ingleton, C. (2015). The impact of the environment on experiences of hospital admissions from the perspectives of patients with palliative care needs. *BMJ Supportive and Palliative Care*. doi:

10.1136/bmjspcare-2015-000891

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7.4 Article: The Impact of the Environment on Experiences of Hospital Admissions from the Perspectives of Patients with Palliative Care Needs.

7.4.2 Background.

The environment of a care setting is known to impact on a patient's recovery from illness, as well as their overall well-being. For example, studies have shown that certain aspects of the physical environment can impact positively on a patient's experiences of care and their quality of life (Douglas & Douglas, 2003; Parker et al., 2004). For those at the end of life, a sense of "homeliness" and an environment that provides opportunities for social interaction and privacy are considered important elements of an inpatient setting (Rigby, Payne, & Froggatt, 2010).

In developed countries, most people with a life limiting illness will spend some time in hospital during the last year of their life (Rosenwax et al., 2011). However, the hospital environment is reported to be a consistent source of dissatisfaction for patients with palliative care needs (Robinson et al., 2015b). An integrative literature review by Brereton et al. (2012) identifying key elements of the physical hospital environment for end of life care of older adults and their families found that more than any other aspect of care, deficiencies in the physical environment was a source of significant dissatisfaction for patients, families, and staff (Brereton et al., 2012).

In response to the recognition of the inadequacies of the hospital setting, hospices have worked towards developing an environment that better meet the needs of patients and their families. The hospice environment is often described as quiet and homely and the ratio of staff to patients is favourable compared to that of the acute hospital (Gardiner et al., 2012). Bereaved families report a high level of satisfaction with hospice inpatient care in terms of their relationship with care providers and with aspects of the physical environment, such as cleanliness of the facility, a home-like feeling, and proximity to nature (Evans, Cutson, Steinhauser, & Tulsky, 2006). It is unsurprising, therefore, that the hospice continues to be overwhelmingly preferred to hospital as a place of care and death (Arnold, 2011). However, the reality is that most people in developed countries will be cared for and die in other care settings, notably hospital (Broad et al., 2013). Given that patients with palliative care needs comprise one-quarter to one-third of the total inpatient population (Gott, Frey, Robinson,

Boyd et al., 2012; Gardiner, Gott, Ingleton, Seymour et al., 2012) identifying how the hospital environment can be modified to better meet their needs must be a priority.

While the environment has been shown to be a key factor influencing patients' experience and satisfaction with hospital care (Brereton et al., 2012), evidence is limited by a lack of definition or conceptualisation of what is meant by "environment" and few studies have collected data prospectively from patients themselves (Brereton et al., 2012). Understanding the difficulties patients experience in relation to the hospital environment is essential if we are to identify strategies that will improve the provision of palliative care in this setting. This paper will address this gap in knowledge by exploring the impact of the environment on experiences of hospitalisations from the patients' perspective.

7.4.3 Design.

Given the exploratory nature of the study, a qualitative approach was adopted. Critical realism was used to inform the study design (McEvoy & Richards, 2006). Critical realism acknowledges "the empirical (that which is experienced and perceived), the actual events that occur (whether perceived or not), and the real underlying structures that can cause changes in those events" (Harwood & Clark, 2012).

The experiences of patients with palliative care needs admitted to a large urban hospital in New Zealand were elicited using face-to-face semi-structured interviews. Participants were interviewed on two occasions. Serial interviewing provides opportunities for me to develop a relationship with the participant, creating a trusting relationship enabling the participant to share personal accounts of their experience over time (Murray et al., 2009). Auckland City Hospital, New Zealand (ACH) is the largest public hospital in New Zealand. A recent census of admissions found that one fifth of adult inpatients at ACH met criteria for palliative care needs, the majority of whom were aged over 70 years (Gott, Frey, et al., 2012). The study sample comprised of patients admitted to ACH between July 2013 and March 2014 who met one of the Gold Standard Framework Prognostic Indicators (GSF-PIG) for palliative care need. The GSF-PIG consists of clinical indicators associated with a range of life limiting illnesses that indicate palliative care need. Whilst primarily developed for the primary health setting, the GSF-PIG has been successfully used in research settings to identify hospital inpatients with palliative care needs (Gott, Frey, Robinson, Boyd et al., 2012; O'Callaghan et al., 2014).

7.4.4 Sampling.

According to hospital admission data (unpublished data, December 2012) general medicine, Oncology (medical and radiation), Urology, and general surgery account for nearly 31% of admissions for patients with a GSF diagnosis. For this reason, recruitment of participants was confined to these four services. Admissions to these services were reviewed along with past and current clinical notes to assess for eligibility. As I was also employed in the hospital palliative care team, any patients that had been referred to the service at the time of screening were excluded. No participants recruited to the study were referred to the service.

A ward nurse approached eligible patients to determine whether they wished to take part in the study. I was contacted directly by the nurse if the patient agreed to take part. Written information regarding the study was provided to all participants. Written consent was obtained from all participants and any family who the participant requested to be present.

A purposive approach to sampling, as described in Coyne (1997), was used. Sample characteristics were not pre-determined, however factors identified from the literature known to influence experiences of hospital admissions, such as age, diagnosis and ethnicity, (Bowling et al., 2010; Gardiner et al., 2010; Pinnock et al., 2011) were taken into account during the initial sampling process. As the study progressed and data were analysed, other characteristics were identified and used to guide subsequent participant selection. Recruitment continued until no new themes were emerging from the data.

7.4.5 Data collection.

Participants were interviewed on two occasions. The first interview occurred within 48 hours of admission, was conducted on the ward by JR, and lasted 20–30 minutes. The purpose of this interview was to understand participants' expectations of the hospital admission. It was also an opportunity for me to establish a relationship with the participant in preparation for the second interview.

Within one week of discharge from hospital participants were interviewed again. The purpose of the second interview was to explore fully participants' experiences of having been in hospital. Participants were given a choice of where this interview took place. Eleven participants chose their place of residence to be interviewed, two were interviewed at the

hospital after attending an outpatient clinic appointment, and one was interviewed at a friend's house. The second interview took between 45–90 minutes.

Separate interview guides were developed for the first and second interviews based on a review of the literature related to patient experiences of hospital admissions within a palliative care context (Robinson et al., 2014). Participants were asked about their perceptions of the expected and actual benefits and burdens associated with being in hospital (see Table 7-4). The interviewer used a relatively unstructured approach to interviewing, which allowed for the emergence of new themes that were relevant to the overall study aim (Kvale & Brinkmann, 2009).

Table 7-4
Examples of Interview Questions

Interview 1	Interview 2
What were the circumstances that caused you to end up in hospital?	Tell me about your experience of having recently been in hospital.
How do you think being in hospital will help you with your illness?	Thinking about what happened during your stay in hospital, was there anything you found particularly difficult or distressing?
What do you think the difficulties will be for you while you are in hospital?	On reflection, was there anything/useful about having that time in hospital? How was it helpful/useful?
How do you feel about being in hospital?	Is there any reason you think might have to go back to hospital again?
If you could have got the help you needed would you have preferred to have stay at home/residential care facility/hospice?	How would you feel about having to go back to hospital again?

7.4.6 Findings.

A total of 14 participants were recruited to the study. Twelve participants completed both interviews; two participants died prior to the second interview. Family were allowed to be present during the interviews if requested by participants. Participation by family during the interviews varied. One participant specifically requested that family be present during both

interviews and they actively participated in the discussion. Three participants had their spouses present at the first interview, however their contribution during the interview was minimal. Participants were at varying stages of their illness. Thirteen participants described a range of factors associated with the environment that impacted on their experiences of being in hospital.

Aspects of the physical environment were particularly challenging for participants who reported difficulties not having access to personal space, including a lack of privacy when sharing bathroom facilities. This was particularly difficult for those whose illness meant they had to access the toilet frequently:

I got the problem with the bladder. I have got to go to the toilet very often for pee and if you got four people in the room, usually it is four people in the room. One is crying and one is snoring. The toilet is 90% occupied and you can't rest. (60-year-old European man with cancer)

As a result of being in multi-bedded rooms some participants reported being near sick and dying people as causing distress. Finding a space that removed them from this environment was often impossible:

I hate being with a whole lot of people. I can't stand a whole lot of squealing people, especially when they are sick. Being around other sick people doesn't help me. It makes me worse and I just want to get away and be in a private room. (57-year-old Māori woman with cancer)

The impact of sharing rooms with very sick people, some of whom were thought to be infectious, was distressing for some participants. One participant reported how staff did not seem to appreciate the significance of this in terms of the required environment to keep patients free from infection:

I was in a crowded room where there was a lot of noise and where a woman had the super bug and the nursing care was very poor. They didn't isolate us. They didn't give us our own toilet and shower. I had to go and ask for them and the nurses just seemed

to not know about it so I had to ask for a private shower. (57-year- old NZ Māori woman with cancer)

Another participant reported feeling vulnerable due to being with other sicker patients who might cause him to become more unwell:

I was in ward XX and there was a guy in there who had a bug of his own. I was terrified that I would catch this and combined with what I had. . . . (77-year-old NZ European man with cardiac disease)

One participant reported the distress associated with a lack of natural light and being in a multi-bedded room with curtains pulled around bed spaces constantly throughout the admission:

What I found really hard this time was that I had a space around the corner as you go into the ward, and what I found really hard was nobody drew their curtains at all so I never got to look out the window the whole week – everybody had their curtains drawn. (69-year-old NZ European woman with cancer)

The physical environment of the hospital also impacted on social relationships. For one participant being in a multi-bedded room was an opportunity to interact with other patients, however constantly having the curtains closed around bed spaces prevented her from doing so:

. . . and there was a nice lady across from me I would have liked to have talked to but curtains shut all the time. (69-year-old NZ European woman with cancer)

For some participants, being alone with little opportunity to interact with others including other patients resulted in feelings of boredom. One participant described how when he was left with nothing to do he could find no reprieve from reminders of his illness:

If the patient has nothing to do, then you start to think. . . . I feel uncomfortable, I feel this, I feel that. If your mind is not thinking you are sick, it's much better. If you think

about your illness then you think about what is happening. It's too much negative thinking. (61-year-old Chinese man with cancer)

Many participants reported a negative impact on their relationships with family as a result of being in hospital. The hospital environment was often not conducive to staying connected with friends and family, and this was distressing for some participants leaving them feeling lonely and isolated:

I would spend the day with T (his wife) and then she would go home. I would walk out to the door with her and I would watch her going down the corridor. I found that difficult staying there, not going with her, but she was there again the next day. (77-year-old NZ European man with cardiac disease)

While some participants did not like being away from friends and family, attempts by staff to accommodate family out of normal visiting hours when a patient was dying was very distressing for one participant:

There were people around the next bed. I kept thinking they would go and then they stayed and they would read their Bible and the preacher would come and pray with them. I found it so distressing. (69-year-old NZ European woman with cancer)

For one participant, saying goodbye to his father was that much harder from his hospital bed. Not being part of family activities as his father prepared to travel overseas was distressing for them both:

My Dad is a bit concerned. He flew out to Samoa today and I wasn't there today. My partner said that when they came to visit last night, he didn't want to go and leave me here. (47-year-old Cook Island Māori man with cancer)

Staff appearing too busy to care was a key factor in participants making positive relationships with hospital staff or not. Participants reported that staff were often very busy, which left them feeling anonymous and an inconvenience:

In the hospital you are an inconvenience and they have always got another person to move on to. It's just too busy; people are too busy. You are an inconvenience. You are a number. You know they are not really interested in you. (57-year-old Māori woman with cancer)

The way in which staff worked within the hospital environment also influenced the way in which participants interacted with clinicians. One participant reported that repeated assessments by clinicians who asked the same questions over and over again were difficult. Added distress occurred when there was a lack of continuity with new staff coming and going:

Always someone new is coming, new one is coming, new one is coming, new one is coming, and they ask you so many same questions. I can't understand after minute, after minute, after minute, and a new one and you didn't see him again. I don't know why. (61-year-old European man with cancer)

Those participants who reported positive relationships with hospital staff experienced a level of continuity with individual staff. One participant had repeated admissions to the same ward and had got to know the staff well, and for another participant, an admission that lasted for several weeks gave him an opportunity to establish a good relationship with ward staff:

The nurses and the doctors were marvellous. I could not say anything against them – they were absolutely wonderful and the nurses having been there for so long, they sort of like adopt you to a degree and they make a fuss of you, you know. You got to the stage where you started to know everybody, like T (his wife) was part of it as well because she would come and spend the whole day with me and they were giving her a meal at night times which was great you know. (77-year-old NZ European man with cardiac disease)

When staff were busy participants felt they were not important and these feelings were exacerbated when they were left waiting for long periods:

You are left just sort of sitting there and I have to go and complain to the senior nurse because I have been sitting in the waiting room for hours. I always go and ask, "How

long will it take”? Because there is always someone who is far more important than you. (57-year-old woman with cancer)

While the way staff behaved in the hospital setting impacted on the social relationships that form between participants and health professionals, these socialised behaviours are often a component of hospital culture. For the purposes of this paper, “cultural milieu” encompasses the shared beliefs, attitudes, values and norms of staff behaviour that contribute to a certain way of working within a hospital setting (Nutley, Davies, & Mannion, 2000). They include the “rules” of the hospital setting (both spoken and unspoken) and the perception that health professionals have the power to make decisions with and/or for the patient.

Restrictions imposed by staff reduced participants’ ability to maintain autonomy and independence. Participants reported a lack of freedom being in hospital, feeling like they were trapped and unable to “get out”. This loss of freedom to do what they wanted was difficult for some participants:

You can’t go home at night. You can’t do this and you can’t do that. You see, I have always been very active. I’m an active person and you are captured, you know. (78-year-old NZ European man with COPD)

Staff were perceived as having control over one participant’s freedom to leave hospital, with him reporting that he would do whatever he was told to do if it meant he would get out of hospital:

I had no option. At the same time I had this worry about the virus and if this was going to fix it. I’m one of those people that whilst in hospital to get out again if they suggested go into the corner and stand on my head, I would go and stand on my head you know. (77-year-old NZ European man with cardiac disease)

Some participants described difficulties in being an active participant in their care and this was exacerbated by examples of poor communication by health professionals. A belief that clinicians did not think he would understand details of his illness left one participant feeling disempowered and unable to actively participate in decisions regarding his treatment:

Some . . . like these people have been good, they tell me but on other occasions you ask and you just get a roundabout answer sort of thing, you know. You don't really get . . . it's almost as if they think, "Well, what does he know about it anyhow"? (77-year-old NZ European man with cardiac disease)

Another participant described how the doctors would stand around her bed talking amongst themselves making decisions about her care:

. . . I'm not used to it . . . when everybody is sort of not talking at you and you are sitting there like this (indicating that she has to look up above her) and there's the doctor and she's saying this, that, and the other . . . (89-year-old woman with COPD)

When participants reported positive communication with staff they felt empowered and this helped to create a positive relationship with staff and enabled them to be involved in decision making about their care:

This is the whole thing . . . if they couldn't get rid of this infection they would have to replace the valve again and the condition of my heart as it is placed me at great risk, but they had my family come in and we had a meeting with B and he explained it all to us. . . . to everybody and it was a decision that we had to make as to whether I would have an operation with the risk or else carry on with this damn virus. But there was really no decision to be made because the virus would have killed me anyhow. (77-year-old NZ European man with cardiac disease)

7.4.7 Discussion.

This study provides a key contribution to the literature regarding the impact of the hospital environment from the perspectives of patients with palliative care needs. The findings suggest that the social environment of a hospital that encompasses the physical surroundings, social relationships, and cultural milieu can impact negatively on the experiences of patients with palliative care needs. However, there is a paucity of research regarding the ideal environment for those with palliative care needs. A study by Gardiner et al. (2012) regarding the optimum physical environment for palliative care in acute hospitals from the perspectives of health professionals found that while health professionals assumed patients would prefer single rooms in order to maintain privacy, staff valued an environment that was conducive to

observing and monitoring patients, which was not always compatible with single rooms. The findings from our study suggest that there is a need for flexibility in regards to providing an appropriate physical environment for patients. Meeting patient preferences whilst ensuring that individual care needs are met are factors that should guide the allocation of an appropriate bed configuration and this may even change over the hospital admission. While most patients who are feeling unwell may express a preference for single-bedded rooms, when feeling well enough to interact with other patients they may prefer to be in a multi-bedded room (Rowlands & Noble, 2008).

As a result of growing pressure to deliver care for patients with complex health care needs, the hospital environment is becoming increasingly busy. Studies have shown that patients and families perceive busy staff as being unavailable (Dunne & Sullivan, 2000) and this can impact on the quality of the relationships patients form with their care providers. The findings from our study suggest that when patients perceive staff as being busy or when they are left waiting for care, they feel like they are an inconvenience, invisible and forgotten.

Health professionals' behaviours can impact on relationships with patients. When families feel cared for, it is often in response to staff who are attentive to their needs, appear approachable and friendly, and check in regularly to make sure they have what they need (Spichiger, 2009b). Furthermore, attitude and helpfulness of staff have been shown to influence the atmosphere of the environment regardless of physical factors such as layout and furnishings. Staff who demonstrate a positive attitude, appear competent and are helpful impact positively on a patient's mood and well-being (Rowlands & Noble, 2008).

Understanding the impact of appearing busy to patients and families is an important component of finding ways to improve the quality of palliative care in the hospital setting.

Effective communication skills have been shown to impact positively on patients forming positive relationships with hospital staff (Schofield & Earnest, 2006). Furthermore, interactions that demonstrate a willingness to find out who the patient is as a person is an important component to establishing a positive relationship with patients. Initiating simple strategies, such as health professionals introducing themselves, can make a significant difference to this process (Grainger, 2015). With an increasing workload in hospitals, care staff may become more focused on the tasks at hand rather than on the patient. Using a patient-centred approach to care by showing empathy and kindness whilst attending to tasks

and interacting with patients, whilst do not require more time, have been shown to leave patients feeling reassured, safe, and cared for as an individual (McCabe, 2003).

Professional and organisational values, beliefs and norms within the hospital setting may influence the way in which care is provided. Organisational rules around how patients should act in this setting can be a burden for patients. For example, there is an implicit understanding that once admitted the patient will largely remain at their bedside, ensuring they are readily available for any health professional that needs to meet with them. This restriction on their sense of freedom and independence can be a burden for patients. A study exploring the experiences of patients with advanced cancer found that although patients accepted being in hospital as a “temporary necessity”, factors such as being unable to make their own decisions, a loss of independence, and the effects of the physical environment all contributed to a sense of imprisonment at times during the admission (Spichiger, 2009a). Similarly, findings from our study suggest that when patients feel they are unable to leave hospital and are isolated from friends and family they feel as if they are “captive” within that environment. Identifying opportunities to challenge the restrictions traditionally seen within the hospital environment to empower and enhance a patient’s sense of freedom and independence may be an important component of providing palliative care in this setting.

Professional culture influences the way in which health professionals interact with patients. Health professionals have traditionally adopted a paternalistic position as the sole decision maker in patient management. A move towards a shared decision making process involving the patient and family has been promoted as a more effective approach to ensure that a patient’s preferences for treatment are taken into consideration. However, a lack of knowledge about their illness as a result of poor communication with health professionals can result in patients being unable to participate in this process. Furthermore, the development of relationships with health professionals has shown to be an important component to patients feeling that they are able to participate in decisions about their palliative care (Lee, Kristjanson, & William, 2009). Examples of poor communication were evident in our findings and some patients perceived hospital staff as the sole decision makers regarding their care. This was particularly in relation to when they could leave the ward or indeed when they might be discharged home, with little evidence that they felt they could influence these decisions. A patient’s ability to be an active participant in health care decision making for themselves is dependent on a number of factors. These include the information they receive

from health professionals and their ability to build positive relationships with staff (Lee et al., 2009; Payne et al., 2010). In our study, despite attempts to engage with health professionals about their illness, some participants were unable to get the information they required and staff behaviours limited their ability to participate in care decisions.

Strengths and Limitations.

The process of purposive sampling was used to maximise the diversity of the sample of patients with palliative care needs. A mix of age, diagnoses, and ethnicities was captured within the selected sample. Furthermore, participants represented a range of prognoses, with 64% of participants having died within 12 months of being interviewed. By using serial, semi-structured interviewing, participants were able to speak freely about their expectations and experiences of being in hospital. This method is considered to be useful in providing opportunities for rich and contextualised accounts of individual experiences over time (Murray et al., 2009). Moreover, the evolving researcher–participant relationship creates an environment of trust, thus enabling the participant to share a more personal account of their experience.

However, some limitations to the study must be acknowledged. Recruitment was confined to one urban hospital in New Zealand and recruitment was limited to four specialty services and therefore the findings may not be applicable to other countries or services. Participants were questioned about their experiences of one particular admission to hospital and assumptions cannot be made that they had similar experiences during previous or subsequent admissions; however, many participants drew upon past experiences of having been in hospital during the interviews. Furthermore, participants’ experiences may have been influenced by the length of time they spent in hospital. Family members were present in a small number of interviews and this may have influenced participants’ responses.

7.4.8 Conclusion.

The limitations of the hospital environment impacts on patients’ experiences of hospitalisation resulting in significant burden for patients with palliative care needs. Emulating the “ideal” environment for palliative care, such as that provided in a hospice setting, is an unrealistic goal for acute hospitals. Further research is needed looking at how changing attitudes and behaviours of busy hospital staff can relieve some of the burden of being in hospital for this patient group. Paying attention to the things that can be changed,

such as enabling family to stay and improving the flexibility of the physical environment whilst improving the social interplay between patients and health professionals, may be a more realistic approach than replicating the hospice environment in order to reduce the burden of hospitalisations for patients with palliative care needs.

7.5 Additional information.

The following section provides supplementary information from the first phase of this study that was unable to be incorporated into the published manuscripts. This includes additional interview data and an overview of the strategies used to promote data quality.

7.5.1 Further analysis of data.

The key themes identified, using a thematic analysis of the interview data, have been outlined in the published manuscripts included in this thesis. However, there were a number of other findings of interest that I will discuss in the following section. This includes additional factors related to benefit and burden and information related to experiences of accessing health care services, reasons for admission, and the nature of care received in hospital.

Benefits of being in hospital.

Despite a significant amount of burden associated with being in hospital, all participants were also able to identify some aspect of their stay in hospital that was of some benefit to them or their family. In addition to the four key themes identified and described in the previous publication, as outlined in Chapter 7.3, four additional sub-themes related to the benefits of being in hospital were identified by participants:

- Being cared for.
- Improving symptom control.
- Receiving reassurance.
- Benefits for the family.

Being cared for.

Two participants felt that being looked after by caring staff contributed to a positive experience of being in hospital. “Being cared for” was perceived as helping one participant to get the treatment he needed:

Well, if I didn't go back to the hospital I don't think I would have got the treatment that I got when I got back in 'cos having the care and . . . from the nurses and doctors and that it sort of helps you in a lot of ways . . . where you know you are going to get the best care to look after you. . . . (47-year-old Cook Island Māori man with cancer)

For one participant, who had been in hospital for over nine weeks, the care he received appeared to take on a different meaning as he developed relationships with the medical and nursing staff involved in his care. This was seen as being something “extra”:

. . . the nurses and the doctors were marvellous. I could not say anything against them – they were absolutely wonderful and the nurses having been there for so long, they sort of like adopt you to a degree and they make a fuss of you, you know. You got to the stage where you started to know everybody. Like T was part of it as well because she would come and spend the whole day with me and they were giving her a meal at night times, which was great, you know. (77-year-old NZ European man with cardiac disease)

The hospital was seen as having all the resources to provide the care that was needed when participants were feeling unwell:

I actually like it here. I dunno, I have got all the necessities. I need to be honest, I mean, you know, compared to being at home, I don't have what I need. Yeah, so actually I like it here on the ward where I am. . . . I like it. (57-year-old Cook Island Māori woman with cancer)

Improved symptom control.

For those participants whose hospital admission was precipitated by poor symptom control, many experienced an improvement in symptoms such as nausea, vomiting, pain, and constipation during the admission. Interventions received included medications, both oral and subcutaneously via a syringe driver, and various other strategies such as dietary advice:

. . . they treated me with pills, which I am still taking for the nausea, and then they got the nausea better and under control so that I was eating more and I had to eat. And they did start getting food – what they called high health food – that would slip down easily

because you find it difficult to swallow with the nausea and that's how they got me on the mend. (83-year-old NZ European woman with cancer)

For some participants, the process of having their symptoms controlled in hospital provided them with the information they needed to manage their own care at home:

And I can sort my pills myself now whereas before I thought I had to take all of these things, you know, to come right. (69-year-old NZ European woman with cancer)

Receiving reassurance about the illness.

Some participants received reassuring information about their illness and the reason for the symptoms they were experiencing. For example, normalising the symptoms as being common and understanding that they weren't responsible for causing the symptoms was reported to be a comfort:

It was a relief knowing . . . I got to know that nothing was wrong. I didn't injure myself or something like that. The only reason why I wanted to have one (an MRI) was because during my radio my nerves just went out of place. I just couldn't walk anymore. (57-year-old Cook Island Māori woman with cancer)

Most participants experienced positive interactions with health professionals in regard to information giving. Repeating information and using support people to help remind them of what had been discussed was useful and provided them with reassurance about their illness:

Yes, they did actually. It was quite good because, this time around, it's actually quite good because everybody is repeating it to me, which is a good time. That's the reason I have my supporters with me because I remember what you say now but then later on I forget and then it comes back again. (57-year-old Cook Island Māori woman with cancer)

In contrast, when communication about the diagnosis was unclear participants were left feeling anxious about their illness. For example, one participant described a conversation

with her GP as he described the cancer as being one that was very likely to recur and how this left her with questions about prognosis that were left unanswered:

Well, wondering whether he meant months or years or five years or two years. Of course they don't know and they can't tell you, you know – that's what I'm worried about and I guess everybody is the last cancer, aye? (69-year-old NZ European woman with cancer)

Benefits for family.

Some participants identified a benefit for their family of being in hospital. Giving them a rest, reducing their anxiety, and generally not being a burden was seen as a positive consequence of being in hospital:

Well, I was absolutely relieved (about going to hospital). Yeah, well I thought there was no good going home to my daughter. My daughter has been marvellous, absolutely marvellous looking after me but then she has started a big, new job today and she's working and she's got four children. (83-year-old NZ European woman with cancer)

One participant felt that her family were happier when she was in hospital because they wouldn't be worrying about her medication. This was often a contentious issue at home with her daughter not believing her mother could manage her own medication:

Well, we have differing things about my tablets for a start off. K is not quite sure that I can manage, you know. Like she will come in in the morning and she will put out all my pills, you know, in neat little containers and if there [are] still some there when she comes home at night, "Why haven't you taken this, Mum"? And, "Why haven't you"? . . . She feels a lot more confident in the doctors than in me. (69-year-old NZ European woman with cancer)

Burdens of being in hospital.

While a significant theme related to the physical environment and cultural milieu of the hospital setting (see Chapter 7.4) was identified in the data, there were a number of additional sub-themes found, which related to a sense of burden from being in hospital:

- Feelings of loneliness.
- Burden on family.
- Communication with health professionals.

Feelings of loneliness.

Feelings of loneliness while being in hospital permeated participants' experiences. For some, it was associated with being "left alone" as family visitors left the hospital at the end of the day:

Like I would spend the day with T and then she would go home and I would walk out to the door with her and I would watch her go down the corridor and I found that difficult staying there and not going with her. But she was there again the next day.
(77-year-old NZ European man with cardiac disease)

However, for this participant, the feeling of being left alone was countered by the knowledge that, in order to "get better", he had to stay no matter how hard it was for him. This participant accepted a significant amount of burden in order to reap the benefits of being in hospital:

I don't think I was, you know (depressed). I knew I had to get better to get out of there but I was frustrated because I couldn't get out. (77-year-old NZ European man with cardiac disease)

For other participants the "quiet time" while being alone led the patient to think about the impact of their illness on their life at home:

. . . everything was very quiet and I thought, "How am I going to manage when I go home"? If I . . . because the reason I went to hospital with my heart was because of heart failure and I thought if that happens again, what will I do? And then the sensible part of me said, "Of course, you will do what you did before – you will ring the ambulance". And anyway I got myself in a tizz. (80-year-old NZ European woman with cardiac disease)

Burden for family.

Some participants reported a level of burden for family caregivers which was associated with family feeling anxious about the implications of having to go to hospital. For example, reasons, some families also worried about the patient dying while they were in hospital:

They think the worst of it (going to hospital), you know . . . us Māoris [sic] are like that. Going to hospital, you know: “Is she going to die”? and all this . . . (Husband of 75-year-old Māori woman with cancer)

For one participant whose experience of a nine-week admission, being in hospital put additional pressure on his wife, which caused him a lot of stress:

I don't like that idea at all. I don't know whether I mentioned to you right at the beginning, I have spent a lot of time in hospital with my heart and it's not a place that I like being, away from my family and the pressures I put on T and that. And the times that I have been in there it has been stressful to me and when I first come out. . . . (77-year-old NZ European man with cardiac disease)

His wife would come every morning and stay all day, not leaving until early in the evening. She did this every day for nine weeks. During the interview his wife described how she would plan her day around getting to the hospital with help from their children. It was apparent that the participant felt he was burdening her with the responsibility of caring for him, even when he wasn't at home. This contrasted with other participants, who saw being in hospital as an opportunity to give their family some respite from the caregiving role:

I was lucky. N, my middle boy, he lives two streets away from Mountain Road and I could park the car at his place and N or E, his daughter, would drop me at the hospital and I would wait for one of the boys to come at night and drive me back, and I used to like to come home before it got dark. I came home one night and of course we have got a new car, too, which I had to get used to and it's quite a bigger one than the one we had. So it was only one night that I found the lights coming towards me were really, really bad. (Wife of 77-year-old NZ European man with cardiac disease)

Communication with health professionals.

Although a number of participants had positive experiences communicating with health professionals during their stay in hospital, two participants described difficulties. One put this down to the fact that the doctor was not fluent in English and came from a different culture:

I did have trouble with one doctor and I think it was more his culture more than anything because he wasn't really fluent in English and the way he . . . thinking about it after, the way he tried to help me, it wasn't my style and I found it very difficult to have too much to do with him. (77-year-old NZ European man with cardiac disease)

Another participant asked frequently for information, but reported not receiving any response. The tension between not wanting to bother staff, yet feeling frustrated by not knowing what was happening, was evident in her response:

Yes and no, because you are sitting there just waiting and anticipating with no-one keeping you . . . no-one is communicating with you about what's going on, so sometimes I don't know whether I feel intimidated about asking the nurse all the time what's going on. I don't really like to ask all the time but I wouldn't have minded if they had just let me know . . . how far, you know. I know they are busy but . . . (57-year-old Cook Island Māori woman with cancer)

This section has outlined additional findings related to benefit and burden from Phase 1 of the study. The benefits included experiences of feeling cared for, improved symptom control, receiving reassurance about their illness, and benefits for family such as the hospitalisation providing a period of reprieve from caregiving. However, participants also experienced difficulties being in hospital. Difficulties related to poor communication with health professionals, feelings of loneliness, the burden for family in relation to hospital visits, and ongoing support for participants while they were in hospital.

The following section will outline my approach to achieving quality data in Phase 1.

7.5.2 Achieving data quality.

Attempts to develop a framework or checklist to promote and demonstrate data quality that aligns itself with that of quantitative researchers has been met with some debate for a number

of reasons. Firstly, qualitative research is diverse in its methodological approaches, and some have argued that it is, for this reason, that applying one framework to assess the quality of the research is not possible (Rolfe, 2006). Secondly, the tendency to evaluate qualitative research against criteria similar to that of quantitative research has been described as being a process of 'self-justification' developed in response to criticisms that qualitative research is inferior to quantitative methodologies (Sandelowski, 1986).

However, despite the lack of consensus, Guba's (1981) principles of assessing rigor and trustworthiness continue to be accepted by many as a useful approach to ensure quality qualitative research (Shenton, 2004). These principles are: credibility, transferability, dependability, and confirmability. I will use these to outline the strategies I used in this study to promote data rigour.

Credibility refers to the way in which the researcher links the study findings with reality (Guba, 1981). To do this the findings need to be believable from the perspectives of the research participants. In this study, I used a range of strategies to ensure the findings accurately reflected participant experiences of being in hospital.

Firstly, I developed the Phase 1 interview schedule (see Appendix 2.5) using questions that were derived from the literature review (see Chapter 4) on patient experiences of palliative care in the hospital setting, as well as my own clinical experience (outlined in Chapter 3). Using these questions as a guide to interviewing, I invited participants to give me examples from their recent experience of being in hospital. Thus, the line of questioning was derived from previous research that attempted to answer similar questions about patient experience in the hospital setting. In addition, the semi-structured approach to interviewing gave participants the space to express their views on their whole experience of being in hospital, including the benefits of the admission. Therefore, it could be said that the way in which the interview questions were developed, given that they were informed by previous research on patient experience, were designed in such a way that they would usefully collect data that was relevant to the research question (Sandelowski, 1986).

Secondly, using individual responses to verify experiences against others, using the same method of data collection can contribute to credibility (Shenton, 2004). During the data analysis, I looked for similarities across multiple participant responses, drawing them

together to create themes that represented a particular aspect of the experience of being in hospital. The data were analysed as a whole before being coded into categories, with examples used to present the data, which also contributes to study credibility (Sandelowski, 1986).

Thirdly, repeated engagement with participants is said to enhance credibility of the study (Morrow, 2005). I interviewed participants twice, which enabled me to collect rich, contextualised data about their experiences of the hospital admission. During the first interview participants were asked about what brought them into hospital, what they expected to find difficult being in hospital, and what they hoped for in terms of benefits. During the second interview, I was able to use responses from the first interview to ask them for actual examples of how they had experienced benefits and burdens from being in hospital.

Fourthly, having a good understanding of the culture of the organisation where data collection will take place is said to contribute to credibility of the research (Shenton, 2004). This provides an opportunity to develop trusting relationships with those who will be involved in the research process, such as recruitment, whilst also being familiar with the context of which participants will be drawing upon. In my role as a palliative care clinician at the study site, I have had prolonged engagement with hospital inpatients admitted with palliative care needs and with hospital clinicians involved in caring for them. This meant I had a comprehensive understanding of the organisation and well established trust relationships with those who would be involved in the research (Shenton, 2004).

Debriefing sessions between the researcher and others, such as supervisors, work groups, or project managers, is said to contribute to achieving credibility (Shenton, 2004). I had regular sessions with my research supervisors, which gave me opportunities to have my assumptions, values, and beliefs about the study context challenged. This helped me to keep open to the possibility of new unanticipated discoveries from the data. In addition, sections of data were reviewed and coded by one of my supervisors to look for areas of congruence or conflict within my coding.

Finally, a process of reflexivity, as outlined in Chapter 3, provides the reader with details of my background, qualifications, and experiences as a researcher and clinician in palliative care. The integrity of the researcher is an important component in demonstrating credibility

as the researcher is considered to be the “instrument of data collection and analysis” in qualitative research (Shenton, 2004) .

Transferability or applicability refers to the degree in which the research findings can be applied in other contexts (Guba, 1981). Addressing the generalisability of qualitative research is challenging given that qualitative researchers have an assumption that multiple perspectives are said to only exist at a particular time and under particular circumstances (Sandelowski, 1986; Shenton, 2004). However, in order to address the issue of transferability, the researcher must provide sufficient contextual information about the study, including the phenomenon under study, to enable others to relate the findings to another area (Shenton, 2004).

In relation to this study, transferability has been achieved through the provision of various aspects of the research process. For example, details regarding data collection with explicit connections to the study context have been provided in Chapters 1 and 2. In addition, palliative care has been clearly defined along with the population palliative care relates to (see Chapter 1). The sociological and clinical influences of the “good death” and its relevance in an acute hospital setting has been provided, thus setting the context of the study (see Chapter 2.2). In addition, a detailed account of where the interviews occurred, the timing of the interviews, and how they were conducted is described in section Chapters 7.3 and 7.4. This information helps the reader of the research to construct the context that surrounds the study and in doing so make a judgement of whether the findings are transferable to other contexts.

Dependability refers to the level at which the study findings are consistent and repeatable (Guba, 1981). However, some have argued that the changing nature of the phenomenon being studied, along with the assumption that there are “multiple truths” in qualitative research, means that repeating the same study will unlikely produce the same findings (Sandelowski, 1986). This should not, however, detract from the quality of the research. Nevertheless, to address the issue of dependability, various strategies can be used such as tracking the emerging research design, noting influences on the data collection, and analysis and recording of emerging themes.

In relation to this study, data collection was appropriately influenced by the nature of the research question and the availability of eligible participants, including their capacity and capability of participating in the research at the time of consent. A framework of thematic analysis was used to code the data and identify key themes. Finally, this thesis has been presented in such a way that a clear “decision trail” is provided in regard to the way in which the research developed. This decision trail is thought to be the only way that qualitative researchers can demonstrate dependability or repeatability (Sandelowski, 1986; Shenton, 2004).

Confirmability refers to the way in which the researcher attends to what quantitative researchers refer to as “objectivity”. Some have argued that qualitative researchers value subjectivity over objectivity as they seek to understand the meanings behind participants’ experiences (Morrow, 2005). However, strategies to ensure that the findings are a reflection of the participants’ experiences, and not those of the researcher, is an important component to achieving confirmability. This approach to “reflective commentary” has been described by Shenton (2004) who argues that details about the researcher’s beliefs about the chosen design must be included. It is therefore the reader of the research who confirms the adequacy of the findings by bringing together the data, the analysis, and the interpretation of the findings (Morrow, 2005).

In relation to this study, my background in palliative care and the way in which my knowledge in nursing has developed has been provided in Chapter 3. In addition, my beliefs about the role of the acute hospital in palliative care has been outlined. This provides the readers with information about the assumptions I bring to the study and how these have influenced the decisions I have made throughout the research process.

7.6 Chapter summary.

This chapter has provided an outline of the findings from the first qualitative phase of this study, which explored the benefits and burdens of hospital admission from a patient perspective. Participants experienced benefits that extended beyond the treatment they received and included a sense of feeling better and getting better, feeling safe, receiving help to manage at home, and relief for family that patients were receiving the care they need. However, at the same time most participants experienced some burden being in hospital. The

factors associated with this burden highlight the challenges associated with providing palliative care in a hospital environment.

In addition, this chapter has provided an overview of the strategies used to achieve rigor and trustworthiness in this phase of my study. Building on this chapter, the following chapter will outline the findings from Phase 2 of the study, which used a quantitative approach. This approach will address the fourth and final aim of this mixed methods study: to identify how experiences of benefits and burdens of hospital admissions impact on patient preferences to return to hospital.

Chapter 8: Phase 2: Circumstances and Predictors of Patient Related Experiences of Benefits and Burdens.

8.1 Preamble.

In this chapter, I will provide an outline of the aims and objectives of Phase 2 of this study and an overview of how the questionnaire was developed. This includes strategies used to maximise reliability and validity. Included in this chapter are two publications that outline Phase 2 findings. Additional information from Phase 2, which was unable to be included in the publications, is included at the end of this chapter.

8.2 Aims and objectives.

The aim of Phase 2 was to identify the predictors of benefit and burden of hospital admissions for people with palliative care needs and examine their influence on a preference to return to hospital in the future. The objectives were to:

- Develop a questionnaire to explore experiences of benefit, burden, and feeling safe in hospital using findings from Phase 2.
- Use the questionnaire to describe the circumstances of hospital admissions from the patients' perspectives identifying differences in patient groups based on age, living circumstances, ethnicity, and diagnosis.
- Identify predictors of perceived benefits, burdens, and feeling safe in hospital and their impact on preferences to return to hospital during a period of acute illness.

Having demonstrated from Phase 1 that patients experience both benefits and burdens being in hospital while at the same time have a preference to be in hospital, the aim of the second phase was to build on these findings to address the final objective of this study: to identify the predictors associated with experiences of benefits and burdens of hospital admission for people with palliative care needs and how these influence preferences to return to hospital.

8.3 Questionnaire development.

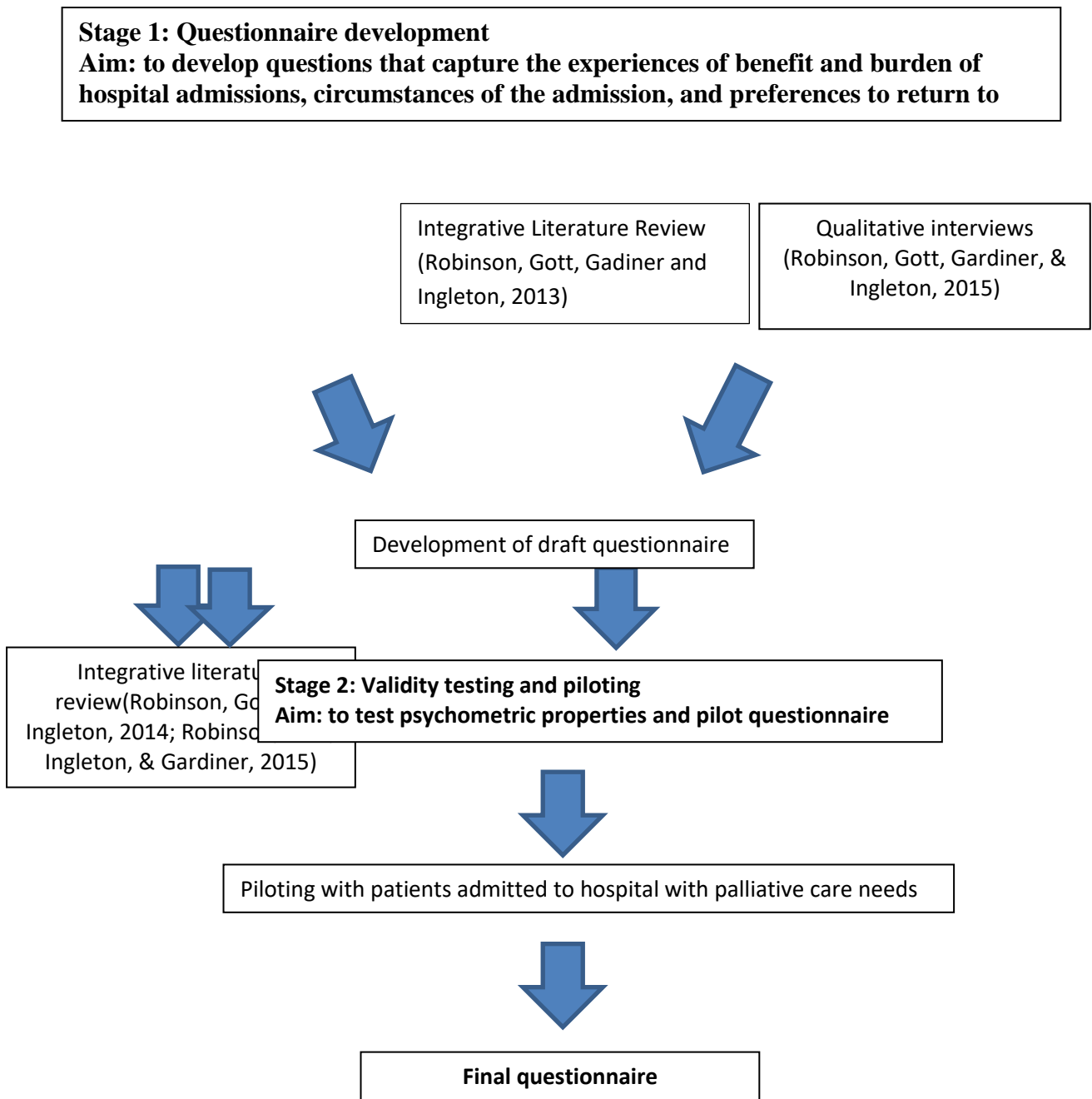
No pre-existing tool exploring benefits and burdens of hospital admissions was found; a questionnaire was therefore developed for Phase 2. The purpose of the questionnaire was to expand on the findings from Phase 1 in order to identify predictors of benefit and burden (as

a result of being in hospital) and the influence these had on a preference to return to hospital. Key features of the questionnaire needed to include the following: be easy to use, valid, and be reliable.

The development of the questionnaire involved four stages: systematic literature review; qualitative research; policy review; and piloting and adaption of the questionnaire tool (see Figure 8-1). Generic content regarding the burden of being in hospital was informed by my systematic review on the experiences of palliative care in hospital (Robinson, Gott, et al., 2014) (see Chapter 4). Specifically, elements of benefit and burden which had been identified by participants in Phase 1 (Robinson, 2015; Robinson, Gott, Ingleton, et al., 2015) (see Chapter 7) were added to the questionnaire items. For example, “Feeling safe” was identified in Phase 1 as a major theme in the qualitative data and was therefore added as a third concept, in addition to the general concepts of benefit and burden.

Questionnaire items relating to preferences for place of care, place of death, and preferences to return to hospital were also added to the questionnaire (see table 8-1). These items were informed by the policy review, which revealed how palliative care in hospital was a problem to solve (Robinson et al., 2016) (see Chapter 2). This “problematization” was based primarily on an assumption that patients with palliative care needs preferred to *not* be cared for in an acute hospital setting.

Figure 8- 1 Questionnaire development



8.3.1 Validity testing and piloting.

A pilot study of the questionnaire was carried out from October to December 2015 and formed the second stage of the questionnaire development process. The purpose of a pilot study is to test the feasibility of the chosen methodology and identify barriers to recruitment, sampling, and data collection, therefore providing opportunities to modify processes prior to the main study (Rattray & Jones, 2007). The pilot study can provide invaluable information to improve the validity and reliability of a questionnaire thereby contributing to data quality (ibid).

While, the sample size required to carry out a pilot study varies, it has been argued that a total of 15–20 is adequate to achieve feasibility, validity, and reliability (Hertzog, 2008). On this basis, 20 participants were recruited for the pilot study. Data were cleaned and items analysed for internal consistency using Cronbach alpha scores.

A range of scales can be used in questionnaires, however each scale is designed to produce different types or levels of data (Rattray & Jones, 2007). Therefore, the incorrect choice of scale can impact on the quality of data. I used a Likert scale to explore the key concepts in the questionnaire as they are particularly useful in measuring opinions or attitudes. Participants were asked to weight each item using a five-point ordinal scale from “strongly agree” to “strongly disagree” with “neither agree nor disagree” provided as a neutral point in the scale. There is some debate in the literature about the usefulness of a “neutral point” (Leung, 2011) however removing this option forces participants to choose a point on the scale that may not accurately reflect their opinion.

Table 8-1

Questionnaire Variables

*negatively worded items reversed prior to collation of scores

Benefits	Burdens	Feeling safe	Preference to return
I got better while I was in hospital.	I found it difficult being away from family and friends.	Being monitored and observed makes me feel safe.	I would prefer to return to hospital if I can't manage at home.
I feel better now compared to on admission.	I found it difficult sharing a room with other patients.	Being looked after by staff makes me feel safe.	I would prefer to return if family can't care for me.
I got help to manage at home.	I found it difficult sharing a bathroom with others.	Getting help from staff quickly makes me feel safe.	I would prefer to return if my illness gets worse.
I enjoyed talking to other patients.	I feel uncared for when staff are busy.	When staff are busy I feel unsafe*.	I would prefer to return if my symptoms get worse.
	I found it difficult being around sick people.	When staff don't check on me regularly I feel unsafe*.	
	I get bored when I'm in hospital.	When I can't get the help I need quickly I feel unsafe*.	
	I get lonely when I'm in hospital.		
	Difficult when I can't leave the ward.	When I don't understand what is happening I feel unsafe*.	
	Difficult if staff don't involve me in decisions.		
	Difficult when visitors are coming and going.		
	Cost of parking makes it difficult for family to visit.		
	The hospital is too noisy.		

Items that were not well understood by participants during the pilot study were reworded. In the pilot questionnaire, the variable related to the role of the GP consisted of a mix of items including issues related to access and opinions regarding the GP relationship. Subsequently, the internal consistency of the variable using the Cronbach alpha score was low, suggesting that the items did not relate well together. Items were therefore separated into two variables – one focusing on the relationship and the other on access barriers. All other variables remained unchanged (see Appendix 3.5 for a copy of the questionnaire).

Table 8-2
Cronbach Alpha Coefficients

Variables	Number of items	Maximum possible score	Cronbach alpha coefficient
Benefits	4	20	0.43
Burdens	11	50	0.72
Feeling safe	8	35	0.73
Preferences to return to hospital	4	20	0.77

Variables were tested for internal reliability (see Table 8-2). Given the small number of items for the fourth variable “benefits”, an inter item correlation was used to test the internal reliability (0.20 with a range of between 0.082 and 0.67) suggesting that the items within the “benefits” variable related to each other. Additional questionnaire items included performance status, which was measured using the Karnofsky Performance Status (KPS) (Peus, Newcomb, & Hofer, 2013). Measures of deprivation were collected using the New Zealand Index of Deprivation (Atkinson, Salmond and Crampton, 2013).

8.2.3 Achieving data quality.

Demonstrating methodological rigor is an important component of producing quality research. Quantitative researchers ensure their research is rigorous by addressing issues of reliability and validity (Heale & Twycross, 2015). The quality of the questionnaire and how it has been developed will inevitably influence the quality of the data. The following section will address each of these in turn, in relation to this study.

Reliability.

Reliability refers to the consistency of measurement used in the research (Heale & Twycross, 2015). In relation to this study, I needed to ensure that the tool of measurement, in this case the questionnaire, achieved a level of internal consistency. Cronbach alpha is the most common way of measuring internal reliability by correlating items within a concept to determine they are measuring the same thing (Heale & Twycross, 2015). Good internal consistency is indicated by a score of >0.70 (Rattray & Jones, 2007).

Cronbach alpha scores were calculated for all variables used in the questionnaire and are included in Table 8-2. All but one variable had a Cronbach alpha score of >0.70 . The variable “benefits” had a Cronbach alpha score of only 0.43. Given the small number of items for the variable “benefits”, an inter-item correlation was used to determine internal reliability (0.20 with a range of between 0.082 and 0.67) suggesting that the items with a “benefits” variable related to each other and were measuring the same thing. Inter-item correlation value is said to be an alternative way of measuring internal consistency in variables with a small number of items (< 10 items) (Robson, 2011).

Validity.

Validity refers to whether the questionnaire is measuring what it claims to (Rattray & Jones, 2007). Validity is assessed in three ways: content or face validity, criterion validity, and construct validity. To achieve face or content validity, multiple sources should be used to generate questionnaire variables and items (Rattray & Jones, 2007). Sources of data to inform the development of questionnaire variables include expert opinion, literature, pilot testing of the questionnaire, and from potential participants.

Content validity.

Content validity refers to how adequately the instrument covers the construct or phenomenon being studied (Heale & Twycross, 2015). Using the study population to generate the items used to describe a certain construct or variable contributes to content validity.

For this study, to ensure that the questionnaire was measuring the constructs it was supposed to, I used findings from the literature review (Robinson, et al., 2014) (see Chapter 4), policy review (Robinson et al., 2016) (see Chapter 2), and Phase 1 (Robinson et al., 2015a;

Robinson et al., 2015b) (see Chapter 7) to develop questionnaire items that were relevant to the study population and the research topic. For example, the key themes identified in Phase 1 were used as the dependent variables: benefit, burden, and feeling safe (see Chapter 7). Each variable was made up of a number of different items related to that concept that had been identified by participants in Phase 1. For example, *benefit* consisted of items such as feeling better, getting better, and getting help to manage at home; *burden* consisted of items such as lack of privacy, poor communication, and missing family and friends. Finally, the variable *feeling safe* was identified by participants during Phase 1 as a significant factor associated with the benefit of being in hospital. For this reason, *feeling safe* was developed into a variable of its own consisting of items such as being looked after by doctors and nurses, being monitored by hospital staff, and understanding details of the illness.

Criterion validity.

Criterion validity refers to how well the instrument predicts the outcome or variable being studied (Heale & Twycross, 2015). This is achieved by comparing the outcomes of prior studies using a validated instrument, which is measuring the same constructs.

In relation to this study, no instruments were identified that measured benefit, burden, or feeling safe in relation to a patient's experiences of palliative care in the acute hospital. Therefore, criterion validity is unable to be demonstrated.

Construct validity.

Construct validity refers to the degree to which the questionnaire items measure what they claim to be measuring (Heale & Twycross, 2015). Construct validity can be tested internally within the instrument, or externally comparing it with similar instruments measuring the same concept or variable and normally develops over time as the instrument is used repeatedly (Heale & Twycross, 2015). In relation to this study, no comparable instrument was identified that measured benefits and burdens of hospital admissions in palliative care. Pre-testing of an instrument using a pilot study can be helpful in achieving construct validity providing the researcher with an opportunity to adjust the questionnaire to ensure that it has the ability to collect what it is supposed to.

A pilot study was carried out for this study, details of which are provided in section 8.1.

The following two published articles each focus on different aspect of the Phase 2 findings. The first article outlines the circumstances surrounding hospital admissions in palliative care using the questionnaire survey to focus specifically on: supports prior to admission, reasons for admissions, enablers to remain at home, and patient priorities on admission. The second article is focused on predictors of benefit, burden, and feeling safe and their influence on a preference to return to hospital.

The first publication is cited as:

Robinson, J., Gott, M., Frey, R., & Ingleton, C. (2017). Circumstances of hospital admissions from the perspectives of patients with palliative care needs. *Palliative Medicine (Under Review)*

This paper is reproduced here in its entirety with permission from *Palliative Medicine*. The journal has an impact factor of 4.22 and a journal ranking of 10/90 (Health Care Sciences and Services (Web of Science)).

8.4 Article: Circumstances of Hospital Admissions in Palliative Care: A Cross-Sectional Survey of Patients Admitted to Hospital With Palliative Care Needs.

8.4.1 Introduction.

On average people will experience 2.28 hospital admissions in the last year of life (Chitnis, et al., 2014) with the likelihood of a hospital admission increasing in the last two weeks of life (Pivodic et al., 2015). Reducing hospital admissions has become a focus for high income countries as they work to manage the financial implications of an ageing population (Department of Health, 2008, 2010). However, the circumstances by which patients with palliative care needs are admitted to hospital remain poorly understood. Studies exploring reasons for admission have largely focused on presenting physical symptoms (De Korte-Verhoef et al., 2014), some of which, it has been suggested, could be anticipated and managed outside the hospital setting with support from community palliative care services (Seow et al., 2014).

This study addresses this knowledge gap by building on previous research (Robinson et al., 2015a; Robinson et al., 2015b) to explore the circumstances of hospital admissions from the

perspectives of patients with palliative care needs at the time of admission. After a review of the literature (Robinson et al., 2014) and policy (Robinson et al., 2016) related to hospital use in palliative care, a decision was made to focus on three key areas: support received prior to admission, enablers to remain at home, and patient priorities at the time of admission.

8.4.2 Study design.

A cross-sectional survey design using face-to-face questionnaires was adopted. Existing questionnaires exploring the circumstances surrounding hospital admissions in palliative care could not be identified, therefore findings from previous work (Robinson et al., 2016; Robinson et al., 2014; Robinson, et al., 2015a; Robinson et al., 2015b) were drawn upon to develop a 24 item questionnaire.

Participants were recruited from an acute hospital situated in an urban area of New Zealand (Auckland District Health Board, 2014) who met the following inclusion criteria: aged > 18 years; admitted to hospital with a life limiting illness that met Gold Standards Framework Prognostic Indicator Guide criteria for palliative care need;(Gold Standards Framework, 2014) ability to understand and speak English; and capable of completing an interviewer administered questionnaire. A purposive approach to sampling was adopted to ensure diversity of participants (Coyne, 1997).

8.4.3 Data Collection.

Participants were asked five questions regarding the support they were receiving prior to admission, who made the decision to come to hospital, and their understanding of the illness (see Table 8-3).

Table 8-3
Items from the Questionnaire

Questions	Selection
What services do you have supporting you at home? What services did you see in the week prior to admission? What services did you see on the day of admission?	a. General Practitioner. b. District Nurse. c. Hospice. d. Home help. e. None.
Who decided you should come to hospital this time?	a. I did. b. My family. c. General Practitioner. d. Ambulance crew. e. Care facility staff. f. Other.
What is your understanding of your current health?	a. It will get better eventually. b. It will never get better and in time it will get worse. c. It will stay the same. d. I don't know.

In addition, participants were asked about a range of factors surrounding the hospital admission (see Table 8-4). Using a five item Likert scale each item within the variable was scored from “strongly agree” to “strongly disagree”.

Table 8-4
Likert Scale Questions and Cronbach Alpha Scores

Variable	Items	Cronbach alpha coefficient
GP Relationships	I have a very good relationship with my GP GP has a good understanding of my illness. I trust my GP will know what to do if I get sick at home. My GP listens and discusses everything with me fully.	.927
Enablers to remain at home	If my GP had visited me at home. If my family knew what to do. If I could have accessed equipment. If I could have accessed medication. If the hospice had visited me at home.	.830
Priorities	I got help from health professionals. I got treatment for my illness. I got treatment for the symptoms. I got information about why I was unwell. I got tests and investigations. I went to hospital.	.802

8.4.4 Data analysis.

Categorical data were summarised as frequencies and percentages and the mean with standard deviation was calculated for continuous variables. Comparative group analysis, using analysis of variance (ANOVA) and independent *t*-tests, was used to identify differences between groups in study outcomes. Chi square tests were carried out to identify relationships

between groups and study outcomes. All statistical analysis were performed using Statistical Package for Social Science for Windows (SPSS) Version 22.

Ethical approval

Research Ethics approval was obtained from the New Zealand Health and Disability Ethics Committees (Ref: 15/CEN/109/AM02).

8.4.5 Results.

Participant Characteristics.

One-hundred-and-sixteen participants completed the questionnaire (see Table 8-3).

Table 8-5
Participant Information

Variable	No. participants (%)
Gender	
Male	59 (50.9)
Female	57 (49.1)
Age	
18–59 years	31 (26.7)
60–79 years	63 (54.3)
>80 years	22 (19.0)
Ethnicity	
NZ European	69 (59.5)
Māori	18 (15.5)
Pasifika	7 (6.0)
Asian	3 (2.6)
Other	19 (16.4)
Diagnosis	
Cancer	95 (81.9)
Lung	19 (16.4)
Breast	16 (13.8)
Upper GI	14 (12.1)
Colorectal	13 (11.2)
Prostate	12 (10.3)
Other	21 (18.1)
Non-cancer	21 (18.1)
Heart disease	10 (8.6)
COPD	8 (6.9)
Other	3 (1.8)
Knowledge of illness	
Will get better	20 (17.2)
Will never get better and in time will get worse	72 (62.1)
Will stay the same	4 (3.4)
Don't know	20 (17.2)
Lives alone	
Yes	28 (24.1)
No	88 (75.9)

Knowledge of illness

Twenty participants (17.9%) thought their illness would get better compared to 72 (62.1%) who knew it would never get better and in time would get worse. Four (3.4%) participants thought their illness would stay the same, and 20 (17.9%) said they did not know. There was no significant difference in knowledge of prognosis by diagnosis, age, gender, or ethnicity.

Decision to come to hospital

Thirty-three (28.4%) participants made the decision to come to hospital themselves. For 26 (22.4%) participants a clinic doctor made the decision for them to be admitted while attending a planned outpatient clinic appointment. The family decided for 25 (21.6%) participants, the GP for 13 (11.2%) participants, the ambulance crew for 13 (11.2%) participants, and for six (5.2%) participants, a hospice doctor or nurse advised them to go to hospital. Those with cancer were more likely to be admitted from clinic ($\chi^2(5, n=116) = 16.28, p=.00$).

Support prior to admission

Community Services

Only 14.7% (17) participants had no services at all involved in their care prior to admission. On the day of admission, 64.6% (75) had contact with at least one community service. 28.4% (n=33) of participants were known to a community hospice service.

Those with a non-cancer diagnosis were less likely to have hospice involved prior to the admission and more likely to be receiving home help services ($\chi^2(1, n=116) = 10.19, p=.00$).

Those aged over 75 years were also less likely to have hospice involved and more likely to be receiving home help services prior to the admission ($\chi^2(1, n=116) = 6.45, p=.01$).

General Practitioner (GP)

All participants were registered with a GP, although only 75.9% (88) considered their GP to be “involved” prior to admission; 15.5% (18) participants had contact with their GP on the day of admission. Most participants (86%, n=100) agreed, or strongly agreed, that they had a good relationship with their GP. Taking into account all questions related to the participants relationship with their GP (see Table 8-4) participants felt well supported by their GP (M=16.94, SD=3.41).

Enablers to remain at home

Only two (1.7%) of the 49 participants known to hospice felt that a hospice visit at home may have prevented the admission. Access to medication was seen as an enabler to remain at home by 10 (8.6%) participants, access to equipment by eight (6.9%) participants, and a home visit by the GP by two (1.7%) participants. Seven (6%) participants felt that if their family had known what to do they could have stayed at home.

Priorities on admission

One-hundred-and-thirteen (97.4%) participants agreed, or strongly agreed, that getting help from health professionals was a priority on the day they were admitted to hospital. Getting treatment for the illness and getting relief from symptoms were equally important for 111 (95.7%) participants (see Table 8-6).

Table 8-6
Priorities at the Time of Admission (Multiple Response)

Priority	Cancer (n=95)					Non-cancer (n=21)					T test	P =
	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree	Strongly disagree	Disagree	Neither agree or disagree	Agree	Strongly agree		
Staying at home	34 (35.7%)	44 (46.3%)	4 (4.2%)	8 (8.4%)	5 (26.3%)	9 (42.8%)	8 (38.0%)	1 (4.7%)	2 (9.5%)	1 (4.7%)	.21	.67
Being with family	5 (26.3%)	26 (27.3%)	13 (13.6%)	28 (29.4%)	23 (24.2%)	0 (0%)	8 (38.0%)	4 (19.0%)	4 (19.0%)	5 (23.8%)	.37	.70
Not being a burden for family	1 (1.0%)	12 (26.3%)	9 (9.4%)	25 (26.3%)	48 (50.5%)	0 (0%)	3 (14.2%)	3 (14.2%)	10 (47.6%)	5 (23.8%)	1.22	.22
Help from health professionals	0 (0%)	1 (1.0%)	0 (0%)	31 (32.6%)	63 (66.3%)	0 (0%)	1 (4.7%)	1 (4.7%)	8 (38.0%)	11 (52.3%)	1.41	.16
Treatment for the illness	0 (0%)	1 (1.0%)	2 (2.1%)	27 (28.4%)	65 (68.4%)	0 (0%)	0 (0%)	2 (9.5%)	7 (33.3%)	12 (57.1%)	1.14	.25
Relief from symptoms	0 (0%)	21 (22.1%)	1 (1.0%)	18 (18.9%)	74 (77.8%)	0 (0%)	0 (0%)	2 (9.5%)	6 (28.5%)	13 (61.9%)	.08	.17
Information about the illness	0 (0%)	4 (4.2%)	3 (3.1%)	31 (32.6%)	57 (60%)	0 (0%)	1 (4.7%)	5 (23.8%)	6 (28.5%)	9 (42.8%)	2.03	.04
Getting tests and investigations	0 (0%)	1 (1.0%)	1 (1.0%)	22 (23.1%)	71 (74.7%)	0 (0%)	2 (9.5%)	2 (9.5%)	7 (33.3%)	10 (47.6%)	2.37	.02
Going to hospital	0 (0%)	2 (2.1%)	1 (1.0%)	18 (18.9%)	74 (77.8%)	0 (0%)	1 (4.7%)	0 (0%)	7 (33.3%)	13 (61.9%)	1.35	.18

An independent sample *t*-test was conducted to compare the priority scores on the item associated with going to hospital between groups. There was a significant difference found between those with cancer ($\bar{x}=27.93$, $SD=2.66$) and those with non-cancer ($\bar{x}=26.19$, $SD=2.97$). Those with cancer placed a significantly higher priority on receiving information about their illness ($t(114)=2.03$, $p=.04$) and receiving tests and investigations ($t(114)=2.37$, $p=.02$) compared to those with a non-cancer diagnosis.

8.4.6 Discussion.

This study shows that patients do not perceive community services such as hospice or GP to have a role in enabling them to remain at home. This finding is inconsistent with previous evidence that shows involvement of community services enables people with palliative care needs to remain at home thereby reducing hospital admissions (Seow et al., 2014). The way in which community services are perceived to have a role in care at home may influence how and when patients and families access these services. If patients do not perceive services as being useful to enable them to remain at home it is unlikely they will access these services. Although most people in this study were receiving some form of support from community-based services, and many had contact with one of these services on the day of admission, there were variations in service involvement by diagnosis. This finding is consistent with those of other studies that have shown that cancer still remains the most common diagnosis in referrals to hospices (Sleeman, Davies, Verne, Gao, & Higginson, 2015). This is despite those with a non-cancer diagnosis experiencing similar symptom prevalence (Solano, Gomes, & Higginson, 2006) and a high symptom burden that impacts significantly on their quality of life (Gardiner, et al., 2010).

GPs are considered to have a significant role in supporting patients with palliative care needs to remain at home (Reyniers, Houttekier, Cohen, Pasma, & Deliens, 2014). Indeed, evidence has shown that an association between increased continuity of care from the General Practitioner and decreased odds of Emergency Department visits, hospital admissions, and hospital deaths (Almaawiy, Sussman, Brazil, & Seow, 2014). In this study, all participants were registered with a GP, however not all considered them to be “involved” in supporting their care at home. Furthermore, despite the vast majority of participants feeling that they had a good relationship with their GP, very few had contact with them on the week prior to, or the day of, admission to hospital. This warrants further investigation, given that current policy is

aimed at strengthening generalist palliative care involvement in New Zealand (Department of Health, 2017) and other countries (Department of Health, 2008).

Only just over half of the participants in this study were aware of their life limiting prognosis. Little is known about how patient knowledge of the illness influences hospital use in palliative care. However, it could be argued that patient knowledge of prognosis might influence the way in which hospitals are used. For example, those with knowledge of a poor prognosis may consider the hospital as being an inappropriate place of care given the limited treatment options available. Conversely, those with inadequate knowledge of their illness may present to hospital expecting treatment which is no longer medically indicated. However, given that most participants in this study knew their prognosis was limited, the motivation to go to hospital may be based on more than just treatment of the illness. Indeed, participants in this study prioritised getting help from health professionals. This included accessing further tests and investigations over remaining at home or being with family and friends. Patients' priorities in the last year of life have been shown to be focused on, amongst other things, understanding their changing health issues.(Appelin & Bertero, 2004). Coming to hospital provides patients with opportunities to increase their understanding of a changing illness trajectory and it appears less relevant to patients and families that the illness is incurable.

8.4.7 Conclusion.

This study has demonstrated the complex nature of hospital admissions in palliative care. Further research is needed to explore patient perceptions of care at home and the role of community services to enable them to remain at home. Further understanding the motivation to come to hospital in the context of an incurable illness and limited treatment options may help to inform the development of services that can enable better care at home and enable hospitals to focus on providing care that can only be provided in this setting.

Declaration of conflicting interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

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8.5 Preamble.

The following article is focused on predictors of benefit, burden, and feeling safe and their influence on a preference to return to hospital.

The publication is cited as:

Robinson, J., Gott, M., Frey, R., & Ingleton, C. (2017) Predictors of patient related benefit, burden and feeling safe in relation to hospital admissions in palliative care: A cross sectional survey. *Palliative Medicine*. Sep 1: 269216317731991. doi: 10.1177/0269216317731991. [Epub ahead of print]

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8.6 Article: Predictors of Patient Related Benefit, Burden, and Feeling Safe in Relation to Hospital Admissions in Palliative Care: A Cross Sectional Survey.

8.6.2 Introduction.

Hospital use within palliative care is under increasing scrutiny, given attempts to curtail rising healthcare costs (Simoens et al., 2010). Palliative care policy internationally has “problematized” the provision of palliative care in the hospital setting, focusing instead on reducing hospital admissions and supporting a patient’s assumed preference to be cared for at home (Robinson et al., 2016). Inadequacies in the hospital’s physical surrounding and the cultural milieu of the hospital have been shown to impact negatively on patients’ experiences of hospitalisation (Gardiner et al., 2010; Robinson et al., 2015b) and are cited as support for the argument that those with palliative care needs should avoid a hospital admission. However, a recent systematic review of patients’ experiences of palliative care in an acute hospital setting suggests that current evidence is limited to the negative aspects of care, with little attention paid to potential benefits of hospital admissions (Robinson et al., 2014).

There is also a paucity of evidence regarding the preference of patients with palliative care needs for place of care during a period of acute illness. Furthermore, although hospital is rarely chosen as a preferred place of death (Arnold, Finucane, & Oxenham, 2013; Thomas et al., 2004) and despite a focus on increasing support for community-based palliative care in many countries, patients return to the hospital frequently during the last year of life (Goldsbury et al., 2015). It may be assumed that patients present to hospital for treatment of their illness and that the benefits they experience are related to the treatment they receive. However, recent qualitative research has shown that the benefits of being in hospital extend beyond the treatment received (Robinson et al., 2015a), and these additional benefits appear to influence patients' preferences to return to the hospital during periods of acute illness. Within this context, the aim of the study presented in this paper was to identify predictors of perceived benefit and burden of hospital admissions and explore how experiences of benefit and burden influence a patient's preferences for place of care during a period of acute illness in palliative care.

8.6.3 Data Analysis.

Quantitative data were coded into SPSS 20. Both descriptive (frequencies, mean, mode, standard deviation) and inferential statistics appropriate to the level of measurement (chi-square, *t*-tests, ANOVA) were utilised in the analyses.

8.6.4 Results.

Of the 163 people invited to be part of the study, 45 declined and 118 patients consented. However, two were unable to complete the survey due to overwhelming fatigue. The final sample size was 116. Participant characteristics are outlined in Table 8-5.

Benefits

Comparative group analysis using analysis of variance (ANOVA) was used to compare groups. A statistically significant difference was found between deprivation groups ($F(4, 109) = 3.15, p=.017$). Post-hoc testing using Tukey revealed a statistical difference between deprivation index areas 3-4 and areas 7-8 ($p=0.04$), with those living in more deprived areas experiencing more benefit being in the hospital compared to those living in less deprived areas.

Feeling safe

There was a statistically significant ($p < .05$) difference between diagnostic groups with those who had a primary non-cancer diagnosis feeling less safe in the hospital compared to those with cancer ($p=.04$). There was also a statistically significant difference between age groups ($F(2, 113) = 3.36, p=.03$). The main effects of age ($F(2, 114) = 4.50, p=.01$) and diagnosis ($F(1, 111) = 5.6, p=.01$) on feeling safe were significant. Younger people felt safer compared to older people, and those with cancer felt safer compared to those with a non-cancer diagnosis (see Table 8-7).

Burden

As determined by one-way ANOVA, a statistically significant difference in burden scores was found between age groups ($F(2, 111)=7.78, p =.000$) and ethnicity ($F(4, 109)=4.44, p =.00$). In addition, compared to NZ European ($\bar{x}=31.77, SD=6.77$), Pacific ($\bar{x}=39.42, SD =5.85$) and Asian people ($\bar{x}=43.33, SD =5.68$) experienced significantly more burden ($p < .05$) being in hospital (MD =7.64, MD=11.55; $p=.00$).

Using two-way ANOVA, an interaction effect was found between living alone and ethnicity ($F(1, 100) =3.50, p =.03$); the effect size was small (partial eta squared = .06). Post hoc testing using Tukey HSD revealed differences between ethnic groups with Pacifica ($\bar{x} = 41.16, SD =3.97$) and Asian groups ($\bar{x}=43.33, SD =5.68$) who were living with others experiencing significantly more burden compared to NZ European who were living with others ($\bar{x}=32.73, SD =6.58$) (see Table 8-7).

Table 8-7
Mean Scores and Standard Deviation in Parentheses ()

	Benefits	Burdens	Feeling safe
Gender			
Male	15.20, (2.15)	33.20, (6.14)	31.37, (3.76)
Female	15.42, (2.71)	33.38, (7.61)	30.29, (4.03)
Age			
18-59 years	15.06, (2.54)	37.83, (6.56)	29.35, (4.26)
60-79 years	15.39, (2.56)	31.46, (6.01)	31.53, (3.60)
>80 years	15.40, (1.96)	32.28, (7.00)	30.95, (3.90)
Ethnicity			
NZ European	15.31, (2.43)	31.77, (6.07)	31.13, (3.54)
Māori	15.00, (3.00)	34.23, (5.86)	30.94, (4.39)
Pacifica	14.57, (2.14)	39.42, (5.85)	27.42, (5.15)
Asian	14.00, (2.00)	43.33, (5.68)	30.33, (3.21)
Other	16.05, (1.98)	33.28, (8.43)	31.05, (4.18)
Deprivation			
Index 1-2	15.65, (2.67)	30.86, (7.20)	32.60, (3.78)
Index 3-4	14.08, (2.50)	35.26, (5.06)	30.04, (2.40)
Index 5-6	14.66, (2.26)	33.76, (5.78)	30.66, (3.43)
Index 7-8	16.35, (1.54)	30.42, (9.19)	30.92, (4.73)
Index 9-10	15.84, (2.38)	34.37, (6.98)	30.45, (4.61)
Diagnosis			
Cancer	15.26, (2.51)	33.05, (7.19)	31.10, (4.13)
Non-cancer	15.52, (2.11)	34.40, (5.04)	29.66, (2.53)
Karnofsky score			
80-100	15.16, (2.24)	34.00, (6.69)	31.13, (3.13)
50-70	15.35, (2.62)	33.20, (6.99)	30.80, (4.39)
<40	15.50, (2.06)	31.58, (6.89)	30.16, (3.43)
Living alone	15.67, (2.27)	31.00, (5.34)	30.39, (2.67)
Not living alone	15.19, (2.49)	34.03, (7.15)	30.98, (4.24)

Preferences to return to hospital

Multivariate regression was undertaken to assess whether benefits, burdens, or feeling safe in hospital significantly predicted a preference to return to hospital. The model was significant ($p=0.02$). When comparing the unique contribution of each independent variable, “feeling safe” had the largest beta coefficient indicating a statistically significant ($B=0.14, p=0.03$) contribution to the dependent variable “preferences to return to hospital” (see Table 8-7).

Table 8-6
Coefficients from Multiple Regression Analysis

Model (dependent variable: preference to return to hospital)		Unstandardised Coefficients		Standardised Coefficients	T	Sig.
		B	Std. Error	Beta		
1	(Constant)	9.987	3.081		3.242	.002
	Benefits of being in hospital total score	.127	.097	.125	1.316	.191
	Total feeling safe	.146	.067	.235	2.197	.030
	Burden total score	-.003	.038	-.007	-.071	.944

8.6.5 Discussion.

This study adds important new information about the benefits associated with hospital admissions for patients with palliative care needs. The findings show that those living in more deprived areas experience greater “benefit” being in the hospital compared to those from less deprived groups. This is consistent with a recent study by Macfarlane and Carduff (2016), showing that those experiencing greater deprivation are more likely to die in hospital and less likely to die in a hospice setting, even if they are known to specialist palliative care services.

We also found that those with a non-malignant illness feel less safe in the hospital compared to those with cancer. Feeling unsafe in hospital may be related to a lack of understanding about the nature of the life threatening illness. A study by Gardiner et al. (2009) showed that patients with COPD expressed concerns about their condition and in particular, the manner in which they would die. However, none of the patients had discussed their fears with a health professional.

In this study, New Zealand European participants experienced significantly less burden being in the hospital compared to Asian and Pacific participants. This is perhaps unsurprising given that Western cultural ideals underpin the delivery of care in acute hospitals. For example,

Asian and Pacific cultures are known to place value on a community or collective approach to decisions regarding their health (McLaughlin & Braun, 1998; Tsai, 2008). However, within a Western framework individual autonomy and support for patient preferences are central to clinical decision making (Tsai, 2008), which creates problems for both staff and patients.

A preference to be cared for outside the hospital setting for those with palliative care needs has been well documented in the literature (Arnold et al., 2013; Stajduhar et al., 2008; Thomas et al., 2004). However indicating a preference for a “home” death may be “premised on a mutual, culturally normative, assumption that the most “natural” place to prefer to die would be the home” (Thomas et al., 2004). As this research demonstrates, this preference cannot be viewed in the abstract. Rather, as circumstances change preferences may also change. “Feeling safe” during the current hospital admission was the greatest predictor to a preference to return to the hospital. This indicates that hospitals can assume a “home-like” aspect for some people, given that feelings of safety are central to notions of “home” (Williams, 2002) .

Surveying participants as they neared the end of their admission meant that participants were drawing upon very recent experiences of being in the hospital (Bhandari & Wagner, 2006). However, some limitations must be acknowledged. Recruitment was limited to one hospital in New Zealand and three specialty services; therefore, the findings may not have the same resonance in other countries or services. In addition, the standardisation of questionnaires means that participants were forced to give set answers to questions that may not truly reflect their individual experiences.

8.6.6 Conclusion.

This study demonstrates that socio-demographic factors including deprivation, diagnosis, age, and ethnicity influence patient experiences of benefit, burden, and feeling safe in hospital within a palliative care context. Furthermore, feeling safe was a significant predictor for a preference to return to the hospital during a period of future acute illness. Further research is needed to understand the factors that contribute to a sense of safety for patients with palliative care needs across different care settings. Furthermore, a better understanding of how experiences of “feeling safe” may contribute to the acute hospital being the “default care provider” when patients feel unsafe at home is needed.

8.7 Additional findings.

The following findings were not included in the publications in this chapter, however they are relevant to the overall thesis. They include a more thorough descriptive analysis of sample characteristics, details surrounding help at home, whether participants believed the admission could have been avoided, and preference for place of care and place of death.

Comparisons have been made between participant groups and was limited to diagnosis. Due to small numbers, and the requirement of chi-square testing (which requires the assumption of “minimum expected cell frequency” to be met), other comparisons using such factors as ethnicity and deprivation could not be made. However, despite this limitation the comparisons between those with cancer and those with a non-cancer diagnosis is an essential one to make given the known inequities in how palliative care is provided in these groups (Boland, Martin, Wells, & Ross, 2013; Dalkin, Lhussier, Philipson, Jones, & Cunningham, 2016).

Co-morbidities

Details regarding co-morbidities were obtained from the clinical notes. 64.7% (n=75/116) of participants had at least one co-morbidity in addition to their main diagnosis. However, there were differences between those with a non-cancer diagnosis and those with cancer; 52.3% (n=11/21) of participants with a non-cancer diagnosis had more than three co-morbidities, compared to only 13.6% (13/95) of those with cancer.

A chi-square test for independence (with Yates Continuity Correction) indicated a significant association between diagnosis and co-morbidities, $\chi^2(1, n=116) = 9.3, p=.002, \phi = -.30$.

Entry into hospital

Data regarding the way in which participants entered the hospital were collected from the hospital’s electronic admission system. In terms of the timing of the admission, there was very little difference between those with cancer and those with a non-cancer illness, with 42.8% (n=9/21) of those with a non-cancer illness admitted within working hours, compared to 49.4% (n=47/95) of those with cancer. However, those with a non-cancer diagnosis were more likely to be admitted through the Emergency Department (85.7% c/t 29.4%). A Chi-square test for independence (with Yates Continuity Correction) confirmed a significant

association between diagnosis and entering the hospital via the Emergency Department, $\chi^2 (1, n=116) = 21.073, p=.000, \phi = -.45$.

In addition, those with a non-cancer diagnosis were more likely to have called an ambulance when they became unwell at home (28.5%; $n=6/21$), compared to those with cancer (7.3%; $n=7/95$). However, it was not possible to confirm the significance of this association due to small numbers.

Primary presenting complaint

Overall, the most common primary presenting complaint as recorded in the clinical notes was pain, with 52.5% ($n=61$) of participants reporting pain on admission. However, whilst 57.8% ($n=55$) participants with cancer reported pain as primary presenting complaint, for those with a non-malignant illness, the most common presenting complaint was lung problems, including breathlessness, pleural effusion, pneumonia or pulmonary embolism (71.4%, $n=15$).

Proposed management plan

Data regarding the proposed management plan was collected from the admission notes. Ninety-four percent of patients had plans for investigations such as laboratory and radiological tests. Little difference was found between disease groups (100% of those with non-cancer compared to 92.6% of those with cancer).

Help at home

Participants were asked about what help they were receiving from family caregivers. Some participants (23.2%, $n=27$) stated that they did not require any help and were independent at home. The most commonly reported assistance from family was help with household tasks (64.1%, $n=86$) such as shopping, cleaning, transport and meal preparation. Assistance with emotional support was reported by 69.8% ($n=81$) of participants. The health of the caregiver was reported as being very good or extremely good by 63.8% ($n=74$) of participants.

Admission avoidable or not

Participants were asked if they believed the admission was unnecessary or avoidable. Very few people agreed or strongly agreed that the admission could have been avoided or was unnecessary. However, there were some interesting differences between diagnostic groups.

The admission was considered potentially avoidable by 7.3% (n=7/95) of those with cancer compared to 19.04% (n=4/21) of those with a non-cancer illness.

Preferences for place of care and place of death

Finally, participants were asked whether having a choice about where they were cared for when they became unwell was important. 81% of participants either agreed or strongly agreed that it was important that they got to choose where they were cared for with little difference seen between diagnostic groups. However, when it came to preferred place of death, those with cancer were more likely to choose hospice (17.8% c/t 4.76%) whereas those with a non-cancer illness were more likely to choose hospital as their preferred place of death (19% c/t 5.2%). Chi-square testing for significance was unable to be carried out due to small numbers.

8.8 Chapter Summary

This chapter has outlined the process of questionnaire development and validity/reliability testing and presented two publications that provide details about the second phase of the study. Phase 2 findings confirmed what was found in Phase 1, namely that patients experienced benefits and burdens related to being in hospital. Extending these findings, Phase 2 also identified how experiences of benefit and burden influenced participants' preferences to return to hospital. This chapter concluded with an overview of additional findings from Phase 2 data, with a particular focus on differences relating to diagnosis. The following chapter will integrate the findings from both phases of this study, outlining the strengths and limitations of each phase, and conclude by providing recommendations for research, practice, and policy.

Chapter 9: Discussion

Using a mixed methods design, I have explored the benefits and burdens of hospital admissions from the perspective of patients with palliative care needs and examined how these experiences influence a preference to return to hospital during a period of acute illness. In doing so I have addressed four core objectives:

1. To understand how the acute hospital is positioned in health policy in the provision of palliative and end of life care.
2. To explore what is currently known about patient and family experiences of palliative care in the hospital setting.
3. To explore the benefits and burdens of hospital admissions from the perspectives of patients with palliative care needs.
4. To identify the factors associated with experiences of benefits and burdens of hospital admissions for people with palliative care needs and how these influence preferences to return to hospital.

In this chapter, I bring together the different phases of work to present an integrated analysis of the findings. I discuss the strengths and limitations of all elements of the study. Finally, I present implications for future research, policy, and practice.

9.1 Integration of findings.

A mixed methods, two-phase sequential approach was adopted for this study. This approach enabled me to adopt an iterative process of using the findings from each element of the study to inform subsequent phases. Firstly, the policy review (see Chapter 2) highlighted the way in which hospitals are perceived as being a default palliative care provider when community services have failed in international palliative care policy. In addition, palliative care and/or death in hospital is measured against the “good death” construct and considered as a problem to be solved. Findings from the policy review revealed similarities across all countries studied, including New Zealand, in how the acute hospital is perceived in palliative care (see Chapter 2).

An integrative review of the literature on how patients with palliative care needs and their families experience the hospital setting (see Chapter 4) revealed an important knowledge

deficit. The review confirmed that current evidence is limited to the negative aspects of care, with little attention paid to the benefits that patients experience as a result of being in hospital. These findings were used to refine the research question and develop the aims and objectives for Phase 1, the qualitative element of the study (see Chapter 8).

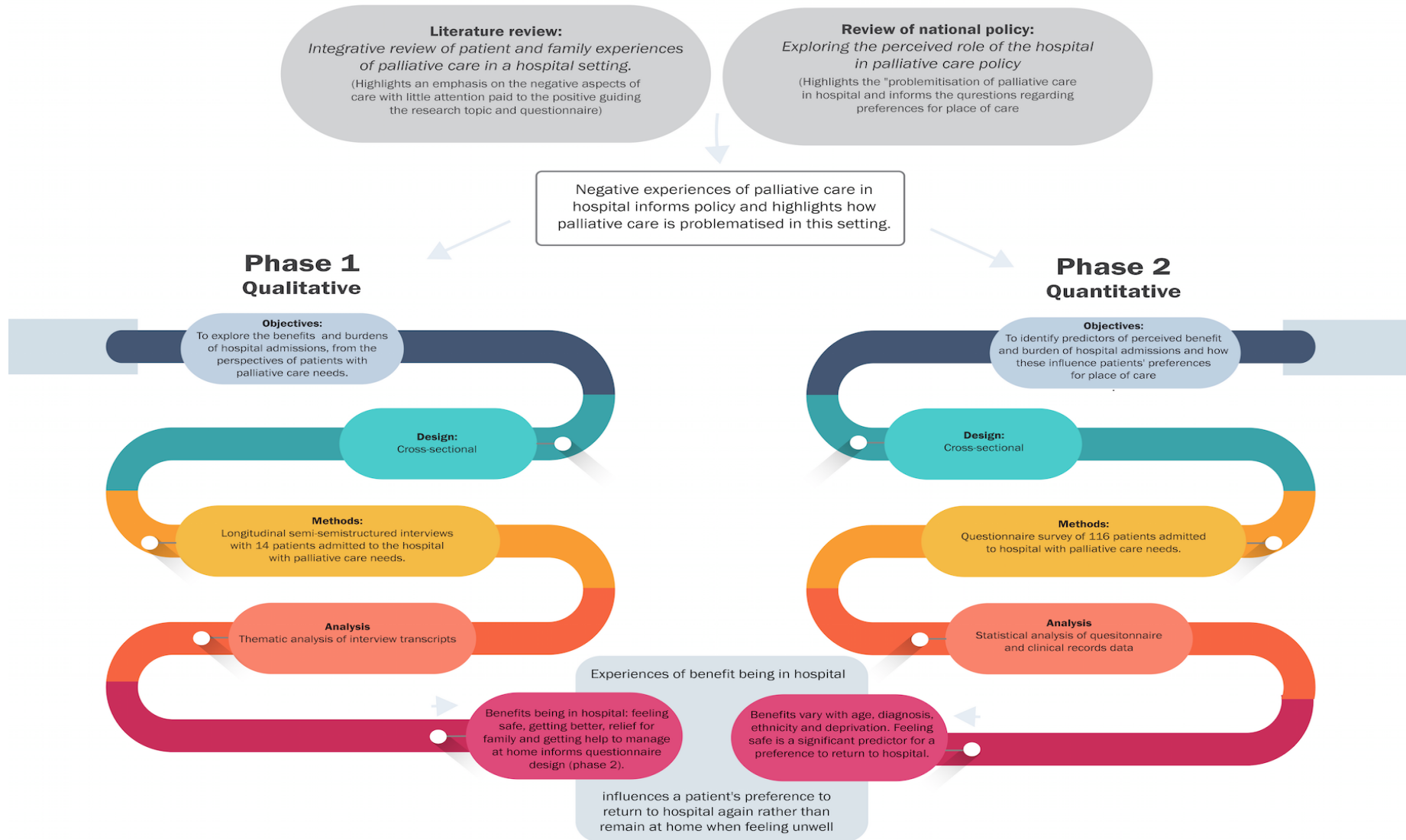
Findings from Phase 1 identified a burden for patients which was associated with both the physical environment and cultural milieu of the hospital setting. Experiences of burden related to hospital admissions for those with palliative care needs was not an unexpected finding, however the experiences of burden did not appear to deter participants from expressing a preference to return to hospital, even if the care they received in hospital could have been provided at home. However, in addition to the burden experienced, participants in phase 1 also identified a range of benefits from being in hospital which extended beyond the treatment they received. These included “getting/feeling better”, “feeling safe”, having tests and investigations, relief for family, and receiving support to manage at home (see Chapter 8).

Combining evidence from the literature review and Phase 1, I developed a questionnaire survey to collect quantitative data in Phase 2 (see Appendix 3.1). Drawing evidence from three different sources ensured that the questionnaire items were relevant to the study topic and population being studied. Findings from Phase 2 revealed that certain patient groups were more likely to experience benefit or burden related to hospitalisation. In particular, Chinese and Pacific people were more likely to experience burden being in hospital compared to those from other cultures. In addition, those who were living in more deprived areas were more likely to experience benefit being in hospital compared to those living in less deprived areas. I also found that diagnosis influenced experiences of “feeling safe” with those who had a non-malignant diagnosis feeling less safe in hospital compared to those who had cancer.

Furthermore, “feeling safe”, a major benefit of being in hospital identified by participants in Phase 1, was found to be a significant predictor in a preference to return to hospital. Further analysis of data related to the circumstances surrounding the hospital admission revealed that participants were unable to identify enablers to remain at home, such as general practice and hospice teams. Indeed, despite the majority of participants having a good relationship with their GP, many felt that the GP was not involved in their current care, nor were they considered to have a role in enabling them to remain at home (see Chapter 9.5).

The inter-relationships between the different phases of the research are presented in Figure 9-1. Following this, I present a discussion of the integration of findings across all elements of the study including the literature review, policy review and the two phases of the study.

Figure 9- 1 Integration of findings



9.2 Experiences of hospital admissions.

This study has focused on patient experiences of hospitalisation in palliative care. In doing so I have attempted to more fully illuminate patients' experiences of being in hospital, focusing on, not only the burdensome aspects of care, but also on the benefits of hospitalisation as understood by patients themselves. Foregrounding the patient experience is important because, as the policy review confirmed, there is an increasing focus in many resource rich countries on preventing or avoiding hospitalisation for those with palliative care needs (Gott, Frey, Robinson, Boyd et al., 2013; Robinson, Boyd, O'Callaghan et al., 2014; Wallace et al., 2012). This policy focus is supported by previous research providing evidence of negative patient experience of care in hospital (Pringle et al., 2015; Reyniers et al., 2014). However, my integrative review of the literature identified this is partly because previous research has not attempted to address any benefits of hospital admission (Robinson et al., 2014). The research presented in this thesis addressed this gap in evidence and made contributions to knowledge and understanding in terms of understanding patient views and experience of: 1) the benefits associated with hospitalisation; 2) the burdens associated with hospitalisation; and 3) preferences to return to hospital. Each of these areas is discussed below in relation to relevant literature.

9.2.2 *Benefits associated with hospitalisation.*

My study found that patients experienced a range of benefits being in hospital (see Chapter 8.4). However, some groups experienced more benefit than others. For example, those experiencing higher levels of deprivation experienced significantly more benefit compared to those living in less deprivation (see Chapter 9.5).

The benefits identified by participants in Phase 1 of this study extended beyond the treatment they received for their illness and included such things as feeling/“getting better”, feeling safe, relief for family and getting help to manage at home.

Feeling better/getting better

“Feeling better” and “getting better” were identified by participants as a major benefit of being in hospital in phase 1. Although participants were unable to articulate what exactly contributed to their sense of “feeling better” or “getting better”, particularly in terms of the treatment they received in hospital, they all “felt better” compared to when they had been admitted. At times participants drew upon the body language and cues provided by health

professionals during their admission to know when they were “getting better”. There is a paucity of evidence in the literature about the concept of “getting better” or “feeling better” in the palliative care context.

However, findings from a study by Beaton et al. (2001) found that the underlying meaning of “being better” for those with a musculoskeletal injury reflected more than just a resolution of the underlying disorder. Instead, it encompassed the person’s experience of the illness, their coping styles and the comparators patients used to define health and illness (Beaton et al., 2001). Similarly, whilst most participants in my study were aware of the incurable nature of their underlying illness (see Chapter 9), the concept of “getting better” or “feeling better” could be linked with how they define their health rather than a modification of their disease state.

Health has been defined within the Ottawa Charter (1986) as being more than just the absence of disease, suggesting that achieving health is more than just managing the underlying illness. However, there is little attention paid to the meaning of health for those with palliative care needs in the literature. Comparisons with how other groups define health may provide some guidance for how health may be experienced for those with a life limiting illness. For example, although the frail older person experiences losses associated with declining physical health, their focus on remaining well is associated with maintaining and creating connections with others (Nicholson et al., 2013). In addition, being validated as a person, being involved and being happy and satisfied with existence while accepting that ageing and death are naturally occurring life events, defines health and wellness for this group (Ebrahimi, Wilhelmson, Moore, & Jakobsson, 2012). Furthermore, these experiences were orientated on the present and varied over time depending on the elderly person’s ability to adjust their perceptions of and adjustment to the changes in their physical health (Ebrahimi et al., 2012).

Parallels could be drawn between the palliative care context and that of frailty. In both sets of circumstances, an experience of health and wellness is more than just control of physical symptoms (Nicholson et al., 2013; WHO, 2015). Whilst palliative care has been criticised as being overly focused on the physical domains of diagnosis and treatment of symptoms (Kellehear, 1999), achieving a state of wellness for those with palliative care needs must encompass all domains including emotional, psychosocial and spiritual aspects. Indeed, a

major outcome for palliative care is maximising quality of life which previous research has demonstrated again relates to more than just the control of physical symptoms (Johansson et al., 2006). Similar, to the frail older person, in this study, people with advanced cancer experienced a good quality of life when they were able to do the “normal” things in life. They maintained a positive perspective on life by keeping memories alive, being valued by others, maintaining relationships through meaningful social contact, and managing their life during periods of illness by maintaining control and being reflective (Johansson et al., 2006) . Charmaz (1997) suggests that a person’s perception of being sick, in the context of chronic illness, is often defined by a sudden medical crisis which results in an interruption of the person’s life course. When the crisis subsides, recovery becomes the sequel to illness and the person returns to “living with” the chronic illness (Charmaz, 1997). This concept of crisis and recovery aligns well with what was described as “getting better” or “feeling better” by participants in my study.

In both phases of my study participants identified a concept described as “feeling better” or “getting better” as a benefit of being in hospital that was more than just a resolution of physical symptoms. Therefore, addressing the meaning of well-being for those admitted to hospital with palliative care needs must encompass more than just the physical impact of the illness.

Feeling safe

“Feeling safe” was identified as a major theme for participants in Phase 1 (see Chapter 8) and was therefore considered separately from other benefits of hospitalisation. Feeling safe was associated by Phase 1 participants with factors such as being cared for by doctors and nurses, being monitored and observed, and being able to get help whenever it was needed. In addition, feeling safe was identified as a significant predictor of preferring to return to hospital in Phase 2 (see Chapter 9) and was more likely to be experienced by younger people and those with cancer. The concept of feeling safe during a hospital admission has been described in the literature (Mollon, 2014), however little attention has been paid to the issue of feeling safe in hospital within a palliative care context. Feeling safe has been described as an emotional state which is defined by attributes such as trust, being cared for, presence (of family and/or health professional) and knowledge (Mollon, 2014). Having trust in health professionals relies on an expectation that the health professional has a certain level of knowledge and skill (Mollon, 2014). Similarly, the findings from Phase 1 of my study

revealed that feeling safe in hospital was linked with a perception that hospital staff were the “experts” in the management of the illness.

Findings from my study showed that feeling safe and cared for was enhanced when participants had a positive relationship with hospital staff. For example, being remembered by ward staff from previous admissions and being called by their first name helped one participant feel cared for during a long and difficult admission to hospital (see Chapter 8.3). This has resonance with a study by Collier et al. (2015), who found that the meaning of home for patients nearing the end of life was closely related to a patient’s feeling of safety (Collier et al., 2015a). For some patients “knowing their own home” equated to a sense of security. For others, the technical ability of hospital staff equated with “feeling safe”, particularly when symptoms were problematic and medications were required. In addition, positive relationships with hospital staff made participants “feel at home” which contributed to their sense of security in hospital (Collier et al., 2015a).

Phase 2 findings from my study showed that patients with palliative care needs experiencing a hospitalisation did not see their GP as having a role in preventing the admission by managing the illness at home. Indeed, most participants had not contacted their general practitioner in the week prior to admission, or even on the day of admission. Feeling safe as a result of being cared for by “experts” has implications for how we provide care at home. In most countries, the general practitioner remains the primary health professional in the community for those with palliative care needs (Quill & Abernethy, 2013). Yet studies have shown that patients do not perceive the general practitioner as being the “expert” and that hospital physicians are perceived to be better placed to manage issues related to the life limiting illness (Beernaert et al., 2014). In addition, access to the GP is challenged by lack of weekend and out of hours cover, cost, and limited options for home visits.

Relief for family

Relief for family was another benefit of being in hospital identified in Phase 1 of my study. Relief was associated with family seeing that finally something was being done and the ill person was getting the “treatment” they needed. Evidence has shown caregivers feel a constant need to observe the patient for changes in their condition and this can result in significant caregiver burden (Skilbeck et al., 2005). In addition, when unexpected changes in the patient’s condition occurs, carers rely on services being responsive with immediate access

to help from health professionals (Stajduhar, et al., 2008). Relief for family can also be considered in the context of deprivation.

In Phase 2 it was found that those living in high deprivation areas experienced significantly more benefit being in hospital compared to those living in less deprivation. Deprivation is known to impact on how patients use hospitals in palliative care. While studies have shown that patients receiving specialist palliative care experience fewer hospital admissions, a study by Spilsbury et al. (2017) found that those living in the most disadvantaged areas had a smaller reduction in Emergency Department visits compared to those living in less disadvantaged areas (Spilsbury, et al., 2017). The authors go on to suggest that this may be due to higher rates of health literacy, self-advocacy, and better access to financial resources to support care at home in those living in less deprivation. The implications for those living in high deprivation is concerning, with evidence that they are more likely to die in hospital and less likely to die at home even if they are known to specialist palliative care community-based services (Macfarlane & Carduff, 2016).

However, this may not be a negative outcome for those living in deprivation as care in hospital may be more desirable if the living conditions at home are inadequate. Similarly, recent findings of a UK study have shown that cancer patients from lower socio-economic groups experience a higher number of emergency admissions and a longer length of stay in hospital compared to those from higher socio-economic groups (Walsh & Laudicella, 2017). The authors go on to suggest that this may be explained by failures in community-based services to manage the care of patients living in more deprived areas.

The way in which hospitals are used by those living in high deprivation has been well researched outside the palliative care context, with evidence of higher use of the hospital system and lower use of primary care, which remains relatively consistent throughout their life (Courneane et al., 2015). In addition, studies carried out in countries that have “free for service” healthcare suggest that financial barriers are not the only contributing factor to Emergency Department use (Walsh & Laudicella, 2017). However, with an increasing focus by hospitals to move care closer to home (Ministry of Health, 2014), financial burden of care is increasingly being shifted to family caregivers. Yet, studies have shown that people on lower incomes feel they have insufficient support to care for dying relatives at home (Hulme, Carmichael, & Meads, 2014). My findings indicate that moving care into the community,

which is often dependent on family caregivers, may indeed cause more burden for patients with palliative care needs and their family.

Within the New Zealand context, a study by Gott, Allen, Moeke-Maxwell et al. (2015) showed that costs of caregiving were significant. Direct costs such as those related to transport, food, and medication along with indirect costs such as those related to employment were reported in the study. In addition, meeting the needs of the patients were prioritised, which resulted in debt, and in some instances bankruptcy (Gott, Allen, Moeke-Maxwell et al., 2015). Furthermore, a recent population-based survey of bereaved family in England found that caregivers provided a great deal of time and money to the caregiving role with a median of 69.5 hours per week and GBP375 per week in caregiving related costs (Rowland, Hanratty, Pilling et al., 2017). The financial challenges for those living in high deprivation may therefore result in a home environment that in some instances may not be conducive to providing adequate care.

Relief for family, identified as an important benefit of being in hospital by participants in Phase 1 of my study, may therefore be related to a number of factors including relief from the financial burden of caregiving, relief from an inadequate home environment, and relief from the responsibility of monitoring the patient for unexplained changes in their condition.

9.2.3 Burdens associated with hospitalisation.

Both phases of my study revealed substantial burden for participants as a result of being in hospital. Phase 1 participants described factors related to the physical environment and the cultural milieu of the hospital. Both impacted negatively on their experiences of being in hospital. Furthermore, analysis of data in Phase 2 showed that burden was significantly greater for older people and those with a non-malignant diagnosis compared to younger people and those with cancer. While the physical environment was a challenge for many participants in Phase 1, impacting on relationships with other patients, families and health professionals, some found it conducive to connecting with others. For example, sharing rooms with very sick patients was distressing for some, while others found that being in a multi-bedded room provided opportunities for socialisation. This diversity in experience is interesting given that the need for privacy has been prioritised in palliative care as a way of maintaining patient dignity and providing an environment that is conducive to sensitive communication with patients, families, and health professionals (Slayter, Pienaar, Williams,

Proctor, & Hewitt, 2015). However, my findings indicate that, as people face a phase of their illness that may result in death, their desire for a quiet, private space to spend intimate time with family and friends may provide them with the human “connectedness” they need to feel safe and secure in hospital.

Yet, the physical environment of the hospital can be difficult for many patients regardless of their reasons for being in hospital (Douglas & Douglas, 2003; Shattell, Hogan, & Thomas, 2005). A study by Shattell et al. (2005) found that the balance between privacy and “connection” with others impacted on a patient’s sense of security in hospital. They reported that, while patients appreciated a single room when ambulatory, this was not always the case for those who were immobile and dependent on others for their care. Moreover, being cared for in a single room while being dependent on others was shown to lead to patients feeling a sense of “disconnection” from staff. This disconnection resulted in feelings of insecurity and vulnerability while in hospital (Shattell et al., 2005).

Similarly, a study exploring patient preferences for single or multi-bed rooms in a hospice setting found that some patients preferred a shared room citing the benefits of being in the company of others. In addition, carers valued the social contact and increased presence of staff in shared rooms. However, they also found that room preference depended on how unwell patients were feeling with some patients and families preferring the privacy of a single room, particularly when the patient was nearing the end of their life (Williams & Gardiner, 2015).

Phase 2 of my study demonstrated that older people were more likely than younger people to feel unsafe in hospital. This finding aligns well with what is known about older people’s experiences of care in hospital. For example, a systematic review of the literature found that older people often take for granted the technical aspects of care and that the quality of their experience in hospital is often based on relational aspects of care (Bridges et al., 2010). Similarly, a concept analysis of “feeling safe” in hospital found relational attributes such as trust and feeling cared contributed to a sense of security (Mollon, 2014). Yet, the busyness of a hospital tends to reduce opportunities for human connectedness, which is fundamental to developing relationships with health professionals in order to feel secure and safe in hospital (Chan et al., 2017).

The acute hospital can be a frenetic environment of busyness and noise. Phase 1 findings showed that a patient's ability to create a positive relationship with staff was dependent on how staff reacted to this environment. When staff projected an attitude of busyness and stress related to their workload, participants were left feeling like they were anonymous, invisible, and an inconvenience. This state of freneticism has been described by Chan et al. (2017) who carried out an ethnographic study on an acute medical ward in Canada. They found that a "logic of care" underpinned by discourses of limited resources and an overwhelming workload meant staff were constantly forced to prioritise their work. Nurses adopted a task-oriented approach to care focusing first on those tasks that were considered life prolonging.

Dying patients received less attention as there were often no biomedical tasks to be done for these patients. The increasing busyness seen in acute hospitals is predicted to worsen as staff shortages continue and the demand for hospital-based care increases (Jiang & Pacheco, 2014). The impact on patient care and in particular those who require palliative and end of life care is therefore concerning.

Along with the physical environment, participants from Phase 1 described the burden of being in hospital; this was associated with the cultural milieu of the hospital. Cultural milieu encompasses the shared beliefs, attitudes, values, and norms of staff behaviour that contribute to a certain way of working (Nutley et al., 2000). The impact of staff attitudes and behaviour on patients' experiences of being in hospital was evident in the Phase 1 findings of my study. For example, participants described a lack of freedom as a result of restrictions imposed by hospital staff. This finding is in line with evidence that a patient's emotional comfort in hospital is directly related to their power of control (Williams et al., 2008). For example, a study of hospital inpatients found that when patients are unable to move freely around the hospital or are forced to follow hospital rules, they feel a loss of personal control, which can lead to a sense of not being valued (Williams et al., 2008).

In my study, Phase 2 participants who identified as Chinese or Pacific were more likely to experience burden associated with being in hospital compared to those from Western cultures. The reasons for this are likely to be multifactorial and require more research to be fully understood (see section 9.5). However, individual autonomy is a dominant paradigm that guides the way in which care is provided in Western hospitals (Tsai, 2008). Patient-centred decision making assumes that the patient is willing and able to be an autonomous

decision maker in regards to their health (Elwyn et al., 2012). However, in some cultures (including Chinese and Pacific) delegating decision making to family/community (McLaughlin & Braun, 1998), or in some cases to the health professional (Belanger, Rodriguez, & Groleau, 2011), is a more acceptable way to manage their illness. My findings may reflect this disconnect between the dominant Western paradigm of individual autonomy and choice at end of life (Wilson, et al., 2014).

Another reason for the burden experienced by those from Chinese and Pacific cultures revealed in my study may be related to how the “good death” is perceived in Western models of healthcare. Despite the life prolonging culture of hospitals, the revivalist model of a good death has influenced the way in which dying patients are cared for in hospital and, in particular, promoted the ideal of death free from technology-driven decision making (Campos-Calderon et al., 2016). This typically results in the withdrawing and withholding of treatments in hospital prior to death (Fidelis & Manolo, 2013). However, in some cultures maintaining life prolonging treatments until death is an important part of families showing care, affection, and love for the dying person (Johnstone & Kanitsaki, 2009). Previous research has identified a tension between what is essentially a model of care informed by the Western model of a good death and the end of life imperatives of other cultures (Gott et al., 2008). This tension may contribute to an increased sense of burden of hospitalisation my study identified for patients from non-Western cultures.

Phase 2 findings showed that those with a non-malignant diagnosis were more likely to experience a sense of burden being in hospital. They were also less likely to feel safe in hospital compared to those with cancer. These findings align well with what is already known about patients with a non-malignant illness and their experiences of hospitalisation. For example, patients with COPD, whilst initially satisfied with their immediate emergency care, report poorer quality care once symptoms have stabilised (Bailey, Hewison, Karasouli, Staniszewska, & Munday, 2016). In addition, a study of intensive care clinicians involved in the care of patients with COPD who died in the intensive care setting, identified difficulties in managing symptoms and concerns regarding the appropriateness of continuing life prolonging therapies. Whilst obviously not all patients with COPD die in the intensive care setting, previous research has also reported a lack of attention to the needs of patients with COPD in hospital once immediate need for urgent care is over (Bailey et al., 2016).

Another explanation for the findings (from both study phases) related to those with a non-malignant illness experiencing more burden and feeling unsafe, may be due to the uncertainty of when to initiate a palliative approach for those with a non-malignant illness. The gradual decline in function over many years – along with repeated admissions to hospital where they are brought back from the brink of death – makes it difficult for patients, families, and health professionals to prepare for when death may occur (Pinnock et al., 2011). Evidence has shown that during periods of acute illness, the emphasis tends towards life prolonging treatment with little time spent on discussions regarding prognosis (Boland et al., 2013). This can occur multiple times during the last year of life before death finally occurs. For example, a qualitative study of patients with COPD found that patients had a poor understanding of the progressive nature of the illness, however they expressed fears of suffocation and difficulties breathing yet none had discussed these fears with their health professionals (Gardiner et al., 2009). This knowledge, along with little opportunity to discuss their fears with health professionals, may be a reason for this group feeling unsafe in hospital.

Being in hospital is not reflective of “normal life” and for many people, the interruption to their lives as a result of being in hospital is an inevitable burden. Therefore, attempts to improve the environment for all patients, regardless of the nature of their illness, is a focus for hospitals. For example, the social media campaign “Hello, my name is . . .” has been picked up by the National Health Service in the United Kingdom, in an attempt to highlight the value of health professionals introducing themselves during interactions with patients and thereby improving the patient experience (Grainger, 2015). In the palliative care context, the Irish Hospice Friendly Hospitals program is an example of supporting hospitals to improve the environment for dying patients and their families. Using various strategies, such as modifying the physical environment and using rituals to acknowledge death on the ward, the program aims to improve the quality of palliative care in the hospital setting (Hospice Friendly Hospitals, 2014). Other countries, including New Zealand, could learn from initiatives such as these to address the burdens of hospitalisation for those with palliative care needs, which have been identified in my study.

There is a plethora of evidence about the burdens associated with being in an acute hospital setting for those with palliative care needs (see Chapter 5). It was therefore unsurprising that experiences of burden were described by all participants in both phases of my study (see Chapters 7 and 8). However, what was surprising was that these experiences of burden did

not deter patients from choosing to return to hospital again. Indeed, all but one participant in Phase 1 expressed a preference to come to hospital even if the care they had received in hospital could be provided at home. In Phase 2 most participants (90.5%) expressed a preference to return to hospital should they become unwell again.

9.3 Preferences to return to hospital.

A preference to return to hospital in the event of an acute illness or deterioration was a recurring theme through both phases of my study. Phase 1 findings showed that participants' experiences of burden as a result of being in hospital did not deter them from expressing a preference to return to hospital again. This finding was confirmed and extended in Phase 2 to show that the preference to return to hospital was likely to be based on a need to "feel safe". It could be argued that the reason for this finding could have resulted from participants not being aware of the treatment limitations of their illness. However, over half (62%) were aware that their illness was incurable and in time would get worse. In addition, in 50% of cases it was a health professional who initiated the hospital admission, suggesting that the decision to come to hospital was not related to participants' perceptions of their illness or its treatment limitations. A study by Reyniers et al. (2014) found that family physicians felt an admission was justified if they felt the caring capacity of the home environment was inadequate, or when an acute medical situation occurred such as uncontrolled pain (Reyniers et al., 2014). In my study, the need to come to hospital for those at the end of life was not dependent on the underlying illness being treatable or not. In addition, patients justified the need to come to hospital based on occurrence of unexplained symptoms. For example, in Phase 1 patients reported the reasons for hospitalisation as being directly related to unexplained symptoms, rather than their family not being able to cope with their needs (see Chapter 9.5). People will never be more seriously ill than they are as they approach the end of their life, therefore going to hospital appears logical for many.

Priorities for those living with a life limiting illness may influence their preferences for place of care. In Phase 2 of my study, when asked about their priorities on the day of admission to hospital, remaining at home and being with family and friends rated lower than getting help from health professionals, having tests and investigations, and receiving information about their illness. Those with cancer placed a higher priority on receiving tests and investigations in hospital than those with a non-malignant illness (see Chapter 8.4.6). This may be related to the increasing treatments available for those with advanced cancer. For example, those with

cancer are increasingly receiving disease modifying treatment, such as chemotherapy and radiotherapy, right up until the last months or even weeks of their life (Patel, Dunmore-Griffith, Lutz, & Johnston, 2014). Many of these treatments require hospital-based care to support treatment complications.

There is evidence that priorities at the end of life vary over the illness trajectory. A critical review of the literature revealed that people nearing the end of their life prioritise the need to hold on to normality, understand and accept their changing health, to feel supported by family and friends and the need to know they will be cared for after death and to have trusting relationships with health professionals (Black, 2011). Yet it is clear from my study that patient priorities are different when they are becoming unwell with no explanation as to why it is happening because receiving medical attention including tests and investigations became a higher priority than being at home and being with family (see Chapter 8).

Overall, my study showed overwhelmingly that people with palliative care needs have a preference to return to hospital in certain circumstances. In both phases, participants described being unwell with unexplained symptoms prompting the admission to hospital. This aligns well with what is known about the reasons for hospital admissions in palliative care. For example, evidence has shown that hospital admissions in the last three months of life are likely due to respiratory, gastro-intestinal and cardiovascular symptoms (De Korte-Verhoef et al., 2014). However, studies that focus on the symptoms that prompt an admission to hospital in palliative care, fail to consider how these symptoms were subsequently managed in hospital. In addition, an assumption that “common symptoms”, such as pain, breathlessness, and vomiting, can be managed at home with support from community services, without any consideration of the underlying cause of these symptoms, is an overly simplistic approach to identifying reasons for admission. In a recent study, an alternative perspective was adopted that surveyed GPs involved in admitting a patient to hospital where the admission resulted in an expected death. They found that factors such as patients feeling safe in hospital, and families perceiving the hospital as being a place of knowledge and expertise, influenced their decisions to go to hospital (Reyniers et al., 2016) .

This section has discussed the integration of findings across the two phases of the study with reference to the literature and policy review. The following section will provide an overview of the strengths and limitations of the study.

9.4 Strengths and limitations of the study.

Currently palliative care provision and expected death in hospital lies outside the understanding of what constitutes a good death in palliative care (Robinson et al., 2016). This study provides an original piece of work addressing an under-researched topic on the experiences of palliative care in a hospital setting. Its unique focus on experiences of both the benefits and burdens of hospitalisation, and how these experiences influence a preference to return to hospital, contribute to a better understanding of the role of the acute hospital in palliative care. This sets the study apart from previous research that has focused largely on the negative aspects of palliative care in hospitals. The importance of this new knowledge has been demonstrated through the publication of seven articles in international, peer-reviewed journals.

The strengths and limitations of the articles and related data can be found at the end of each publication. In the following section, I will expand on the strengths and limitations of each element of the study, with reference to the wider literature providing details on the strategies used to increase the strengths of the study while reducing the impact of the limitations.

Strengths.

A strength of this study is that it addresses a gap in current knowledge about patient experiences of palliative care in the hospital setting, which was identified by a systematic review of the literature (see Chapter 4). The integrative approach to the literature review allowed me to synthesise evidence, which used qualitative, quantitative, and mixed methods methodologies.

Adopting a mixed methods approach was a real strength of this study, allowing me to broaden the research questions I addressed by looking beyond the experiences of benefit and burden. My study included how these experiences influenced a patient's preference to return to hospital again. This enabled me to expand the inferences I drew from the findings. Using both qualitative and quantitative methodologies meant I was able to use patient experiences of benefit and burden and use this to develop a tool that would measure these experiences. The grounding in critical realism enabled me to use the methods required to most appropriately answer the questions I needed to address integrating both the meaning of the experience (in Phase 1) with the reality of the experience (in Phase 2). This was important in

order to develop a comprehensive understanding of the benefits and burdens of hospital admissions in palliative care and relate this to a patient's preferences to return to hospital.

Although methods of data collection differed in each phase of the study, there were a range of strengths associated with the way in which data was collected. Firstly, I carried out all interviews in Phase 1 and delivered all questionnaires face-to-face with participants in Phase 2. This provided me with an opportunity to develop a relationship with participants, which enhanced the quality of the data collected. Furthermore, given my familiarity with the aims and objectives of the study, I was able to confidently clarify exactly what was being asked of each question. This contributed to consistency and quality of the data collected. This was pertinent for both the qualitative interviewing and delivery of the questionnaire survey in Phase 2.

Interviewing at two time points in Phase 1 captured greater breadth and depth of experience and built the relationship between myself and the participant (see Chapter 4) (Calman, Brunton, & Mollassiotis, 2013). In turn, this data provided a perspective of the issues relevant to their experiences of benefit and burden, ensuring content validity of the questionnaire used in Phase 2 (see Chapter 8). Indeed, as a critical realist my view about the nature of truth is supported by the combination of understanding the experience as constructed by the participant with the realities of a world, which exists independently of that perception. This is one that, as a health professional, I have some insight into.

Secondly, I completed the transcription of all interviews during Phase 1. This provided me with an opportunity to completely immerse myself in the data enabling me to really hear what the participants were saying. I was so familiar with the interview data that when I began to code excerpts I instantly knew which participant I was coding without having to refer to the participant details. As I transcribed and read through each transcript, I could easily imagine myself back in the interview listening to their story of being in hospital. I could remember their gestures and the nuances they placed throughout the interview process. This familiarity with the data helped me to promote data rigor.

Thirdly, when analysing the qualitative data emerging themes were discussed with my supervisors. Indeed, involving three supervisors at varying stages of the research process contributed to the credibility and trustworthiness of the data analysis and interpretation

(Braun & Clarke, 2006). Transcripts were cross-coded by one of the supervisors for similarities and differences in emerging themes (see Chapter 7.5.2). Furthermore, consultation with a statistician and a researcher skilled in questionnaire design and analysis occurred throughout the design, collection, and analysis of Phase 2 data.

Limitations.

Bringing extensive knowledge in palliative care – particularly in the acute hospital setting – could be viewed as both a strength and a limitation to the study. I had been working in hospital palliative care as a Nurse Practitioner for many years. This meant that I came to the study with assumptions about how patients experience palliative care in the hospital context including the way in which they might experience benefits and burdens. However, the reflexive stance I adopted throughout the research process helped to maximise methodological rigor (see Chapter 4).

Further challenges to the study are related to my employment in the hospital where the study took place. Firstly, I could be viewed as having a vested interest in revealing only those experiences that are based on the positive aspects of care. However, regular meetings with my supervisors provided me with periods of reflection and discussion challenging my assumptions and the interpretations I was making of the data.

There were some limitations in relation to generalisability due to the study sample I was able to recruit for both phases. In particular, I was unable to include those who did not speak English (as I had no resource to support the involvement of translators) or those who were cognitively impaired. Although my intention in Phase 1 was to include those with dementia by inviting family carers to participate, recruitment proved difficult. This meant that the sample did not include the perspective of anyone with dementia, despite this being an increasingly important group in need of palliative care. This limits the generalisability of the findings across cultural and diagnostic groups. In relation to the quantitative phase, as described in Chapter 8, the sample size in certain groups meant there was not sufficient power to carry out some statistical tests.

9.5 Recommendations for Research, Policy and Practice.

My study explored both the benefits and burdens of hospital admissions in palliative care from the perspectives of patients with palliative care needs and examined how these

experiences influence preferences to return to hospital. The findings reveal important information and considerations for research, policy and practice.

Research.

Patient experiences of care is an essential element of identifying the ways in which we can improve service provision. With a significant increase in palliative care need forecast (McLeod, 2016b), and the increasing focus on the way in which patients with palliative care needs use the hospital setting (Mercadante, Masedu, Marco, Mercadente, & Aielli, 2016; Pivodic et al., 2015; Reyniers et al., 2016), my study confirms the need for research that contributes to a more comprehensive understanding of patient experiences of care in hospital and how this influences their use of the acute hospital.

Other areas requiring further research include an exploration of the concept of “feeling safe” for those with palliative care needs who are experiencing unexplained symptoms or deterioration, and how this can be replicated in other settings. In addition, theoretical work may also help to elucidate a more nuanced understanding of concepts such as “feeling safe” and “getting better”. My findings indicate that if patients feel safe at home during a period of acute illness or deterioration they may be less likely to present to hospital; however, I only included participants who had made the decision to come to hospital. Future research focusing on the issue of “feeling safe” at home should include participants who experience an acute illness or deterioration at home, but where a hospital admission does not occur. More research is required on the impact of deprivation and the use of the hospital in palliative care. In line with Macfarlane and Carduff (2016), my study supports the need to understand how deprivation influences hospital use in palliative care (Macfarlane & Carduff, 2016) and draws specific attention to the notion that care, and potentially death, at home may not be preferred by those living in high deprivation (Gott et al., 2004). Overall, the impact of deprivation on how palliative care is provided at home from the perspectives of patients and families is poorly understood and deserves further attention. In addition, there are implications for equity of access to palliative care, ensuring that those who are most in need of care receive it in an appropriate and timely manner regardless of their level of deprivation or setting of care (Dixon, King, Matosevic, Clark, Knapp, 2015).

My findings also indicate the need to explore more widely societal attitudes and beliefs about the role of the hospital during periods of serious illness. Research to date has focused

predominantly upon setting of care in relation to place of death. Future work could usefully contribute to a better understanding of how decisions regarding place of care and place of death are shaped by our beliefs about the role of the acute hospital in the care of those with an incurable, life limiting illness. In addition, understanding how these values and beliefs align with those of the health professional (who is often the facilitator of hospital-based care), would begin to reveal the complexities surrounding the decision to be admitted to hospital in palliative and end of life care.

This study was limited to patients' perspectives. A future study could gather multiple perspectives from all those involved in the decision to come to hospital: patients, families, and health professionals from community, hospital, and hospice services. Information of this type could further help explore the multiple factors relating to admission, particularly given that current efforts focus on to the provision of community-based services in the hope that this will change how hospitals are used in palliative care (Morris, Fyfe, Momen, Hoare, & Barclay, 2014).

The findings from this study showed how the hospital environment impacts negatively on experiences of hospital admissions for patients with palliative care needs. Although the limitations of the hospital environment are well documented in the literature, little research has been done to date on identifying ways in which the hospital environment could be improved. Whilst the physical environment of the hospital is relatively fixed, future research could explore the way in which the cultural milieu (staff values, attitudes, and behaviours) could be modified and thus reveal the resultant impact on patient experience.

Finally, a key finding in my study was the impact of ethnicity on experiences of care in hospital, with those from non-Western cultures experiencing more burden. Future research needs to explore the impact of hospitalisation for people with palliative care needs whose valued and beliefs regarding death and dying may contradict or diverge from dominant Western understandings.

In summary recommendations for research are:

- Identify aspects of the hospital environment (including the cultural milieu) that would influence and improve patient and family experiences.

- Explore the impact of the Western model of hospital care and palliative care provided in this setting on the experiences of people from Asian and Pacific backgrounds.
- Explore the concept of “feeling safe” during periods of acute illness to identify ways in which “feeling safe” can be replicated across all care settings.
- Identify the specific aspects of patient management, during different points in the illness trajectory, that can only be provided in the hospital setting.
- Explore the differences, and differences in outcome, between people with palliative care needs who come to hospital during a period of acute illness or deterioration with those who do not in terms of benefit, burden and feeling safe.
- Explore societal perceptions of the role of the acute hospital in the management of life limiting illnesses.
- Understand the impact of deprivation on preferences for place of care and place of death.

Policy.

Health strategy is increasingly focused on developing policy that remodels the way in which hospitals are being used because of widespread views internationally that the current model of hospital care is unsustainable (Ministry of Health, 2016). In New Zealand’s National Health Strategy (2016), the future health care system is being described as one that “. . . provides services closer to home, is designed for value and high performance and works as one team in a smart system” (p. 13). The findings from this study provide important context to these recommendations, which needs to be considered when guiding health services on service configurations aimed at providing care closer to home.

Similar to other high income countries, palliative care policy in New Zealand is formulated in response to the good death model and evidence that suggests the majority of people prefer to be cared for and die at home (Ministry of Health (2012). However, findings from this research indicate an urgent need for a more balanced model of care whereby equal value is placed on all care settings including hospice, residential care facilities, home and, crucially, the acute hospital. In addition, a major focus of palliative care policy should be to highlight how all care settings can work together to provide a coordinated approach to inpatient care, ensuring that all patients with a life limiting illness receive the appropriate level of care at the right time according to their preference at the time. Without this approach, the acute hospital

will always remain the default provider of inpatient palliative care when care in the community fails. Rather, hospitals should be viewed as a provider of particular aspects of palliative care that can only be provided in the hospital setting. My specific recommendations for New Zealand policy are:

- Develop an integrated model of palliative care that places equal value on all care settings including residential care, hospital, home, and hospice.
- Improve the integration of specialist hospital services and community services to ensure that decisions regarding hospitalisation are made in a timely and appropriate manner (not by default).
- Address issues of deprivation and their impact on how palliative care is provided in the home setting.
- Attend to diversity of the patient population, particularly cultural diversity and the different needs of people with conditions other than cancer.
- Clarify the specific aspects of patient management that are best provided in the hospital environment and develop service innovations that use these services appropriately.
- Focus on identifying ways to reduce patient burden with a particular focus on:
 - Improving the physical environment.
 - Supporting staff behaviours that promote compassion and caring.
 - Promoting feelings of safety, particularly for those with a non-malignant illness.

However, while policy may guide service development, it does not change individual health behaviours or societal attitudes about how healthcare services should be used at the end of life. Therefore, there is an urgent need to explore societal attitudes and beliefs regarding the role of the acute hospital in the care and management of those with palliative care needs.

Practice.

In relation to practice, there are a number of findings from this study that can help to influence the ways in which we provide palliative care in the acute hospital setting. Firstly, findings related to the benefits of being in hospital will inform clinicians' practice by highlighting those aspects of care that increases the likelihood of patients having a positive

experience. In addition, the factors that contribute to a sense of burden for patients will assist clinicians to identify opportunities to reduce or minimise those aspects of care that cause difficulties for those in hospital with palliative care needs.

Specific recommendations related to practice are to:

- Educate and inform hospital clinicians on the factors that contribute to patients' experiences of benefit, burden, and feeling safe in hospital.
- Focus on opportunities for organisational change such as flexible visiting hours, changes in ward configuration to promote quiet spaces and privacy when it is needed, and systematically integrating strategies into practice that will ensure patients are informed of changes in care as they occur.
- Involve the multi disciplinary team in preparing the patient for discharge ensuring that their care needs at home are assessed and they receive the support they need to manage at home.
- Increase emphasis from allied health staff to prepare patients for discharge with a particular focus on the resources required to self-manage care needs at home.
- Develop targeted and resourced support to assess and improve the home care setting particularly in areas of greater deprivation and when home is chosen as the preferred place of care and place of death.
- Integrate cultural support workers to work alongside those whose beliefs and values may not align with the Western model of death and dying, advocating and negotiating an approach to care that better meets the needs of those from non-Western cultures.
- Emphasise the use of strategies to promote communication and connection with patients and families such as introducing yourself by name, sitting when consulting with patients, and regularly checking in, particularly with patients in single rooms.
- Prompt staff to find out who the person is; do they want to socialise or do they prefer to be on their own? Recognise this may change over the admission period depending on how they feel.

9.6 Summary.

In this thesis, I have outlined research that has generated important new evidence related to the experiences of people with palliative care needs in the hospital setting. A review of

literature and policy provided a foundation on which the research developed, informing the research question and guiding the research process.

During the process of conducting this research, I developed an understanding of different methodological approaches, finally settling on a mixed methods approach underpinned by a critical realist framework, which resonated with my philosophical outlook and aligned well with my chosen research question.

My intention throughout has been to emphasise the importance of understanding the experience of people with palliative care needs in hospital. Furthermore, I have demonstrated how, without this knowledge, there is a danger of contributing to an inequitable system of care that excludes those with an incurable life limiting illness appropriately accessing the acute hospital system. This is evident in the increasing attention being paid in many countries to identifying ways to reduce hospital-based care, with little or no attention being paid to the benefits that patients with palliative care needs experience being in hospital. I hope that through this research I have contributed to a more balanced understanding of the potential role for hospitals in the provision of palliative and end of life care in the future.

Appendices

Appendix 1: Appendices from Publications

Appendix 1.1 Summary of Key Findings from National Policy Review (Robinson et al., 2016)

Country	Year	Authors	Summary of key points relating to hospital palliative care
Australia	2010	Policy makers	<ul style="list-style-type: none"> • People prefer to be cared for and to die at home yet most die in hospital. • Potential for cost savings by avoiding inappropriate hospital admissions. • Burden of hospitalisation on the health care system and poor quality of death in hospital.
England	2008	Advisory board supported by six key working groups	<ul style="list-style-type: none"> • People prefer to be cared for and to die at home yet most die in hospital. • Key strategy aims to reduce number of hospital deaths. • Lack of community responsiveness results in admissions and prolonged hospital stay. • Improved community provision reduces admissions enabling people to die in place of choice. • Poor quality of care in hospitals. • Care for dying people is a core role of the hospital in the “foreseeable future”.
Ireland	2001	National advisory committee of clinicians, leaders, and policy makers	<ul style="list-style-type: none"> • People prefer to be cared for and to die at home yet most die in hospital. • Unresponsive community services result in emergency hospital admissions. • More investment in community services would reduce unnecessary hospital admissions. • Poor quality of care in hospitals.

Singapore	2011	Working group comprised of health professionals	<ul style="list-style-type: none"> • More understanding needed regarding people's preferences at the end of life including preferences for place of care in Singapore. • A majority of patients are admitted to hospital for symptom control and more patients are cared for in hospital than is necessary. • Home care teams need to be able to provide treatment at home to reduce the need for hospital admissions. • Patients identified late have poorer outcomes of care and unnecessary hospital admissions.
Switzerland	2009	Government based steering committee and expert working groups comprised of experts in palliative care	<ul style="list-style-type: none"> • Most people die in nursing homes yet the majority prefer to die at home. • Adequate community-based services enable people to stay at place of choice and avoid unnecessary hospital admissions. • The patient should be supported to choose where they would like to spend their last phase of life.

Appendix 1.2 Publications included in systematic review (Robinson et al. 2014)

Authors	Aims and objectives	Diagnosis	Participants	Data collection	Findings
Addington-Hall and O'Callaghan (2009) UK	To compare hospice in-patient care and hospital care for cancer patients in the UK from the perspective of bereaved relatives	Cancer	40 bereaved family members	Postal survey	Bereaved relatives rated hospice care more highly than care in hospital. Variables explored included communication, involvement in decision making, symptom control and personal cares.
Baker, Wu et al (2000) USA	To examine factors associated with family satisfaction with end of life care in the study to understand prognoses and preferences for outcomes and risks of treatment	Multiple	767 bereaved family members	Telephone administered survey	84% reported satisfaction with all aspects of patient care. 69.5% were satisfied with all aspects of communication and decision making. Satisfaction was greater if: <ul style="list-style-type: none"> - patient was perceived to have less pain - when patient preferences were followed - when death occurred during the index admission - when financial impact was less
Billings and Kolton (1999) USA	To assess family satisfaction with end of life care in the hospital and to gauge the extent of bereavement follow up	Multiple	153 bereaved family members	Telephone administered survey	57% were most satisfied with the overall care and communication. Comments expressed concerns regarding: <ul style="list-style-type: none"> - lack of privacy, dignity and comfort for patients and families - communication issues - emergency room problems - lack of follow up

Borum, Lynn and Zhong (2000) USA	To review the effects of patient race on intervention and end of life decisions in seriously ill patients	Multiple	9105 seriously ill hospitalized patients	Patient interviews	Race was not associated with level of pain or control of pain. Differences in care based on patient race were either small or were shown not to affect outcome adversely
Cantor, Blustein, Carlson and Gould (2003) USA	To explore whether perceiving that a physician was clearly in charge is associated with reports by surviving next of kin about the responsiveness of physicians to symptoms in hospitalised patients	Multiple	1271 bereaved family members	Telephone administered questionnaire survey	More than 80% reported that the patient experienced serious pain, dyspnoea or affective distress often during their final hospital admission. Ratings of the adequacy of physicians to respond to distressing symptoms were not consistently positive. More than half had not expected that the patient would die during the hospital admission until near death
Claessens, Lynn, Zhong, Desbiens, Phillips et al (2000) USA	To compare the course of illness and patterns of care for patients with non small cell lung cancer and severe COPD	Lung cancer and COPD	939 hospitalized patients with lung cancer AND 1008 hospitalized patients with COPD	Telephone administered survey	Patients and families reported pain and dyspnoea being problematic for both groups. Patients with lung cancer more frequently had severe pain and patients with COPD more frequently had severe dyspnoea. Overall patients reported low levels of anxiety and depressive affects.
Connor, Allport, Dixon and Somerville (2008)	To explore the views of patients referred to specialist palliative care teams about the health care services, including but not confined to	Not stated	10 patients who had experienced a hospital admission	Unstructured face to face interviews	Participants reported difficulties in communicating with health professionals including information regarding diagnosis and prognosis. Hospital environment left people feeling like they were not valued.

UK	palliative care				Specialist skills and knowledge was valued by participants
Desbiens, Mueller-Rizner, Connors, Wenger, Lynn (1999) USA	To identify the symptom combinations and factors associated with symptom burden in seriously ill hospitalised patients	Multiple	1582 hospitalized patients	Face to face interviews	Pain, dyspnoea, anxiety and depression caused the greatest symptom burden and accounted for 67.3% of all symptoms that were at least moderately severe at least half of the time.
Dunne and Sullivan (2000) UK	To gain understanding and insights into the lived experience of families who journeyed with their loved one through the palliative phase of illness as inpatients in the acute hospital setting	Not stated	8 bereaved family members	Unstructured, in-depth interviews	The hospital was felt to be an inappropriate place to die because of a lack of privacy and the busy environment. Hospitalization prior to death was filled with helplessness, loss of control and frustration with an inability to perform their usual role as carer. All participants focused on pain as the symptom that caused most distress to them and to the patient. Some found communication with health professionals unsatisfactory while others had a positive experience
Dzul-Church, Cimino, Adler, Wong and Anderson (2010) USA	To describe experiences of serious illness including concerns, preferences, and perspectives on improving end of life care in underserved inpatients	Multiple	20 hospitalised patients	Semi structured face to face interviews	Relationships with health professionals were often difficult with some participants feeling that they were not treated with respect or dignity and not valued as human beings

Field and McGaughey (1998) Northern Ireland	To measure, through the perceptions of relatives/main carers, the quality and nature of care provided to people dying of cancer in the two main places of death: the domestic home and hospitals.	Cancer	55 bereaved lay carers	Semi structured interviews	18 participants stated good care and 4 excellent care; 5 unsatisfactory. 23 made positive comments about care which focused on: <ul style="list-style-type: none"> - good explanations - staff being available or spending time with the patient or carer - staff providing care to the best of their ability 28 made negative comments related to: <ul style="list-style-type: none"> - understaffing - lack of service provision - poor communication - decisions made by doctors - nursing care
Formiga, Olmedo, Lopez-Soto et al (2007) Spain	To evaluate the circumstances related to death in end stage non cancer patients dying in two acute care hospitals and their caregivers opinions about death	End stage dementia and congestive heart failure	102 bereaved family members	Telephone administered questionnaire survey	67.6% were satisfied with information provided by medical teams. Aspects of care that needed improving: <ul style="list-style-type: none"> - more information from doctors - a single room - better treatment from nurses - better communication between medical teams - better control of symptoms - better access to doctors
Herd (1990)	To describe terminal care in one health authority district comparing the findings	Cancer	93 bereaved family members	Semi structured interviews	41% did not know the patient was dying. High degree of satisfaction with care provided by hospital nurses and doctors. Wards were criticised and

UK	in a rural area with those in urban areas				being busy and noisy
Heyland, Groll, Rocker et al (2005) Canada	To enhance our understanding of what high quality end of life care means from the perspectives of Canadian hospitalized patients who have end stage medical disease and their family members	Multiple	440 hospitalised patients and 160 family care givers	Face to face administered questionnaire	Elements rated as “extremely important” AND not “completely satisfied” by patients and FCG’s: <ul style="list-style-type: none"> - To have an adequate plan of care and health services available upon hospital discharge - To have relief of symptoms - To receive adequate information
Jacobs, Bonuck, Burton and Mulvihill (2002) USA	To characterise and identify factors influencing the quality of care provided to dying hospitalized patients and to find opportunities for improvement	Multiple	31 bereaved family members	Telephone administered structured interview	53% of participant’s were much more satisfied with the physical aspects of patient care compared to emotional care. 60% felt involved in patient care decisions. Over ½ did not expect death until the final week. Frequent reports of inadequate communication with physicians with limited information given and explanations insufficient
Koffman and Higginson (2001) UK	To compare the final year of life of first generation black Caribbean’s and white patient with advanced disease focussing on their satisfaction with service provision in both primary care and acute	Multiple	100 bereaved family members	Face to face administered questionnaire survey	Participants ratings of care for Caribbean patients were inferior across all care settings. Less Caribbean patients reported they were given a choice about their treatment in hospital compared to white patients. Doctors faced criticism for lack of cultural sensitivity to black Caribbean families. Nurses were criticized for their lack of

	settings				empathy with dying patients, their reluctance to devote adequate time to patients and their carers, and their insensitivity to family who wanted to stay with the dying patient
Payne, Burton, Addington-Hall and Jones (2010) UK	To identify patients and family members experiences of acute stroke and their preferences for end of life care	Stroke	29 hospitalised patients and 25 of their family members	Semi structured interviews	Difficulties related to communication and information giving was highlighted by patients and families. Whilst participants expressed a desire to be involved in medical decision making they found this difficult when they were asked to make choices about interventions that they perceived as being life or death choices. Uncertainty regarding potential for recovery or likely death was confusing for families.
Rocker, Dodek and Heyland (2008) Canada	To describe ratings of importance and satisfaction with elements of end of life care, information needs, decision making preferences, obstacles to preferred location of death, clinical outcomes and health care use before and during hospital admissions for patients with COPD	COPD	118 hospitalized patients with advanced COPD AND 166 patients with cancer	Face to face administered questionnaire survey	Important elements of care: <ul style="list-style-type: none"> - Not to be kept alive on life support when there is little hope of meaningful recovery - To have relief of symptoms - To have adequate plan of care and health services available to be cared for at home Most satisfaction with elements: <ul style="list-style-type: none"> - To receive adequate information about disease and treatment options - To have trust and confidence in doctors - To know which doctor is in charge

Rogers, Karlsen and Addington-Hall (2000) UK	To investigate the sources of dissatisfaction with hospital care in the last year of life and to assess the potential of the palliative care approach to improve patient satisfaction	Cancer	138 bereaved family members	Postal survey	31% made only positive comments 59% made at least one negative comment. Dissatisfaction with: <ul style="list-style-type: none"> - Communication with health professionals - Getting information - Communication between hospital and community services - Personal care - Bureaucracy - Late or prolonged diagnosis - Medical interventions - Hospital environment
Russ and Kaufman (2005) USA	A descriptive account of families assessments of communication at life's end in the hospital focusing in particular on their understanding of conversations about prognosis and its implications	Not stated	26 bereaved family members	Semi structured interviews	Variation about how much family wanted to know and how much they wanted the patient to know which went unnoticed by doctors. Families felt let down by doctors who would not clearly address prognosis and make recommendations for palliative care. Conversations about prognosis were vague and often tempered with information about more treatment left families confused. Family were unprepared for discussions about withdrawal of treatment and felt they had to choose life or death for their family
Seale and Kelly (1997)	To compare the quality of inpatient care for dying people in hospice	Cancer	66 bereaved spouses	Structured interviews	Hospital staff more likely to be seen as busy, atmosphere large and noisy and less 'like a family'. Patients less likely

UK	and hospital and make comparisons with findings from earlier studies.				to know they were dying. Symptom control good in both groups
Spichiger (2008) Switzerland	To explore terminally ill patients and their families experiences of hospital end of life care	Cancer	10 hospitalised patients	Participant observations, informal conversations and open interviews	Experiences of being in hospital were on a continuum of feeling like being in a prison to it being a relief from suffering with uncontrolled symptoms. Health professionals friendly behaviour were valued but had to be rooted in empathy, consideration and respect to be valued. Experience with care interventions generally very positive.
Spichiger (2009) Switzerland	To explore the experiences of family members of terminally ill patients with hospital end of life care	Cancer	10 family members	Open interviews with integration of observation data from larger study	Witnessing suffering and experiencing negative reactions from patients were difficult for families. Integration occurred if families were made to feel welcome, were well informed and had access to the patient at all times. Family place needs of patients ahead of their own but were limited by their living situations. Patient and illness the focus of their thoughts with no space for anything else such as friends, social activities.
Spichiger (2009)	To elicit patients' experiences of hospital life and the meanings they assigned to the hospital as their	Cancer	10 hospitalised patients and 10 family members	Participant observation, patient conversations and semi	The patient describes existence in the hospital on a continuum from "prison" to "heaven" and could be described as "guests of necessity". Patient's experience of hospital was not constant

Switzerland	temporary residence			structured and interviews with family members	and changed over the time of a hospital stay and some experiences faded away.
Sykes, Pearson and Chell (1992) UK	To evaluate the satisfaction with palliative care services among a balanced population drawn from one health district	Cancer	106 bereaved family carers	Semi structured interviews	All preferred care in a smaller hospital. Only 40% of those who died in hospital had a family member present.
Tanaka, Iwamoto, Kaneyasu and Petrini (1999) Japan	To clarify how terminally ill patients think and feel while hospitalised	Cancer	8 hospitalised patients	Semi structured interviews	Participants reported feeling safe in hospital when pain was controlled. Feelings of anxiety about impact of long hospital stay on families was expressed by participants.
Teno, Clarridge, Casey, Welch et al (2004) USA	To evaluate the US dying experience at home and in institutional settings	Multiple	1578 bereaved family members	Telephone administered questionnaire survey	Overall those dying in institutions have unmet needs for symptom management, physician communication, emotional support and being treated with respect compared to those dying at home.

Young, Rogers, Dent and Addington-Hall (2009) UK	To explore the determinants of satisfaction with health and social care services in the last 3 months and 3 days of life as reported by bereaved relatives of those who died from a stroke in an institutional setting	Stroke	165 bereaved family	Postal survey	More likely to rate care as excellent if they: - felt actively involved in discussions with doctors and nurses about patients condition - were able to discuss their worries and fears - perceived that doctors and nurses know enough about their condition - received enough help available to help with personal care needs
Costello (2001) UK	To explore the experiences of dying patients and nurses working in three elderly care wards focusing on the management of care for dying patients	Not stated	74 hospitalised patients	Participant observation, informal conversations and semi structured interviews	Relatives were not informed by the doctor that the patient was dying and when they were told they felt unprepared for it.
Lynn, Teno, Phillips, Wu, Desbiens et al (1997) USA	To characterise the experience of dying from the perspective of surrogate decision makers, usually close family	Multiple	3357 bereaved family members	Semi structured interviews	Almost 40% patients were said to have had a symptom that at least half of the time was moderate or extreme in severity in the last three days of life. 73% of participants said that patients found it difficult to tolerate these physical symptoms
SUPPORT Principal Investigators (1995)	To improve end of life decision making and reduce the frequency of a mechanically support,	Multiple	9106 patients	Face to face semi structured interviews	22% of patients reported moderate to severe pain at least half the time. 50% of family members felt the patient experienced moderate to severe pain at

USA	painful and prolonged process of dying				least half the time during the last 3 days of life.
Desbiens, Norman, Wu, Broste, Wenger, Connors et al (1996)	To evaluate the pain experience of seriously ill hospitalized patients and their satisfaction with control of pain during hospitalization.	Multiple	5176 patients	Face to face interviews	Nearly 50% of participants reported pain; 14.9% reported extremely severe pain of any frequency or moderately severe pain occurring at least half of the time. 14.9% were dissatisfied with pain control. Higher reports of pain were associated with:
USA	To understand the relationship of level of pain and dissatisfaction with pain control to demographic, psychological and illness related variables				<ul style="list-style-type: none"> - older age - high dependence in ADL's - more co-morbid conditions - increased anxiety and depression - poor quality of life
	SUPPORT				

Appendix 1.3 European Association of Palliative Care Blog (Robinson, 2015)

Are there any benefits to hospital admissions for people with palliative care needs?

For many working in palliative care, enabling death at home is the ultimate achievement in supporting a patient at the end of their life. However, for most of my nursing career I have practiced palliative care within a hospital setting. I have met many patients who have preferred to be in hospital during periods of acute illness; for some, their preference has been to remain in hospital until death. I believe that many patients have been supported to die well in this setting. Therefore, the seemingly prevailing view within palliative care policy, practice and research that hospitals have little meaningful role to play in end of life care has been a concern for me.

My PhD research began with an integrative review relating to patient experience of palliative care in a hospital setting. Findings from the review were unsurprising, with patients describing poor symptom management, poor communication with health care professionals and an inadequate environment (Robinson, Gott, et al., 2014). However, what was surprising was that most of the studies did not ask patients directly about their experience, nor provide any opportunity for them to identify any benefits of hospitalisation.

Phase 1 of my PhD addressed the gap identified in my literature review by exploring the benefits and burdens of hospital admission for people with palliative care needs. What was striking was that participants indicated a preference to be in hospital, even if the care they received in hospital could be provided at home. Furthermore, they reported benefits of hospitalisation beyond the treatment they received, including feeling “safe” and “cared for”, relief for family, receiving help to manage at home and a sense of feeling and/or getting better. (Robinson, Gott, Gardiner, et al., 2015) The findings suggest that during periods of rapidly changing care needs, the hospital may be perceived as a safe space with easy access to help when needed.

However, it is also important to note that participants described a range of factors associated with the hospital environment which impacted negatively on their experience including problems associated with the physical setting and difficulties with social relationships, including relationships with family, other patients and health professionals. (Robinson, Gott, Ingleton, et al., 2015) This indicates that we have much work to do to in optimising

the hospital environment for patients, many of whom we now know welcome a hospital admission.

However, in the context of a global recession with rising hospital related costs and increasing pressure to reduce public health spending, the potential to save money by keeping people with palliative care needs out of hospital is an attractive option. Therefore, understanding the role hospitals play in palliative and end of life care is essential if patients are to receive the best possible palliative care, regardless of where they are cared for or die.

Appendix 2: Phase 1 Study Documentation

Appendix 2.1 Ethics Application and Approval (Phase 1)

University of Auckland Human Ethics Application

GENERAL INFORMATION

***Is this a Research Project or Coursework Application?** **Research**

SECTION A: PERSONNEL

*R	A:1 Principal Investigator	Name:	<input type="text" value="Merryn Gott"/>
		Department:	<input type="text" value="School of Nursing"/>
		E-Mail Address:	<input type="text" value="m.gott@auckland.ac.nz"/>
		I.D. Number:	<input type="text"/>
		Signature:	<input type="text"/>
	A:2 Co-Investigator	Name:	<input type="text"/>
		E-Mail Address:	<input type="text"/>
		I.D. Number:	<input type="text"/>
	A:3 Student	Name:	<input type="text" value="Jackie Robinson"/>
		Degree/Course	<input type="text" value="PhD"/>
		E-Mail Address:	<input type="text" value="j.robinson@auckland.ac.nz"/>
		I.D. Number:	<input type="text"/>
		Signature:	<input type="text"/>
*C	A:1 Course Coordinator	Name:	<input type="text"/>
		Department:	<input type="text"/>
		E-Mail Address:	<input type="text"/>
			<input type="text"/>

I.D. Number:

Signature:

***C** **A:2 Course Administrator** Name:

I.D. Number:

A:4 Ethics Advisor Name:

E-Mail Address:

I.D. Number:

Signature:

A:5 Māori Ethics Advisor Name:

E-Mail Address:

I.D. Number:

Signature:

*** A:6 Head of School / Department**

Name:

E-Mail Address:

I.D. Number:

Signature:

SECTION B: RESEARCH PROCEDURES

***R** **B:1 Project Title**

***C** **B:1 Paper Name & Number**

*** B:2 Aims/Objectives of Project**

The aim of this study is to explore the benefits and burdens of hospital admissions for patients with palliative care needs with a focus on patient experience and expectations

Objectives:

- To describe the precipitating factors that cause patients with palliative care needs to be admitted to hospital
- Explore the anticipated benefits and burdens of a hospital admission for patients with a life limiting illness
- Describe what is achieved during a hospital admission in relation to improved health status for patients with a life limiting illness
- Explore how patients with a life limiting illness perceive the role of the acute hospital
- Identify the factors that influence patients' perceptions of the benefits and burdens of a hospital admission in the context of living with a life limiting illness

Describe in plain language the purpose, hypothesis/research questions and objectives of the research in language that is comprehensible and free from jargon.

NOTE: All acronyms must be written out in full the first time they appear in the application, recruiting materials, Participant Information Sheet (PIS) and Consent Form (CF).

***R**

B:3 Summary of the Project (max 2000 characters)

In most developed countries, acute hospitals play a significant role in palliative care provision. Evidence shows that at any one time 13-36% of hospital inpatients meet the criteria for palliative care need. Hospitals are often the setting where a life limiting diagnosis is made and where patients present when symptoms develop or when they are not well managed. Furthermore for people with illnesses such as chronic obstructive pulmonary disease and congestive cardiac failure, hospitals provide episodic care over many years for illness exacerbations during which death could occur. In most developed countries, hospitals are also the setting in which most people will die.

One factor that is impacting upon the role of the acute hospital in palliative care is the increasing use of technology. Wide-spread use of life supporting technologies that keep people alive who would otherwise die within a foreseeable, but usually uncertain period of time, has radically transformed the life expectancy of some people with a life limiting illness. Like other areas of health care, palliative care has embraced the advancement of health technologies and it is now common place to offer, what some may consider as being invasive, interventions to achieve symptom control and improve quality of life whilst at the same time, in some instances, extending life. Many of these interventions can only be provided in a hospital environment and they have radically impacted on the way in which palliative care is delivered.

As a result of the global economic crisis, governments are searching for ways to make limited public health spending go further. Studies looking at inappropriate or avoidable admissions amongst patients with palliative care needs and economic analyses of hospital use in the last year of life are being carried out to ensure that

health resources are being used wisely. In addition patient and family preferences to be cared for at home or in a hospice rather than in a hospital setting, have been well established in the literature. Furthermore, the hospital environment has been criticised in the literature as an inappropriate environment to provide palliative care. These factors are becoming key drivers at a policy level to reduce the use of acute hospitals by patients with a life limiting illness.

Knowledge of patient and family experiences of palliative care in an acute hospital remains limited to discrete aspects of care. Patient expectations are known to influence individual's experiences of health care. Using patient expectation as a benchmark, the purpose of this study is to explore the experiences of hospital admissions for patients with palliative care needs with a focus on perceived benefits and burdens in order to better understand the role of the acute hospital in palliative care.

If more space is required, please attach a more detailed description of the project and its background which places the project in perspective and allows the Committee to assess its significance.

***R B:4 Project Duration**

Start Date:

July 2013

End Date:

July 2015

*** B:5 Describe the study design**

This is a two phase mixed methods, exploratory sequential study. This ethics application is for the first phase of the study only. Phase 1 involves case note review (for collection of patient information and details regarding the hospital admission) and semi structured interviews with patients admitted to Auckland City Hospital with a life limiting illness. For those patients who are cognitively impaired or are too unwell to be interviewed, families will be invited to participate in the study.

A further application for ethics approval will be made prior to commencing the second phase of the study which will involve the development and delivery of a questionnaire survey to patients with palliative care needs and their families. Development of the second phase will be informed by the results of the first phase.

*** B:6 List all the methods used for obtaining information.**

1. Case note review – to identify eligible participants and to collect data related to the hospital admission and illness. See Clinical Record Data Collection Form.
2. Semi structured interviews – the first interview will occur shortly after admission to hospital and the second more detailed interview will occur one week after being discharged from hospital.

Interviews: Yes

Note: If “yes”, please attach the Interview Schedule (list of interview questions) when submitting your application.

Focus Groups: No

Note: If “yes”, please attach the Focus Group Questions when submitting your application.

Questionnaires: No

Note: If “yes”, please attach the Questionnaire when submitting your application.

Observations: No

Other: Yes

Using the Gold Standards Framework Prognostic Indicator Guide (see C:4) a case note review will be performed to scan for eligibility. During the screening process access to clinical notes will be made by Jackie Robinson. Patient information will not be collected during the screening process.

Data relating to the hospital admission will be collected from participant’s clinical notes after the patient has been discharged from hospital (see Clinical Record Data Collection Form).

As an employee of the Auckland District Health Board, Jackie will be working under the ADHB Confidentiality Agreement as she accesses clinical information.

* **B:7 Does the research involve processes that involve EEG, ECG, MRI, TMS, FMRI, EMG, radiation, invasive or surface recordings? No**

(If “yes”, please explain)

* **B:8 Does the research involve processes that are potentially disadvantageous to a person or group (for example, the collection of information which may expose the person/group to discrimination)? No**

(If “yes”, please explain)

* **B:9 Who will carry out the research procedures?**

Jackie Robinson (JR), Palliative Care Nurse Practitioner with the Auckland District Health Board and PhD candidate

If the research procedures will be carried out by a third party other than the researcher or co-investigators, please attach a copy of the confidentiality agreement when submitting your application.

* **B:10a Where will the research procedures take place?**

Two interviews will take place with each participant:
Interview 1 will take place on a ward at Auckland City Hospital.
Interview 2 will take place at the participant's place of choice likely place of residence (home, hospice or residential aged care facility).
Case note review will be completed using computer based clinical work stations based at ACH.

Please attach the appropriate Request for Site Access and Consent Form when submitting your application, if necessary.

***R** **B:10b Will the research be conducted overseas? No**

(If "yes", please indicate which countries are involved.)

Please provide local contact details as well as those of contacts at the University – all of these should appear in the PIS.

If the study is going to be carried out by using methods such as video conferencing, Skype, Google Talk (in which the participants are overseas), then the study is considered an overseas study.

***R** **B:10c If the study is based overseas, explain what special circumstances arise and how they will be dealt with. Include any special requirements of the country (e.g. research visa) and/or the community with which the research will be carried out.**

(If study is based overseas, please explain.)

Please also provide an undertaking to abide by any local laws relating to research, privacy and data collection.

* **B:11a If a questionnaire is used, is the questionnaire web-based? Yes / No**

Note: If "yes", please indicate this on the PIS

* **B:11b If a questionnaire is used, is it an anonymous questionnaire? Yes / No**

(If "yes", please explain (and indicate on the PIS) how anonymity will be preserved.)

* **B:12 How much time will participants need to give to the research?**

Interview 1 will be carried out within 3 days of admission to hospital and is expected to take approximately 30 minutes.
Interview 2 will be carried out within 1 week of discharge from hospital and is expected to take approximately 1 hour. This will take place at the patients preferred location likely their current place of residence e.g. home, residential care facility or hospice.

Please indicate this on the PIS.

***R** **B:13 Will information on the participants be obtained from third parties?** No

(If “yes”, please explain)

Note: If Yes, please explain (and indicate on the PIS) and attach a copy of the Support Letter where necessary when submitting your application. For example: information is to be obtained from participant's employer, teacher, doctor, etc.

***R** **B:14 Will any identifiable information on the participants be given to third parties?**

No

(If “yes”, please state who and explain)

Normally identifiable information or recorded interviews cannot be shared with third parties. If this is intended it must be clearly documented in the PIS for all concerned.

* **B:15 Does the research involve evaluation of University of Auckland services or organisational practices where information of a personal nature may be collected and where participants may be identified?** No

(If “yes”, please explain and indicate this on the PIS)

* **B:16 Does the research involve a conflict of interest or the appearance of a conflict of interest for the researcher?** Yes

Jackie Robinson is employed by the Auckland District Board and works as a Nurse Practitioner in the Auckland City Hospital Palliative Care Team (HPCT). This is a potential conflict of interest.

It has been estimated that only 10-12% of patients with palliative care needs are referred to the Hospital Palliative Care Team so the chances of patients being referred to the HPCT while at the same time being involved in the study are relatively

small.

The potential conflict of interest will be managed by the following:

4. Patients already referred to the HPCT at the time they are identified as being eligible to participate will be excluded from the study.
5. Where possible, patients referred to the HPCT who have already been recruited to the study, will be seen by other members of the team.
6. In the unlikely event that Jackie (in her role as Nurse Practitioner) needs to become involved in the patients care, the participant will be given the option of withdrawing from the study.

or

***R** B:17 **Does the research involve matters of commercial sensitivity?** No

(If “yes”, please explain and indicate this on the PIS)

***R** B:18 **Has the study design or the use of data been influenced by an organisation outside The University of Auckland?** No

(If “yes”, please explain)

***R** B:19 **Are you intending to conduct the research in The University of Auckland class time?** No

Please attach the approval from the Course Coordinator when submitting your application.

***** B:20 **Does the research involve deception of the participants, including concealment or covert observations?** No

(If “yes”, please justify its use and describe the debriefing procedure on the PIS)

Please attach the debriefing sheet when submitting your application.

***R** B:21 **Is there any koha, compensation or reimbursement of expenses to be made to participants?** No

(If “yes”, please explain the level of payment and indicate in the PIS)

***** B:22a **Is this an intervention study?** No

(If “yes”, please explain and indicate this on the PIS)

* B:22b **Does this research involve potentially hazardous substances?** No

(If “yes”, please explain and indicate this on the PIS)

*C B:23 **Will there be participants from outside this class?** Yes / No

(If “yes”, please explain who they are and how much time will be required)

SECTION C: PARTICIPANTS

* C:1 **Who are the participants in the research?**

- Adults: **Yes**
- Own Colleagues: **No**
- Own Students: **No**
- Persons whose capacity to give informed consent (other than children) is compromised: **Yes**
- Persons who are in a dependent situation, such as people with a disability, residents of a hospital, nursing home or prison, or patients highly dependent on medical care: **Yes**
- Persons aged less than 16 years old where parental consent is being sought: **No**
- Persons aged less than 16 years old where parental consent is NOT being sought: **No**

Note: If you answered “yes” to the question (above) on where parental consent is not sought for persons aged less than 16 years old, please indicate the age range of the persons below and explain in Section D2a & b

Less than 7 years old: **Yes / No**

Greater than 7 and less than 16 years old: **Yes / No**

- Other: **Yes / No**

(If “yes” to Other, please explain)

- * **C:2 How many organisations and departments within the organisations within or outside of the University of Auckland will participate in your project?**

The study will be carried out with patients admitted to Auckland City Hospital. Hospital admission data shows the top four admitting services for patients with a diagnosis listed on the Gold Standards Framework Prognostic Indicator Guide (GSF-PIG) are General Medicine, Medical Oncology, Radiation Oncology, Urology and General Surgery. These services account for 30.8% of admissions for patients with a GSF diagnoses. Participants will be recruited from these four services.

If you have letters of support, please attach these when submitting your application.

- ***R C:3 How many individual participants (research participants) will participate in your project? 20**

- * **C:4 How will you identify potential participants and by which method are participants invited to take part in the research?**

The Gold Standards Framework (GSF) was developed in the United Kingdom as a care programme to support primary health practitioners to identify patients in the last year of life. The GSF Prognostic Indicator Guide (GSF-PIG) is designed to assist clinicians in identifying patients that have palliative care needs. It lists clinical indicators for several life limiting illnesses. Whilst primarily developed for the primary health care setting, the GSF-PIG has been shown to be effective in identifying patients with palliative care needs in a hospital setting. The GSF-PIG will be used in this study to identify eligible participants (see attached).

A list of patients admitted with a diagnosis listed on the GSF-PIG will be sent to JR each 24 hour period by the hospital Decision Support Services. JR will review the notes of patients using the electronic patient record system CONCERTO. As an employee of Auckland District Health Board, JR will be working under the ADHB Employee Confidentiality Agreement as she accesses patient information.

Using the GSF-PIG if the patient meets any of the indicators they will be invited to participate in the study.

Using a direct approach to recruit participants is not recommended. Please see the Applicant’s Manual for further information. Please attach the advertisement, media release, or notice, etc and the letter of permission from the agency supplying them (if applicable) when submitting your application.

- * **C:5 Who will make the initial approach to potential participants?**

The nurse caring for the patient on the ward will be asked by JR to introduce the study to the patient and provide them with a copy of the Patient Information Sheet. If the patient is interested in participating in the study a nurse specialist from the Hospital

Palliative Care Team will meet with the patient to obtain consent. JR will carry out both interviews.

If family are present on the ward and the patient is unable to give consent the nurse caring for the patient will approach family to provide them with a copy of the Family Information Sheet. If family are interested in participating in the study a nurse specialist from the Hospital Palliative Care Team will meet with the family to obtain consent. Jackie Robinson will carry out both interviews.

* **C:6 Will access to participants be gained with consent of any organisation?**

Yes

Approval from the Auckland District Health Board Research Office is pending.

If the research is to be conducted in any organisation, such as a business, non-governmental organisation or school, a separate PIS and CF needs to be provided for the Chief Executive Officer, Principal or the owner of the business (i.e. the effective employer) seeking permission to access the employees as participants. See Applicant's Manual Sections 2c-iv.

* **C:7 Is there any special relationship between participants and researchers? No**

(If "yes", please explain)

It will not be appropriate, usually, for the researcher to recruit members of their own family and friends as participants.

***R C:8 Does the research involve University of Auckland staff or students where information of a personal nature may be collected and where participants may be identified? No**

(If "yes", please explain and indicate this on the PIS)

* **C:9 Does the research involve participants who are being asked to comment on employers? No**

(If "yes", please explain and indicate this on the PIS)

***R C:10 Are there any potential participants who will be excluded? Yes**

Due to the difficulties associated with using interpreters and the associated cost patients who do not speak English will be excluded from the study.

Patients or families of patients who die during the admission will be withdrawn from

the study. The rationale for this exclusion is that collecting data using post bereavement interviews is beyond the scope of this project.

SECTION D: INFORMATION AND CONSENT

* **D:1 By whom and how will information about the research be given to participants?**

Eligible patients will be given a copy of the Patient Information Sheet by the nurse caring for them on the ward. If the patient is interested in participating in the study a nurse specialist from the HPCT will meet with the patient to obtain consent.

Where eligible patients are unable to give informed consent family will be contacted by a nurse specialist from the HPCT by telephone. If the family are present on the ward the nurse caring for the patient will provide them with a copy of the Family Information Sheet. If they express an interest to participate in the study a nurse specialist from the HPCT will meet with them to obtain consent. If initial contact is made by telephone, verbal consent will be sought, followed by written consent at the time of the first interview.

Confirmation of informed consent will be made at the time of the second interview by JR.

For example: A copy of information to be given to prospective participants in the form of a PIS must be attached to this application, whether this is to be given verbally or in writing.

* **D:2a Will the participants have difficulty giving informed consent on their own behalf?**

Yes, patient participants who are seriously ill may have difficulties giving consent.

Consider physical or mental condition, age, language, legal status, or other barriers.

* **D:2b If participants are not competent to give fully informed consent who will consent on their behalf?**

Caregiver: **Yes (family)**

Other: **Yes / No**

Where patients are unable to give consent due to cognitive impairment or if they are too unwell to be interviewed, family members will be invited to participate in the study as a patient proxy.

Patients with a previously documented diagnosis of dementia will not be approached. In these cases family will be invited to participate in the study.

Patients who are seriously ill can experience fluctuating cognitive impairment due to delirium. The nurse caring for the patient on the ward will be asked about the current cognitive state of the patient. If there are any concerns about the patient's mental capacity they will not be approached. If at any time during the consent process the nurse specialist recognises signs of cognitive impairment the discussion will be discontinued. If during the interview process JR identifies concerns about the patient's cognitive state the interview will be discontinued.

Both JR and the Nurse Specialist will use their expert clinical skills and judgement in assessing patients with cognitive impairment to make these decisions. Confirmation of informed consent will be made at the start of each interview to allow for the potential of fluctuating capacity.

In cases where patients are identified as lacking capacity family will be invited to participate in the study as the patient proxy. Family will be asked about their understanding of the patient's expectations and experiences while in hospital. Cognitive impairment, both permanent and temporary, is common in patients with a life limiting illness. As a result there is a paucity of research that incorporates the experiences of patients with palliative care needs who have a cognitive impairment. Using family as patient proxies is one way of ensuring that this group is represented in palliative care research. The Mental Capacity Act UK (2005) will be used as a guiding document to assessing mental capacity.

- * **D:3a If a questionnaire is used, will the participants have difficulty completing the questionnaire on their own behalf? Yes / No**

Note: If yes, please answer the next question. If no, please skip the next question.

Consider physical or mental condition, age, language, legal status, or other barriers.

- * **D:3b If participants are not competent to complete the questionnaire, who will act on their behalf?**

Parent or Guardian/Caregiver: **Yes / No**

Other: **Yes / No**

(If "Other", please specify)

- * **D:4 Does the research involve participants giving oral consent rather than written consent? No**

(If "yes", please explain and justify and indicate this on the PIS)

- * **D:5 Does the research use previously collected information or biological samples for which there was no explicit consent? No**

- ***R** **D:6 Is access to the Consent Forms restricted to the Principal Investigator and/or the researcher? Yes**

(If “no”, please explain and justify and indicate this on the PIS)

In general, the CF can only be accessed by the PI and the researcher.

- * **D:7 Will Consent Forms be stored by the Principal Investigator, in a secure manner?**

Yes

(If “no”, please explain and justify and indicate this on the PIS)

In general, the CF has to be stored in a locked cabinet on University of Auckland premises.

- ***R** **D:8 Are Consent Forms stored separately from data and kept for six years?**

Yes

(If “no”, please explain and justify and indicate this on the PIS)

In general, the CF has to be stored separately from other data for six years.

SECTION E: STORAGE AND USE OF RESULTS

- * **E:1 Will the participants be audio-taped, video-taped, or recorded by any other electronic means such as Digital Voice Recorders? Yes**

Interviews will be digitally recorded and transcribed verbatim by JR.

Note: If “no”, please skip question E2 (a-d).

If recording is essential to the research, it should be indicated as such in all relevant PISs. The CF should state, “I understand that I will be recorded”.

If recording is optional, this should be explained in the PIS. The CF should state “I agree / do not agree to be recorded”. It should also state that, “Even if you agree to being recorded, you may choose to have the recorder turned off at any time”. The PIS to Chief Executive Officers, Principals, and Board of Trustees should state recordings will be made only with the agreement of those recorded.

* **E:2a Will the recordings be transcribed or translated? Yes**

Note: If “yes”, please indicate this on the PIS & CF.

*Where any document is to be distributed to participants, it is to be provided for those participants in the language that will provide the most readily accessible presentation of adequate information. The UAHPEC requires English versions of documents to be submitted with an application. The UAHPEC does not require translations to be submitted with the application, but does expect to receive them after approval of the application and before they are used. For Languages other than English, see **Applicant’s Manual Section 3j**.*

* **E:2b Who will be transcribing the recordings?**

Jackie Robinson (JR)

(If “Researcher” and/or “Other”, please explain in PIS and CF who will do the transcription (if not the researcher) and how confidentiality of information will be preserved. Please attach Confidentiality Agreement when submitting).

* **E:2c If recordings are made, will participants be offered the opportunity to edit the transcripts of the recordings? Yes**

Participants will be offered the opportunity to review their interview transcripts to ensure it reflects what they have said.

Only those who are recorded should be given the opportunity to review tapes or transcripts. Chief Executive Officers, for example, normally should not be given access to recordings made of their employees, nor to transcripts of these. If those who have been recorded are permitted to review tapes or transcripts, a clear description should be provided in the PIS of the procedures for doing this. Where participants are asked to make a choice, this should be explained in the PIS and CF.

* **E:2d Will participants be offered their tapes or digital files of their recording (or a copy thereof)? No**

Participants will not be offered copies of digital recordings. They will be informed that the recordings will be destroyed after transcription and data analysis.

Indicate in the PIS who will own the recorded data and how the data will be disposed of at the completion of the study. Options include, but are not limited to the participants retaining the recording, agreeing that the recording be destroyed, or consenting to its storage in a research archive.

If the data have not been publicly archived, which requires the participant's agreement, storage should be accessible by the researcher and supervisor only. Where participants are asked to make a choice, this should be explained in the PIS and CF.

- * **E:3 For the questionnaire, is any coding scheme used to identify the respondent?**
Yes / No

(If "yes", please explain)

Explain the coding procedure in the PIS. For example: Questionnaires are numbered 1-999 and a list is maintained to link participants with the questionnaire

*E:4a **Explain how and how long the data (including audio-tapes, video-tapes, digital voice recorder, and electronic data) will be stored.**

Digital recordings and electronic copies of transcribed interviews will be stored on a password protected computer. Paper copies of the transcribed interviews will be stored in a secure cabinet at the School of Nursing. Transcriptions and recordings will be held for a period of six years after which time they will be securely destroyed.

*Explain in the PIS and CF in what format data will be stored. The period data is to be kept will be commensurate to the scale of its research. For peer reviewed publication that might be further developed, the University expects six years. See **Applicant's Manual Section 2c-ii and 3n.***

- * **E:4b Explain how data will be used.**

Data from the interviews will be used to write a thesis and be included in reporting and publications. Any reporting and publication of data will be done in a way that does not identify those who took part in the study.

Note: Please indicate this on the PIS.

- ***R** **E:4C Explain how data will be destroyed.**

After six years the digital recordings and transcriptions along with any other records of data will be securely destroyed – paper documents will be shredded and electronic files will be wiped.

Please explain in the PIS and CF how data will be subsequently destroyed.

- * **E:5 Describe any arrangements to make results available to participants.**

A summary of the results will be made available to participants at the completion of the study. The option of having this emailed to them will be made during the consent process. Māori participants will be offered a face to face meeting to share the research findings.

Researchers should be aware that there is an ethical dimension to the formulation and publication of results and loss of copyright. The researcher must remain sensitive to the uses to which the research findings may be put. Wherever possible, the findings should be conveyed in a comprehensible form to those who participated in the research. Explain this in the PIS.

***R E:6a Are you going to identify the research participants in any publication or report about the research? No**

Note: If “yes”, the PIS must inform the participants, and this must be part of the consent obtained in the CF. If “no”, please answer the next question.

***R E:6b Is there any possibility that individuals or groups could be identified in the final publication or report? No**

(If “yes”, please explain here and describe in the PIS)

SECTION F: TREATY OF WAITANGI

*** F:1 Does the proposed research have impact on Māori persons as Māori? Yes**

Note: If “yes”, please answer the remaining questions in this section. If “no”, please go straight to Section G.

*** F:2 Explain how the intended research process is consistent with the provisions of the Treaty of Waitangi.**

Using the guiding Treaty principles of partnership, participation and protection the rights of Māori will be respected throughout the research project by:

Partnership – recognition of Māori as partners in research and respect for their cultural knowledge, values and beliefs. This will be particularly important when interviews are being held in a participant’s home. Involving whānau as a support to participants during the interview will be offered.

Participation – a Māori advisor has been consulted to ensure the research design is appropriate for Māori. For example, using face to face interviews is suggested to be more appropriate for Māori participants.

Protection – this project is relevant to improving Māori health outcomes. Despite the fact that Māori are over represented in the incidence of cancer and chronic diseases, they continue to be under represented in referrals to palliative care services. Exploring the experiences of hospital admissions for Māori patients who have a life limiting illness will contribute to a better understanding of why this inequity currently exists in palliative care.

- * **F:3 Identify the group(s) with whom consultation has taken place, describe the consultation process, and attach evidence of the support of the group(s) when submitting the application.**

Consultation with the ADHB Māori Ethics Advisor (Helen Wihongi) was made during the ethics application process. This included a review of the research proposal to ensure that the project design respected the needs of Māori participants.

- * **F:4 Describe any on-going involvement the group(s) consulted has in the project.**

- * **F:5 Describe how information will be disseminated to participants and the group consulted at the end of the project.**

All participants will be invited to provide their contact details at the time of obtaining informed consent. A summary of findings will be posted or emailed to participants. Māori participants will be offered a face to face meeting to discuss the findings.

- * **F:6 List all the Māori methodology used for obtaining information.**

Predominant use of a kanohi ki te kanohi (face-to-face) approach when establishing networks, interacting and engaging with individuals and organizations: **Yes**

The use of karakia and appropriate protocols to conduct hui: **No**

The use of powhiri, whakatau and mihimihi processes: **No**

The use and promotion of te reo Māori: **No**

The use of protective mechanisms regarding cultural and intellectual property of participants: **Yes**

The use and significance of kai: **No**

The use and active practice of culturally appropriate processes wherever possible: **Yes**

Other: **Yes / No**

(If "Other", please explain)

SECTION G: OTHER CULTURAL ISSUES

* **G:1 Are there any aspects of the research that might raise any specific cultural issues?**

No

Note: If “yes”, please answer the remaining questions in this section. If “no”, please go straight to Section H.

* **G:2 What ethnic or cultural group(s) does the research involve?**

* **G:3 Identify the group(s) with whom consultation has taken place, describe the consultation process, and attach evidence of the support of the group(s) when submitting your application.**

* **G:4 Describe any on-going involvement the group(s) consulted has in the project.**

***R** **G:5 Describe how information will be disseminated to participants and the group(s) consulted at the end of the project.**

Note: Please indicate this on the PIS and CF.

SECTION H: RISKS AND BENEFITS

***R** **H:1 What are the possible benefits to research participants of taking part in the research?**

Although considered by some as a vulnerable population, patients with a life limiting illness report positive effects by being involved in palliative care research particularly when the topic has the potential to improve access to and the quality of health care services for future patients. In addition involvement in research has been shown to have therapeutic benefits to individuals as participation enables a sense of personhood

to be maintained reducing the potential of a “social death”.

* **H:2 Is the research likely to place the researcher at risk of harm? No**

(If “yes”, please clearly identify/explain these risks here and in the PIS and CF)

* **H:3 Is the research likely to cause any possible harm to the participants, such as physical pain beyond mild discomfort, embarrassment, psychological or spiritual harm? No**

(If “yes”, please clearly identify the potential harm”

* **H:4 Does the research involve collection of information about illegal behaviour(s) which could place the researcher or participants at risk of criminal or civil liability or be damaging to their financial standing, employability, professional or personal relationships? No**

(If “yes”, please clearly identify/explain these risks here and in the PIS and CF)

* **H:5 Is it possible that the research could give rise to incidental findings? No**

(If “yes”, please explain how you will manage the situation)

Note: Clearly identify/explain these risks in the PIS and CF.

* **H:6 Describe what provisions are in place for the research participants should there be adverse consequences or physical or psychological risks.**

Counselling services offered by organisations such as hospice, cancer society and other diagnosis based support services are familiar to the researcher in her work as a Palliative Care Nurse Practitioner. With permission from the participant a referral to appropriate support services will be offered if they require emotional support.

Note: Please explain this in the PIS and CF.

SECTION I: HUMAN REMAINS, TISSUE AND BODY FLUIDS

* **I:1 Does the research involve use of human blood, body fluids, or tissue samples? No**

Note: If “no”, please go to Section J. If “yes”, please explain in the PIS. Provide a copy of the information to be given to the Transplant Coordinator (if necessary), and

state the information that the Transplant Coordinator will provide to those giving consent. Complete the remaining questions in this section.

- * **I:2 Are these samples obtained from persons involved in research or will the tissue be obtained from a tissue bank?**

- * **I:3 Is the tissue imported or taken in New Zealand? Imported / NZ**

(If “imported”, please indicate the country of origin)

Note: If ethics approval is obtained from the country of origin, please attach the approval when submitting your application.

- * **I:4 Describe how the sample / specimen is taken.**

- * **I:5a Is blood being collected? Yes / No**

Note: If “yes”, please indicate this on the PIS and answer the next 4 questions. If “no”, please skip the next 4 questions.

- * **I:5b What is the volume at each collection?**

- * **I:5c How frequent are the collections?**

- * **I:5d Who is collecting it?**

- * **I:5e Is the collector trained in phlebotomy? Yes / No**

(If “no”, please explain)

- * **I:6a Will the sample / specimen be retained for possible future use? Yes / No**

(If “yes”, please explain and state this in the PIS and CF)

Note: If “yes”, please answer the next 2 questions. If “no”, please skip the next 2 questions.

- * **I:6b Where will the material be stored?**

- * **I:6c How long will it be stored for?**

- * **I:7a Will material remain after the research process? Yes / No**

(If “yes”, please explain and state this in the PIS and CF)

Note: If “yes”, please answer the next 2 questions. If “no”, please skip the next 2 questions

***I:7b How will material be disposed of?**

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*** I:7c Will material be disposed of in consultation with relevant cultural groups?**
Yes / No

(If “yes”, please explain and state this in the PIS and CF)

SECTION J: CLINICAL TRIALS

***R J:1 Is the research considered a clinical trial? No**

Note: If “yes”, please include the declaration of the trials in the PIS under “Compensation” and attach Form A or Form B when submitting your application and answer the remaining questions in this section. If “no”, please go straight to Section K.

UAPHEC adopts the definition of clinical trial of the World Health Organisation and New Zealand Ministry of Health. That definition is “a clinical trial is any research study that prospectively assigns human participants or groups of humans to one or more health-related interventions to evaluate the effects on health outcomes”. See Applicant’s Manual Section 5d for the declaration of the trials and Forms A and B.

***R J:2 Is this project initiated by a Pharmaceutical Company or any other Company involved in health research, including a manufacturer or distributor of the medicine or item in respect of which the research is carried out? Yes / No**

Note: If “yes”, please attach the letter from the Company when submitting your application.

***R J:3 Are there other NZ or International Centres involved? Yes / No**

Note: If “yes”, please attach the support letter when submitting your application.

***R J:4 Is there a clear statement about indemnity? Yes / No**

(If “no”, please explain)

Note: If “yes”, please attach a copy of the indemnity when submitting your application.

***R J:5 Is Standing Committee on Therapeutic Trials (SCOTT) approval required? Yes / No**

Note: If “yes”, please attach a copy of the SCOTT approval when submitting your application.

***R J:6 Is National Radiation Laboratory (NRL) approval required? Yes / No**

Note: If “yes”, please attach a copy of the NRL approval when submitting your application.

***R J:7 Is Gene Therapy Advisory Committee on Assisted Human Reproduction (NACHDSE) approval required? Yes / No**

Note: If “yes”, please attach a copy of the NACHDSE approval when submitting your application.

SECTION K: FUNDING

***R K:1 Have you applied for, or received funding for this project? No**

Note: If “yes”, please answer the remaining questions in this section. If "no", please go straight to Section L.

***R K:2 From which funding institution?**

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***R K:3a Is this a UniServices project? Yes / No**

***R K:3b Is this a Research contract? Yes / No**

***R K:3c Is this a Commercial or consulting contract? Yes / No**

***R K:4 Contract reference number**

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***R K:5 Do you see any conflict of interest between the interests of the researcher, the participants or the funding body? Yes / No**

(If “yes”, please explain)

SECTION L: OTHER INFORMATION

*** L:1 Have you made any other related applications?**

<i>If “yes”, please provide Approval Reference Number</i>	No
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*

L:2 Is there any relevant information from past applications or interaction with UAHPEC?

<i>If “yes”, please indicate it here and attach the relevant information when submitting your application.</i>	No
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*

L:3 Please provide a summary of all the ethical issues arising from this project and explain how they are to be resolved.

(For example: confidentiality, anonymity, informed consent, participant’s rights to withdraw, conflict of interest, etc.)

<p>Informed consent</p> <p>During each interaction with the patient details of the study will be discussed fully and written information provided. Opportunities to withdraw from the study without explanation will be provided to each participant. Written consent to participate in the study will be obtained at the initial interview. A process of confirming consent again and opportunities to ask more questions will be repeated at the start of the second interview.</p> <p>Due to the deterioration of physical health in the study population a fluctuating level of cognition is not uncommon. As a result, obtaining informed consent can be a challenge. This issue will be addressed by periodic checking of the patient’s ability to consent particularly at the start of each interview.</p> <p>Confidentiality</p> <p>The privacy of participants will be maintained at all times. Any data collected will not identify individual participants. In addition the way in which results are reported will not identify individual participants. Storage of electronic data will be password protected. Paper based data will be stored in a secure cabinet at the School of Nursing. Access to the data will be limited to the researchers.</p> <p>Access to clinical information will be limited to JR who as an ADHB employee will be working under the ADHB Confidentiality Agreement. During interviews in the hospital setting, participant’s privacy will be maintained by keeping curtains pulled around bed spaces during the interview and where possible and practical interviews will take place in a private meeting room on the ward.</p> <p>Rights to withdraw</p> <p>The participant’s right to withdraw will be highlighted during the consent process. At the start of the second interview an overview of the study will be provided again and participants will have the option to withdraw from the study at that time. Participants will be reminded that the interview can be discontinued at any time.</p> <p>Role conflict</p> <p>The researcher (JR) is employed by the Auckland District Board and works as a Nurse Practitioner with the Auckland City Hospital Palliative Care Team. Some patients eligible for the study may be referred to the service during the study admission. A small number may have already been referred at the time of the first interview.</p> <p>A conflict of interest arises as a result of the researcher having a dual role; as researcher and as a health professional involved in the participant’s care during the study</p>
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admission. This could result in the patient feeling pressured into consenting for fear that their care may be compromised if they decline to participate. Furthermore participants may provide inaccurate information about their experiences knowing that the researcher is also a hospital employed health professional.

The risk of conflict in roles will be mitigated by the researcher explaining the intentions of each visit to the patient and clarifying their role. Where possible the researcher (JR) will avoid becoming involved with patients who are already enrolled in the study by deferring the referral to a colleague.

Vulnerability of study population

In view of deteriorating physical health along with the presence of symptoms that may be causing some discomfort, involving patients with a life limiting illness in research can be tiring for participants. Conversations exploring participants feelings about the impact of hospitalisations on themselves and their family may raise sensitive issues related to the knowledge that time may be short. For some people this may be distressing. Furthermore exploring patient's experiences of care in hospital may cause distress particularly if the experience has not been positive.

The researcher (JR) will use her skills and knowledge in palliative care to ensure participants are well supported throughout the study period. Her well developed communication skills in dealing with sensitive issues will ensure that participants are well supported during the interviews. If participants are seen to be tiring or becoming upset during the interview, the researcher will offer to discontinue the interview. When necessary she will offer referrals to participants that may benefit from ongoing emotional or practical support. In view of deteriorating physical health along with the presence of discomfort and other symptoms, patients with a life limiting illness may find being involved in research burdensome. In addition conversations regarding sensitive issues such as the impact of hospitalisations on themselves and their family in light of a limited prognosis can be distressing. Exploring patients experiences of care in hospital may cause some distress if the experience has not been particularly positive.

UAHPEC expects applicants to identify the ethical issues in the project and explain in the documentation how they have been resolved. The application will not be considered if this is not answered adequately. A "Not applicable" response is not acceptable.

SECTION M: APPLICATION CHECKLIST

- * Have you attached the Participant Information Sheet? (See Applicant’s Manual Sections 2b-ii, 2c and 5a for explanation and sample): **Yes – Patient Information Sheet AND Family Information Sheets attached**
- * Have you attached the Consent Form? (See Applicant’s Manual Sections 2b-iii, 2d and 5b for explanation and sample): **Yes – Patient Consent Form AND Family Consent Form attached**
- * Have you attached the advertisement?: **Yes / No**
- * Have you attached the questionnaire?: **Yes / No**
- * Have you attached the list of interview questions?: **Yes – Patient Interview Schedule AND Family Interview Schedule attached**
- * Have you attached the confidentiality agreement? (See Applicant’s Manual Sections 2b-vii and 5c for explanation and sample): **Yes / No**
- * Have you attached any other supporting documents (for example: approval from Course Coordinator, debriefing sheet)?: **Yes – Clinical Data Form AND Gold Standards Framework Prognostic Indicator Guide attached**
- * Have you completed the Application Checklist (Preliminary Assessment)?: **Yes**

APPLICATION CHECKLIST (Please delete whichever is not applicable)

Preliminary Assessment				
A.	Risk of Harm			
	1.	Does the research involve situations in which the researcher may be at risk of harm?		NO
	2.	Does the research involve the use of any method, whether anonymous or not, which might reasonably be expected to cause discomfort, pain, embarrassment, psychological or spiritual harm to the participants?		NO
	3.	Does the research involve processes that are potentially disadvantageous to a person or group, such as the collection of information which may expose the person/group to discrimination?		NO
	4.	Does the research involve collection of information about illegal behaviour(s) which could place the researcher or participants at		NO

		risk of criminal or civil liability or be damaging to their financial standing, employability, professional or personal relationships?		
*	5.	Does the research involve any form of physically invasive procedure on participants, such as the collection of blood, body fluids, tissue samples, DNA, human tissue from a tissue bank, exercise or dietary regimes or physical examination?		NO
*	6.	Does the research involve any intervention administered to the participant, such as drugs, medicine (other than in the course of standard medical procedure), placebo, environmental conditions, food/drink?		NO
*	7	Does the research involve processes that involve EEG, ECG, MRI, TMS, FMRI, EMG, radiation, invasive or surface recordings?		NO
*	8.	Is the research considered a clinical trial?		NO
	9.	Does the research involve physical pain beyond mild discomfort?		NO
B.	Informed and Voluntary Consent			
	1.	Does the research involve participants giving oral consent rather than written consent? (If participants are anonymous the response is “No”).		NO
	2.	Does the research involve participation of children (seven years old or younger)?		NO
	3.	Does the research involve participation of children under sixteen years of age where parental consent is not being sought?		NO
	4.	Does the research involve participants who are in a dependent situation, such as people with a disability, residents of a hospital, nursing home or prison, or patients highly dependent on medical care?	YES	
*	5.	Does the research involve participants who are being asked to comment on employers?		NO
	6.	Does the research involve participants (other than children) whose capacity to give informed consent is in doubt?		NO
	7.	Does the research use previously collected information or biological samples for which there was no explicit consent?		NO

C.	Research conducted overseas		
	1.	Will the research be conducted overseas?	NO
D.	Privacy and confidentiality issues		
	1.	Does the research involve evaluation of University of Auckland services or organisational practices where information of a personal nature may be collected and where participants may be identified?	NO
	2.	Does the research involve University of Auckland staff or students where information of a personal nature may be collected and where participants may be identified?	NO
	3.	Does the research involve matters of commercial sensitivity?	NO
	4.	Does the research involve Focus Groups?	NO
E.	Deception		
	1.	Does the research involve deception of the participants, including concealment or covert observations?	NO
F.	Conflict of interest		
*	1.	Does the research involve a conflict of interest or the appearance of a conflict of interest for the researcher (for example, where the researcher is also the lecturer/teacher/treatment provider/colleague or employer of the participants, or where there is a power relationship between researcher and participants)?	YES
G.	Cultural sensitivity		
	1.	Does the research have impact on Māori?	YES
	2.	Does the research raise any specific ethnic or cultural issues not relating to Māori?	NO
H.	Requirements imposed from outside The University of Auckland		
	1.	Does the research involve a requirement imposed by an organisation outside The University of Auckland?	YES

Office of the Vice-Chancellor
Research Integrity Unit



The University of Auckland
Private Bag 92019
Auckland, New Zealand

Level 10, 49 Symonds Street
Telephone: 64 9 373 7599
Extension: 87830 / 83761
Facsimile: 64 9 373 7432

UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE

28-Jun-2013

MEMORANDUM TO:

Prof Caryl Gott
Nursing

Re: Application for Ethics Approval (Our Ref. 9499)

The Committee considered your application for ethics approval for your project entitled **Experiences of hospital admissions for patients with palliative care needs**.

Ethics approval was given for a period of three years. The expiry date for this approval is 28-Jun-2016.

If the project changes significantly, you are required to submit a new application to UAHPEC for further consideration. In order that an up-to-date record can be maintained, you are requested to notify UAHPEC once your project is completed.

The Chair and the members of UAHPEC would be happy to discuss general matters relating to ethics approvals if you wish to do so. Contact should be made through the UAHPEC Ethics Administrators at humanethics@auckland.ac.nz in the first instance. All communication with the UAHPEC regarding this application should include this reference number: **9499**.

(This is a computer generated letter. No signature required.)

UAHPEC Administrators
University of Auckland Human Participants Ethics Committee

c.c. Head of Department/School, Nursing
Mrs Jacqueline Robinson
Mrs Jacqueline Robinson
Dr Rosemary Frey

Appendix 2.2 Participant Information and Consent Form (Patient)



The University of Auckland
School of Nursing
Level 2
Building 505
85 Park Road
Grafton, Auckland
Participant Information Sheet (Patient)

Experiences of hospital admissions for patients with a serious illness

For any further information or questions, please contact:

*Jackie Robinson, ph: (09) 3074949 extn 23918
Professor Merryn Gott, ph: (09) 923 1655 extn 81655*

You are invited to take part in a study which is being conducted by Jackie Robinson, a PhD Student from the School of Nursing at the University of Auckland. Jackie is also a Nurse Practitioner with the Auckland City Hospital Palliative Care Team. Her Supervisor in this research is Professor Merryn Gott from the School of Nursing.

You have been selected to take part because you have recently been admitted to Auckland City Hospital. Your participation is entirely voluntary (your choice). You do not have to take part in the study. If you do agree to take part in the study, you are free to withdraw at any time or withdraw any information traceable to you up to December 2013 without having to give a reason. Your decision to participate or not will not affect your relationship with/treatment at the hospital.

You may take as much time as you like to consider whether or not to take part in the study. To help you make your decision, please read this information sheet carefully.

What is the purpose of the study?

The purpose of this study is to explore the experiences of hospital admissions for patients with a serious illness.

What will it involve?

It will involve participating in two interviews which will be carried out by the researcher (Jackie Robinson). The first interview will take place shortly after you are admitted to hospital. This interview is expected to take approximately 20–30 minutes and will take place on the ward. During this interview you will be asked about what brought you into hospital and what you hope will be achieved during your stay.

A second interview will take place at your place of choice, at a convenient date and time, approximately one week after you have been discharged from hospital. This interview is expected to take approximately one hour. During this interview you will be asked to reflect

on your experience of being in hospital. To acknowledge the time you have given by participating in this study you will be provided with a \$30 petrol voucher.

In addition to the interviews your clinical notes will be reviewed by the researcher to gather information about your time in hospital and your illness. If you do agree to take part in the study, you are free to withdraw from the study at any time.

What happens if I decide to take part?

If you decide that you would like to take part, it would involve talking to the researcher. You will be asked to sign a consent form to show that you agree to take part in the study. We will arrange an appropriate time and place to conduct the interviews. Information provided during the interview will be confidential. If the information provided is included in a report or published, this will be done in a way that does not identify you or the hospital where you are a patient at.

Will the interview be recorded?

Yes. With your permission, the interview will be audio-recorded. These recordings will be stored on a password protected computer at the University of Auckland and only members of the research team will have access to them. They will be transcribed by the researcher who has signed a confidentiality agreement. No material that could personally identify you will be used in any reports on this study. The recordings will be destroyed after the analysis is complete (within 12 months). Following the completion of the study, all transcripts and other information will be stored in a locked cupboard and on a password protected computer at the University of Auckland for 6 years.

What is the time-span for the study?

The study is expected to start in August 2013 and will finish in August 2014.

The risks and benefits of the study

There are no specific risks associated with taking part in this study. However, if you have cause to complain, please contact a member of the research team or the Chair of the Ethics Committee immediately. Taking part will take some of your time and will require you to answer a series of questions. It will also give you the opportunity to express your views about being in hospital. Your participation may also help to inform the care that other people receive in the future.

What will happen to the results of the study?

The findings will be reported in a range of professional and academic journals and conferences. It will also be written into a report (thesis) for completion of the researcher's PhD study. A summary of the findings will be made available to you upon request.

Who is organizing the research?

The research is based at the School of Nursing at the University of Auckland. The Principal Investigator is Jackie Robinson. The study has received ethical approval from the University of Auckland Human Participants Ethics Committee. It has also been approved by the Auckland City Hospital Research Office.

Contact for further information

If you require any further information about the study, please contact:

- Principal Investigator: Jackie Robinson (09) 3074949 extn 23917 or email jrobinson@auckland.ac.nz
- PhD Supervisor: Professor Merryn Gott (09) 923 1655 extn 81655
- Head of School of Nursing: Associate Professor Judy Kilpatrick 09 373 2897

Ethics Chair: For any queries regarding ethical concerns you may have please contact: The Chair, The University of Auckland Human Participants Ethics Committee, The University of Auckland, Office of the Vice Chancellor, Private Bag 92019, Auckland 1143. Telephone: 09 373 7599 Extension 83711.

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS
ETHICS COMMITTEE ON 28/06/2013 for a period of 3 years, Reference Number 9499



THE UNIVERSITY OF AUCKLAND
NEW ZEALAND

School of Nursing
Faculty of Medical and Health Sciences
The University of Auckland
Level 2
Building 505
85 Park Road, Grafton
Auckland
Participant Consent Form (Patient)

The experiences of hospital admissions for patients with a serious illness

For any further information or questions,
please contact: Jackie Robinson (09) 3074949
extn 23918
Professor Merryn Gott (09) 923 1655 extn
81655

“The experiences of hospital admissions for patients with a serious illness”

This form will be kept for a period of 6 years

Names of Researchers: Jackie Robinson and Professor Merryn Gott

I have read the information sheet provided to me and I have understood the nature of the research.

- I have read and have understood the information sheet for the above study. I have had the opportunity to discuss and ask questions about the study and I am satisfied with the answers I have been given. I agree to take part in the study.
- I understand that taking part in this study is voluntary and that I may withdraw myself or any information traceable to me at any time up to December 2013.
- I understand that the study has been approved by the ADHB Research Office and that my decision to participate or not will not affect my relationship with, or the treatment that I receive at the hospital.
- I understand that any information gathered from my interview may be included in academic publications and that all information will be carefully anonymised prior to publication. No material which could identify me will be used in any reports based on this study. I understand that my identity will remain strictly confidential.
- I understand that both interviews will be digitally recorded and transcribed.
- I understand that my clinical records will be accessed by the researcher.
- I understand that these recordings will be stored on a password protected computer at the University of Auckland and the recordings will be destroyed after the analysis is complete (within 12 months).
- I understand that all transcripts and other information will be stored in a locked cupboard and on a password protected computer at the University of Auckland for 10 years and then securely destroyed.

- I understand that I may be contacted again during a subsequent admission to hospital.

A summary of study findings is available upon request. Please include an email address to request a copy

Name of
Participant _____ Signature _____ Date _____

Name of
Researcher _____ Signature _____ Date _____

Email (to request a summary of study findings)

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS
ETHICS COMMITTEE ON 28/06/2013 for a period of 3 years, Reference Number 9499

Appendix 2.3 Participant Information and Consent Form (Family)



The University of Auckland
School of Nursing
Level 2
Building 505

Experiences of hospital admissions for patients with a serious illness

*For any further information or questions, please contact:
Jackie Robinson, ph: (09) 3074949 extn 23918
Professor Merryn Gott, ph: (09) 9231655 extn 81655*

Participant Information Sheet (Family)

You are invited to take part in a study which is being conducted by Jackie Robinson, a PhD Student from the School of Nursing at the University of Auckland. Jackie is also a Nurse Practitioner with the Auckland City Hospital Palliative Care Team. Her Supervisor in this research is Professor Merryn Gott from the School of Nursing.

You have been selected to take part because your family member has recently been admitted to Auckland City Hospital and they are not well enough to participate in the study. Your participation is entirely voluntary (your choice). You do not have to take part in the study. If you do agree to take part in the study, you are free to withdraw at any time or withdraw any information traceable to you up to December 2013 without having to give a reason. Your decision to participate or not will not affect your relationship or your family members relationship and treatment with/at the hospital.

You may take as much time as you like to consider whether or not to take part in the study. To help you make your decision, please read this information sheet carefully.

What is the purpose of the study?

The purpose of this study is to explore experiences of hospital admissions for patients with a serious illness.

What will it involve?

It will involve participating in two interviews, which will be carried out by the researcher (Jackie Robinson). The first interview will take place shortly after your family member has been admitted to hospital. This interview is expected to take approximately 20–30 minutes and will take place at your place of choice or by telephone. During this interview you will be asked about what brought your family member into hospital and what you hope will be achieved during their stay.

A second interview will take place at your place of choice, at a convenient date and time, approximately one week after your family member has been discharged from hospital. This interview is expected to take approximately one hour. During this interview you will be asked to reflect on your family member's experience of being in hospital. To acknowledge the time you have given by participating in this study you will be provided with a \$30 petrol voucher.

In addition to the interviews your family member's clinical notes will be reviewed by the researcher to gather information about the hospital admission and their illness. If you do agree to take part in the study, you are free to withdraw from the study at any time.

What happens if I decide to take part?

If you decide that you would like to take part, it would involve talking to the researcher. You will be asked to sign a consent form to show that you agree to take part in the study. We will arrange an appropriate time and place to conduct the interviews. Information provided during the interview will be confidential. If the information provided is included in a report or published, this will be done in a way that does not identify you, your family member or the hospital.

Will the interview be recorded?

Yes. With your permission, the interview will be audio-recorded. These recordings will be stored on a password protected computer at the University of Auckland and only members of the research team will have access to them. They will be transcribed by the researcher who has signed a confidentiality agreement. No material that could personally identify you will be used in any reports on this study. The recordings will be destroyed after the analysis is complete (within 12 months). Following the completion of the study, all transcripts and other information will be stored in a locked cupboard and on a password protected computer at the University of Auckland for 6 years.

What is the time-span for the study?

The study is expected to start in August 2013 and will finish in August 2014.

The risks and benefits of the study

There are no specific risks associated with taking part in this study. However, if you have cause to complain, please contact a member of the research team or the Chair of the Ethics Committee immediately. Taking part will take some of your time and will require you to answer a series of questions. It will also give you the opportunity to express your views about your family member being in hospital. Your participation may also help to inform the care that other people receive in the future.

What will happen to the results of the study?

The findings will be reported in a range of professional and academic journals and conferences. It will also be written into a report (thesis) for completion of the researcher's PhD study. A summary of the findings will be made available to you upon request.

Who is organizing the research?

The research is based at the School of Nursing at the University of Auckland. The Principal Investigator is Jackie Robinson. The study has received ethical approval from the University of Auckland Human Participants Ethics Committee. It has also been approved by the Auckland City Hospital Research Office.

Contact for further information

If you require any further information about the study, please contact:

Principal Investigator: Jackie Robinson (09) 3074949 extn 23917 or email

jrobinson@auckland.ac.nz

PhD Supervisor: Professor Merryn Gott (09) 923 1655 extn 81655

Head of School of Nursing: Associate Professor Judy Kilpatrick 09 373 2897

Ethics Chair: For any queries regarding ethical concerns you may have please contact:

The Chair, The University of Auckland Human Participants Ethics Committee, The University of Auckland, Office of the Vice Chancellor, Private Bag 92019, Auckland 1143.

Telephone: 09 373 7599 Extension 83711.

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS ETHICS COMMITTEE ON 28/06/2013 for a period of 3 years, Reference Number 9499



**THE UNIVERSITY OF AUCKLAND
NEW ZEALAND**

School of Nursing
Faculty of Medical and Health Sciences
The University of Auckland
Level 2
Building 505
85 Park Road, Grafton
Auckland
Participant Consent Form (Family)

The experiences of hospital admissions for patients with a serious illness

For any further information or questions,
please contact: Jackie Robinson, (09)
3074949 extn 23918
Professor Merryn Gott (09) 923 1655 extn
81655

“The experiences of hospital admissions for patients with a serious illness”

This form will be kept for a period of 6 years

Names of Researchers: Jackie Robinson and Professor Merryn Gott

I have read the information sheet provided to me and I have understood the nature of the research.

- I have read and have understood the information sheet for the above study. I have had the opportunity to discuss and ask questions about the study and I am satisfied with the answers I have been given. I agree to take part in the study.
- I understand that taking part in this study is voluntary and that I may withdraw myself or any information traceable to me at any time up to December 2013.
- I understand that the study has been approved by the ADHB Research Office and that my decision to participate or not will not affect my relationship with, or the treatment that my family member receives at the hospital.
- I understand that any information gathered from my interview may be included in academic publications and that all information will be carefully anonymised prior to publication. No material which could identify me or my family member will be used in any reports based on this study. I understand that my identity will remain strictly confidential.
- I understand that both interviews will be digitally recorded and transcribed.
- I understand that my family member’s clinical records will be accessed by the researcher.
- I understand that these recordings will be stored on a password protected computer at the University of Auckland and the recordings will be destroyed after the analysis is complete (within 12 months).

- I understand that all transcripts and other information will be stored in a locked cupboard and on a password protected computer at the University of Auckland for 10 years and then securely destroyed.
- I understand that I may be contacted again during a subsequent admission to hospital.

A summary of study findings is available upon request. Please include an email address to request a copy.

Name of Participant _____ Signature _____ Date _____

Name of Researcher _____ Signature _____ Date _____

Email (to request a summary of study findings)

APPROVED BY THE UNIVERSITY OF AUCKLAND HUMAN PARTICIPANTS
ETHICS COMMITTEE ON 28/06/2013 for a period of 3 years, Reference Number 9499

Appendix 8: Interview Schedule 1 (Patient)

Participant No:

Research project: Experiences of hospital admissions for patients with palliative care needs

Participant No:

Time of Interview:

Date:

Place:

Thank you taking part in this interview. Your responses will remain anonymous and no records of the interview will be kept with your name on them. I would like your permission to record the interview and take some notes while we are talking.

1. What were the circumstances that caused you to end up in hospital?
2. How do you think being in hospital will help you with your illness?
3. What do you think the difficulties will be for you while you are in hospital?
4. How do you feel about being in hospital?
5. How do you think your family feels about you being in hospital?
6. If you could have got the help you needed would you have preferred to have stayed at home/residential care facility/hospice?

Thank them and remind them that you will make contact by phone within a week of discharge to arrange a time to interview them again.

Appendix 2.4 Gold Standards Framework Prognostic Indicator Guide

<p>Cancer (must fulfil at least ONE of following criteria)</p> <ul style="list-style-type: none"> [] Cancer that is metastatic or not amenable to treatment [] Lung Cancer [] Cancer & severely impaired functional ability (e.g.>50% of time in bed/lying down) 	<input type="checkbox"/>
<p>Heart Disease (must fulfil at least ONE of following)</p> <ul style="list-style-type: none"> [] Chronic Heart Failure New York Heart Association (NYHA) stage III or IV [] Repeated hospital admissions (>3 in last year) with symptoms of Heart Failure [] Difficult physical/psychological symptoms despite optimal tolerated therapy 	<input type="checkbox"/>
<p>Chronic Obstructive Pulmonary Disease (must fulfil at least ONE of the following)</p> <ul style="list-style-type: none"> [] Severe COPD (FEV<30% predicted) [] >3 admissions in last year for COPD exacerbations [] Long Term Oxygen Therapy [] Signs or symptoms of right heart failure [] More than one of: anorexia, previous ITU/NIV/resistant organism, depression 	<input type="checkbox"/>
<p>Renal Disease (must fulfil at least ONE of following)</p> <ul style="list-style-type: none"> [] Stage 5 kidney disease and not receiving or seeking dialysis or transplant [] CKD stage 5 (eGFR <15 ml/min) OR symptomatic renal failure (anorexia, nausea, pruritus, reduced functional status, intractable fluid overload) 	<input type="checkbox"/>
<p>Motor Neurone Disease</p>	<input type="checkbox"/>
<p>Parkinson's Disease (must fulfil at least ONE of following)</p> <ul style="list-style-type: none"> [] Drug treatment no longer effective/increasingly complex treatment regime [] Reduced independence, need for help with daily living [] Condition has become less controlled/predictable with "off" periods [] Dyskinesias, mobility problems and falls [] Swallowing problems [] Psychiatric signs (depression, anxiety, hallucinations, psychosis) 	<input type="checkbox"/>
<p>Multiple Sclerosis and at least ONE of following criteria</p> <ul style="list-style-type: none"> [] Significant complex symptoms, [] Communication difficulties e.g. dysarthria ± fatigue [] Cognitive difficulties [] Swallowing difficulties/poor nutritional status [] Breathlessness ± aspiration [] Medical complication e.g. recurrent infection 	<input type="checkbox"/>
<p>Frailty as defined by one of following</p> <ul style="list-style-type: none"> [] Multiple co-morbidities with signs of impairments in day-to-day functioning [] Combination of a least 3 symptoms of: weakness, slow walking speed, low physical activity, weight loss, self reported exhaustion 	<input type="checkbox"/>
<p>Dementia and at least ONE of the following</p> <ul style="list-style-type: none"> [] Unable to walk without assistance, urinary & faecal incontinence, lack of meaningful verbal communication, unable to dress without assistance [] Barthel Score <3 [] Reduced activities of daily living [] Any of the following: 10% weight loss in prev 6 months without cause, pyelonephritis or UTI, Serum albumin 25g/l, severe pressure sores e.g. stage III or IV, recurrent fevers, reduced oral intake/weight loss, aspiration pneumonia. 	<input type="checkbox"/>

<p>Stroke and at least ONE of the following</p> <p>[] Persistent vegetative or minimal conscious state/dense paralysis/incontinence</p> <p>[] Medical complications</p> <p>[] Lack of improvement within 3 months of onset</p> <p>[] Cognitive impairment/post-stroke dementia</p>	<input type="checkbox"/>
<p>Other (e.g. AIDS, muscular dystrophy, cystic fibrosis)</p> <p>[] To include patients diagnosed with other progressive life limiting conditions , please specify:</p> <p>.....</p>	<input type="checkbox"/>
<p>Patients over the age of 85 years</p>	<input type="checkbox"/>

Appendix 2.5 Interview 1 Schedule

Patient Interview 1

Research project: Experiences of hospital admissions for patients with palliative care needs

Participant No:

Researcher: Jackie Robinson, Palliative Care Nurse Practitioner and PhD Candidate

Time of Interview:

Date:

Place:

Thank you taking part in this interview. Your responses will remain anonymous and no records of the interview will be kept with your name on them. I would like your permission to record the interview and take some notes while we are talking.

1. What were the circumstances that caused you to end up in hospital?
2. How do you think being in hospital will help you with your illness?
3. What do you think the difficulties will be for you while you are in hospital?
4. How do you feel about being in hospital?
5. How do you think your family feels about you being in hospital?
6. If you could have got the help you needed would you have preferred to have stayed at home/residential care facility/hospice?

Thank them and remind them that you will make contact by phone within a week of discharge to arrange a time to interview them again.

Appendix 2.5 Interview 2 Schedule

Research project: Experiences of hospital admissions for patients with palliative care needs

Participant No:

Researcher: Jackie Robinson, Palliative Care Nurse Practitioner and PhD Candidate

Time of Interview:

Date:

Place:

Thank you for taking part in this follow up interview. Your responses will remain anonymous and no records of the interview will be kept with your name on them. I would like your permission to record the interview and take some notes while we are talking.

Reflecting on you recent admission to hospital:

1. Tell me about your experience of having recently been in hospital

Prompts if needed: What brought you in? What happened while you were there – investigations, treatment, discussions with health professionals (information about illness/future planning etc)?

2. Thinking about what happened during your stay in hospital, was there anything you found particularly difficult or distressing?
3. On reflection, was there anything/useful about having that time in hospital? How was it helpful/useful?
4. Is there any reason you think might have to go back to hospital again?
5. How would you feel about having to go back to hospital again?
6. How do you think your family might feel if you had to go back to hospital again?
7. If the circumstances that caused you to go to hospital this time were to happen again, would you prefer to stay at home or go back to hospital?
8. What do you think you would need in order for you to remain at home in those circumstances?
9. Has your family member ever talked about plans for the future/preferences for treatment/preferences for place of care? Have they ever discussed these with their health professionals?

Thank them and remind them that you will make contact by phone in 7–10 days to make sure they are okay.

Appendix 2.6 Case Note Review Data Collection Form

PARTICIPANT DETAILS

Date of

Birth.....**Age**.....

Gender M/F

Ethnicity

- NZ European
- Māori
- Samoan
- Cook Island Māori
- Niuean
- Chinese
- Indian
- Other

Is a palliative care clinical alert present?

YES Circle S C W N H
NO

Co-morbidities

- Cardiac disease (e.g. CHF/IHD/Cardiomyopathy)
- Respiratory disease (e.g. COPD/bronchiectasis)
- Chronic neurological conditions
- Stroke
- Cancer
- Diabetes
- Peripheral vascular disease
- Cerebro-vascular disease
- Dementia
- Chronic endocrine disorders
- Musculo-skeletal disorders
- Substance abuse
- Chronic renal disease
- Chronic liver disease
- Other (please specify)

PREVIOUS ADMISSIONS

Number of hospital admissions in the last 12 months.....

Number of days spent in hospital in the previous 12 months.....

CURRENT ADMISSION DETAILS

Presenting complaint.....

Primary GSF Diagnosis.....

Attach completed GSF-PIG)

Admission time and date:

Origin of admission

Living Arrangements

- Home
- Hospice
- Residential care facility
- Other

- Lives alone
- Lives with others
- Residential care
- Other

Procedures

- Blood tests Number.....
- Imaging (e.g. x-ray/CT/MRI) Number.....
- Infusions (IVF/blood/bisphosphonates etc)
- IV medications
- IV antibiotics
- Radiotherapy
- Chemotherapy
- Ureteric stenting
- GI stenting
- Dialysis
- Feeding tubes
- Venting or drainage tubes
- Intra spinal analgesia
- Surgery
- Other

Were they outlying at any time during the admission? Yes No

For how long?.....

Did they transfer wards at any time during the admission? Yes No

How many times?.....

Did this transfer involve a change of medical teams? Yes No

How many different health professionals did they see during the admission?

Nurses.....

Doctors.....

Allied Staff.....

Was there any evidence of the patient changing bed spaces or rooms? Yes No

How many times?.....

Palliative Care Needs While in Hospital

		Addressed?	Comments/Details
Symptom control	<input type="checkbox"/>	Yes/No	
Pain	<input type="checkbox"/>	Yes/No	
Delirium	<input type="checkbox"/>	Yes/No	
Nausea/vomiting	<input type="checkbox"/>	Yes/No	
Constipation	<input type="checkbox"/>	Yes/No	
Other	<input type="checkbox"/>	Yes/No	
End of life care	<input type="checkbox"/>	Yes/No	
Psychosocial	<input type="checkbox"/>	Yes/No	
Emotional	<input type="checkbox"/>	Yes/No	
Spiritual	<input type="checkbox"/>	Yes/No	
Cultural	<input type="checkbox"/>	Yes/No	
Other (please state)	<input type="checkbox"/>	Yes/No	

Were they referred to the HPCT during the admission? Yes No

Were they referred to hospice on discharge? Yes No

Discharge Date: Total length of stay in days

Discharge destination

Home

Hospice

Another hospital

Residential care facility

Other.....

Details of discussions regarding diagnosis/prognosis/goals of care/future care/decision making with patient and/or family

Appendix 2.7 Thank You Letter



THE UNIVERSITY OF AUCKLAND
NEW ZEALAND

Date

FACULTY OF MEDICAL AND HEALTH SCIENCES,
School of Nursing

Dear Participant,

Earlier this year you were interviewed about your experience of being in hospital. The findings from this study will be used to improve the services that patients receive during their stay in hospital and after being discharged. Sharing your experience has been invaluable to the study and I would like to take this opportunity to thank you for your time.

I am mindful that our discussion may have left you with some questions about your illness. I am also aware that such discussions can sometimes be difficult. There are a variety of different support services available in the community and I would be happy to discuss how you might access these if you feel this would be of benefit to you. Please feel free to contact me directly either by email or phone if you wish to discuss this further.

Thank you again for your support with this research.

Kind regards,

Jackie Robinson, RN, MPallCare
PhD Candidate
University of Auckland
j.robinson@auckland.ac.nz

Appendix 2.8 Example of an Interview Transcript

INTERVIEW 1 WITH P2

JR: We are going to record it today and we can stop it any time you want and your responses will be reported anonymously. So we won't know who you are and . . . so can you just confirm for me when you arrived in hospital – what time that was?

P2: 3. . . . about 3 o'clock, wasn't it? (turns to daughter)

JR: Yesterday?

P2: Yes.

JR: And what were the circumstances by which you came in to hospital? . . . What happened yesterday that you ended up in hospital?

P2: There was two or three things actually. . . . One was I hadn't got on top of my nausea. I had chemotherapy on Monday and . . .

JR: Was that in hospital?

P2: Chemotherapy was . . . where was my . . . ? (turns to daughter)

Daughter: It was building 8. . . . You were an outpatient – it was only a few hours here.

JR: So you had some chemotherapy as an outpatient on Wednesday?

P2: On Monday.

JR: On Monday, yep, okay and then what happened after?

P2: Well, I just kept retching and vomiting. That was one of the things I couldn't control that. . . . Also I had constipation, is the second one but . . . the main thing was that I have got thrombophlebitis in my leg and that was getting worse, and I could see it tracking up the vein. . . . And it was getting harder to walk without pain, so I thought I have to see somebody about this you know. . . . Those are the three reasons why I came.

JR: Okay, so that got worse as the week progressed?

P2: Yes, yes. . . .

JR: And then what happened yesterday? How did you end up coming into hospital?

P2: I just decided I had to ring somebody up and get some help, and they have an information line.

JR: Okay, yep. Does that put you through to the ward?

P2: It puts me through to the ward and usually a nurse answers it and they give you . . . they take the information from you and ask, you know. . . . You got questions you want to ask and then they will ring you back. . . . "I will talk to a doctor and I will ring you back", usually.

JR: Okay, and they suggested that you come in?

P2: Yeah, they suggested that I come in mainly because of my leg because they...apparently you can get clots from the chemo and the cancer so they won't sure.

JR: And so they were worried about that? . . . And did you come through the Emergency Department or did you come straight up to the ward?

P2: No, I came through APU.

JR: APU, okay...you didn't make contact with your GP or anything like that at that time?

P2: No, because I thought there was no point because he's only going to send me in, you know.

JR: And what are you hoping that they are going to be able to help you with during the admission to hospital?

P2: They have helped with the pain so far. I have got a graseby, which has got umm . . .

JR: That was started?

P2: It was started last night. They put the . . . it was about midnight and they started the graseby they put, they put it in about 9pm, but it was [. . .] by the time it was got everything sorted.

JR: Okay, so that's . . . ?

P2: It's a 24 hours.

JR: Okay, is there anything you are hoping the . . . will be able to help you with during the admission?

P2: Constipation.

JR: Yeah?

P2: Umm. . . . I think they are getting on alright with the pain relief. But I think someone is coming from the Haematology Department to see my leg at some stage, and they might suggest some intramuscular Clexane, which my heart sank at when they said that.

JR: Did it? Why's that?

P2: It's so painful.

JR: Is it, have you had it before?

P2: No, I haven't had it before but I'm a nurse so . . .

JR: Oh, I see. . . . sometimes a little bit of knowledge is not that good, is it?

P2: Oh, I know. . . . We give it to everybody but you know it's so different when it's you. . . .

JR: So how do you think being a nurse affects your . . .

P2: Terrible.

JR: In what way?

P2: Well, I think you know your own specialty best and I know nothing about . . . which is probably a good thing. I don't know anything about oncology but I also know when they mention things I know, what it involves, and I know a little of . . . is bad sometimes, you know.

JR: So your expectations are different, I think?

P2: Yeah, I get so worried about things. I don't know whether it's me or I got a CT scan in the morning, and I'm so worried about not the scan. It's drinking that iso-scan you know. . . . I can't drink water, I've never drunk water.

JR: So he thought of having to drink that . . . probably because you have tried to help patients drink it?

P2: It's horrible. . . .

JR: Have you actually tasted it?

P2: Yeah, I have. . . . It's horrible.

JR: So that's going to influence your experience quite a lot, or perhaps your expectations of what might happen?

P2: Expectations, I think.

JR: Yeah, because of that prior knowledge that you have. . . . and what do you think . . . do you think there will be any difficulties about being in hospital during this time for you?

P2: I don't see anything. . . . no. . . . the only thing is what they are going to do. . . . I mean when I say that, like the Clexane. . . . but no, not in general.

JR: So do you worry about the things that they might do to you while you are here in hospital?

P2: Yeah, I would be lying if I said I didn't. . . . You know. . . . but they are all really nice people here, you know.

JR: So is that fear around the interventions that they are going to do?

P2: Yeah, I think it's the interventions, really.

JR: That they might hurt or that they might be uncomfortable or?

P2: Mmm. . . . I'm a nervous person but I think it's because of the knowledge I've got. . . . if I didn't know anything about them, I wouldn't worry about them.

JR: You would be oblivious, wouldn't you. . . . Yeah, absolutely. . . . And how do you feel about being in hospital when you know that you have to end up coming back . . . is this the first time you have been in hospital?

P2: No, I was in a fortnight ago on this same ward. I came in with pneumonia after chemo the first time.

JR: So how did you feel about having to come back?

P2: I didn't worry about coming back because I know it's got to be done, you know. . . . And I had a good experience a fortnight ago, so I really wasn't worried about coming back – it's just what they're gonna do.

JR: It's what they're going to do. . . . Do you feel a bit vulnerable to that sometimes?

P2: Yeah, I do. . . .

JR: I guess you have the power to say no.

P2: Yeah, but it wouldn't make . . . I mean, there is no point, is there?

JR: It's that vulnerability about being a patient. . . . Nurses talk about when you are on the other side, it's . . .

P2: It's totally different, isn't it?

JR: Yes, it is. . . . and I don't know how you feel about your daughter sitting here . . . but I'm wondering how you think your family feel about you being in hospital?

P2: I think they are very anxious.

JR: Do you?

P2: Aren't you? (Turns to daughter)

Daughter: Am I allowed to talk?

JR: Yeah, sure.

Daughter: I mean, we know you are getting the best care possible so . . .

P2: That's a good answer, R.

JR: So, you think they might be anxious about?

P2: About the future obviously. . . . you know – until we get some answers and that.

JR: Maybe some of that fear is around what might be discovered?

P2: Mmm. . . . I think it was a big shock. R (*daughter*) was there when they told me and it was the one thing I had a real bad experience and it was the only thing, is when he told us, wasn't it. R: . . . and I think there are ways of telling people but this . . .

JR: Can you tell me a bit about that?

P2: This man came in – he was a registrar and he brought two medical students with him and – I'm not complaining, don't get me wrong – it's just it was the only bad experience I've had. And he sat down and he said well . . . I mean, I came in with . . . my GP said it was . . . umm . . . (turns to daughter) . . . What's the word, R? I can't think . . .

Daughter: He was thinking you had diverticulitis.

P2: Diverticulitis. . . . and that it was in my notes 'cos I saw it written there and my GP said he thought it most probably was that. . . . And it was written in the notes: *query diverticulitis*.

And, you know, I just thought it was that and I had a scan and then this doctor came up a bit later with these students and he said, “Well, I’m sorry, I have got some very bad news for you, you have a widespread cancer”. And it came out. . . . didn’t it, R . . . more or less, just like that. . . . just like that, and I thought well . . .

JR: You weren’t expecting it at all?

P2: I wasn’t expecting it, but I know you have to be blunt in some ways. But he could have sort of lead up to it a bit, you know. . . . in front of students, you know, and then we were both in shock, weren’t we? (turns to daughter)

Daughter: I think the difficult thing was Mum asked whether it was likely there would be treatment and he basically said, “No”. And of course, that’s not what happened because Mum’s getting chemo, so it was no business of his to say what the treatment would be without consulting some oncologists and to immediately, in the first time, say “No” . . .

JR: And checking out what you mean by treatment.

Daughter: Well, we did. . . . Mum asked him, “Will there be surgery? Will there be whatever?” and she left, we both left thinking it was palliative only and it wasn’t.

P2: I mean, the first thing was, you know, thought, after for that first week . . . I rushed home, I did my will, I did. You know, I was thinking hospice care, you know you . . . all these things come into your mind. It took us about three weeks to get over it.

JR: I’m really sorry. . . . it sounds like a terrible thing.

P2: It was a horrible thing. I mean, he could have lead up to it and then said, “Well, we think it may be cancer”, you know, or something. . . . But not to come straight out like that.

JR: Does that worry you sometimes that somebody might do that while you are here?

P2: I get angry.

JR: Come out with something just out of the blue that you are not expecting? Do you think it will happen again?

P2: No, no I haven’t thought about that. No, I don’t think so. I think it was just . . .

JR: Just that one time.

P2: But, you know, you left, you go home thinking all these worst . . . I mean, I was in hospice the next week. I was just thinking what can I do, what can I do, and yet all the others have been pretty positive and so far the results have been okay. . . . It just all hinges on tomorrow on the CT scan apparently.

JR: In terms of the decision making from here you mean?

P2: Yeah, in terms of what the doctors decide to do. . . . it all hinges on tomorrow. Are you a nurse?

JR: Yeah, yes I am. . . .

P2: But anyway, I am trying to forget . . . I was angry, I went to see one of the counsellors, didn't we (*turns to daughter*) . . . at Domain Lodge. And I was talking to her about it and when I started I couldn't stop. . . . I just wanted to tell everybody about this horrible thing.

JR: Unfortunately it's not an uncommon experience. . . . We struggle to do it well – breaking bad news.

P2: Anyway, that's the only other thing. . . . That was the only thing really.

JR: If you . . . thinking back to yesterday when you came in, if there had been some help that you could have got at home, would you have preferred to stay at home than come into hospital?

P2: Probably not because I have got confidence really. I know, you know, I mean so many positive things have happened even today, haven't they. (*turns to daughter*)

Daughter: Yep, it's been good.

P2: You know, you list . . . You talk to these doctors and you list what you are worrying about and they deal with them, you know. . . . It has been really good and I have got, I love the two registrars – they're both lovely. It's funny 'cos when we first went to see M, the registrar, he was saying, "Oh yeah, this will be pretty straight forward". He said, "You will be feeling better". The first week I got bronchopneumonia and this week I have got thrombophlebitis. . . .

JR: Have you seen him since?

P2: Yeah, today. . . . he says, "Well," he says, "I was wrong". What did he say, love? (*turns to daughter*) . . . something like that. . . . but I just laugh about it really.

JR: So, what we will do now, as I said, I track your admission so while you are here I will just look each day what has happened to you in terms of blood tests and interventions and things like that, and then I will track the day you are discharged. And I will give you a call probably within a day or two of you getting home to arrange a time that's convenient for you to pop around, is that okay?

P2: Yeah, that's fine.

JR: And I'm more than happy if you want your family around or not. . . . Whatever you feel.

P2: No, that's fine, I don't mind.

JR: So we will basically be talking about what actually happened while you were in hospital and how that was for you, and in hindsight looking back and how things were and that sort of stuff.

INTERVIEW 2: P2

JR: Last time we met we talked a little bit about what brought you in, so I am just wondering if you could just briefly go over that again – this last admission – what brought you in?

P2: It was a combination of things but it was mainly the pain in my right leg that was getting worse and the inflammation that was spreading up my leg, apart from the usual things of the vomiting and the . . . yeah, mainly the vomiting and the pain in my leg – they were the two things, I think.

JR: And you were talking about how you rung the ward?

P2: Yes, we are given a number and this is on the ward. And you can ring that and it's usually a nurse who answers it and they take all the details, and then they say I will ring you back when they have spoken with a doctor on the ward. And then it is up to them as to whether they decide they want you to come in.

JR: So was that on the Saturday or the Sunday?

P2: That was on the Sunday.

JR: On the Sunday . . . and do you get given that number because you are having chemotherapy, is that . . . are you having chemotherapy at the moment?

P2: Yeah, I am having chemotherapy. I think we were given that number in the beginning, very early on, if there was any problem. We are given quite a few numbers. . . . Do you want to stop it (*indicates to the audio recorder*) and I will show you them, I will get the book. (*leaves the room*).

JR: Yeah, yeah – no, we can keep it going. There is plenty of room on there.

P2: I just put everything in my book because this is where I write my diary of what tablets I have taken and everything, but this is the one I just put everything in here. . . . that's the one we are given if there's any problem and then we . . . you know there's so many numbers.

JR: Do they give you any guidance as to . . . in what circumstances you should ring them?

P2: They just said if you feel, you know, if you are not sure about anything if you feel unwell, or just ring if you have got pain that you can't control or nausea or anything like that.

JR: And they give you those numbers when you first [were] starting your chemo?

P2: They gave me some of those...they gave me when I first went into hospital. This lady we had a lot to do with – I haven't seen her since because they are different . . . different places, and I think I have got some more in the back as well . . . This is the Cancer Society ones and home services and things like that.

JR: So do you ever get a bit confused about which number you should ring depending what's happening or do you just. . .

P2: Well, that's pretty straightforward that one, but you know you have to look two or three times because there are different services. . . .

JR: And everyone has different roles, perhaps?

P2: It was confusing in the beginning because we met these people first and then. . . .

JR: That's the gynae oncology.

P2: Yeah, then they were talking about gynae medical oncology, gynae surgical. You know, they were all different things, we couldn't work [out] who was what. To begin with it's a bit complicated and they are all different doctors and different teams and sometimes you don't see the same doctors. You see different doctors, you know.

JR: So that was . . . you just rung the ward straight through and then they told you what to do?

P2: Very good service.

JR: So when you were in hospital, how long were you in hospital for?

P2: I went in on Sunday afternoon about 3 o'clock and I came home Friday. . . . this Friday that's just gone – about 4 o'clock in the afternoon.

JR: So tell me, over those five days, what did you get up to? I think when we spoke on the Monday you were waiting to have the CT scan or you . . .

P2: Yeah, I was waiting to have the CT on the Tuesday.

JR: What else happened while you were in that time?

P2: What else happened? A lot of doctors' visits. . . . Well, first of all, when I went in they put the graseby in my stomach to control the nausea and the pain. . . . that was on the Sunday afternoon and then they put some IV antibiotics up, and then I had the CT on the Tuesday. . . . What else did I have? I think that was pretty much it.

JR: So just the CT scan; you didn't have any other x-rays or . . . ?

P2: Oh yeah, sorry, yeah, I did have x-rays.

JR: They had a look at your leg?

P2: Abdominal x-rays and, yeah, because I have a problem with constipation and that was another problem that took me in as well.

JR: Did they sort that out while you were there?

P2: More or less, yeah. . . . but I think I have sorted it myself the last three days. I think I have found the key to it.

JR: Good for you.

P2: Well, I hope I have anyway. . . . Yeah, lots of doctors rounds.

JR: So lots of doctors. . . . Did you feel like you saw lots of different doctors?

P2: No, actually I didn't this time. It was pretty much the one team, you know, different junior doctors but the same Registrar. . . . Yeah.

JR: And did you . . . how did the communication with them go? Did you feel like you got everything that you needed in terms of the information?

P2: I got what I wanted to know about some things I haven't asked about, to be perfectly honest, I think the doctors and nurses have been very, very good. Excellent and I got everything I asked for – I don't think there was one particular thing that I didn't get.

JR: So you mentioned you got exactly what you asked for but there were some things you didn't ask about?

P2: I have things I don't want to know about. . . . about my diagnosis and things. . . . I think it will come in time but I'm just not ready for a whole lot of information.

JR: Are you confident that they are not going to tell you unless you want to know?

P2: I can never be truly confident but because you know what it's like, things come out and, yeah, I mean like my daughter, she's reading all these booklets that I'm given and all the wealth of information and looking on the internet and I just don't want to know, you know. Not at the moment. I'm finding that very hard because they are so . . . they are worried, you know, and of course they want to know and . . .

JR: This is your family?

P2: This is my family but no, the hospital . . .

JR: But you don't necessarily want to know what they are wanting to know – is that what . . . at the moment?

P2: Yeah.

JR: That's okay.

P2: Yeah. . . . The only thing I said to K last night – just find out . . . because I'm going to have surgery now. Did I tell you?

JR: No.

P2: Yes, and I said, "All I want to know is – am I going to get a pain pump"? (laughs)

JR: That's the practical side of you.

P2: I know, I know.

JR: So how are you feeling about the surgery? Was that a decision they made during this admission?

P2: Well, funnily enough the doctors had talked about it before, but they hadn't specifically said I was going to have surgery. They said it all. . . . In fact, the consultant I saw once (KC) – and she said, she said, “We will have the chemo”, she says. But to be perfectly honest, everything revolves around what's on the CT scan.

JR: The scan you had during this admission?

P2: Yes, whether or not it's . . . I said, “Have I got any metastases?” You know, that's one question I did ask. . . . I forced myself to ask, and she says it all depends what's on the CT and how you have reacted to it. And she says, because to be perfectly honest, she said, “You know, if there is anything in the chest it makes it very difficult”. And I gathered then that you know, she didn't tell me directly, but of course being a nurse I knew what she was talking about.

JR: So having the scan, that CT scan that you were quite worried about and we spoke about. .

..

P2: I was very worried about it.

JR: . . . on Monday was hinging on quite a lot of big stuff, wasn't it?

P2: Yeah, it was actually. But he said that my body had reacted well to the chemo. I'm not sure until tomorrow. Well I've got an appointment tomorrow morning with the surgeons and my daughter is coming with me, too, and then I've got one on Thursday morning with the oncologists again. And I'm not sure but they said they may possibly do another chemo before the surgery, but I haven't heard if I'm having that yet. So perhaps on Thursday I will get to know.

JR: Still a bit of unknown stuff?

P2: Still a bit unknown at the moment.

JR: So you got the results of your CT scan while you were in hospital?

P2: In fact, the day after, I was surprised because I thought they would wait until we met with them. And again there was a bit of controversy over that because the morning after this junior doctor that I had never met before came and said, “Oh well”, she says, “We won't need to be putting you through surgery”, she said. “Because it's a huge thing”, she said, “and you don't really want to have it unless you are . . .” and I thought, *Oh, they were setting me up for something here*, and that did worry me.

JR: Because that wasn't quite what you expected?

P2: No, well, no, it wasn't. But then the next . . . was it the next morning, I think? I saw M – my ordinary registrar came around and said, he said, “We are going to go ahead with the surgery”. You know, so it was all a little bit.

JR: So it was different?

P2: Different . . .

JR: What do you think the first doctor was trying to say?

P2: I don't know. I thought at first she was just trying to say that I had got probably, got some secondary's or something in my chest because it was after the CT scan. And I thought maybe she knew something I don't know you know. . . . and that worried me. But then M came breezing along and said no, no we are going ahead, we are going to have the surgery. People generally do better with the surgery, and he said we might then do three more chemos, which he had told me about.

JR: After the surgery . . .

P2: After the surgery. . . . but he said, "The thing is, your body has reacted so well, so far", he said. "We are only going to give you the one dose, the one drug".

JR: Oh, instead of the combination. . . .

P2: Instead of the combination, and that again made me wonder, but no, I have to take them. . . you know.

JR: So you have these little wonderings going on when people tell you things but you are not quite, you are not quite sure you want to ask?

P2: Yeah, I know – it's terrible isn't it?

JR: No, not at all.

P2: You see, I can talk to you about it but I can't with my family over things like that. My family are very good, don't get me wrong, but they are just very concerned and . . .

JR: We all feel protective of our family. . . . I think, you know.

P2: In the beginning they told me it was one of . . . in fact, my GP told me as well that it was one of the ones that do recur quite a lot and I have been mulling over that a lot recently.

JR: Wondering what he meant by that?

P2: Well, wondering whether he meant months or years or five years or two years. Of course, they don't know and they can't tell you, you know – that's what I'm worried about and I guess everybody is the last cancer, aye?

JR: I think sometimes it's the uncertainty of knowing.

P2: Is it? Yeah. . . .

JR: And nobody has all the answers.

P2: No, no, I know.

JR: It sounds like . . . I guess the thing I was quite interested in is that you had one doctor come in and say one thing and then M . . .

P2: And another doctor come in and say another?

JR: . . . say another? And what was the timespan space? Was that overnight?

P2: Yeah, it was overnight.

JR: Was there anything . . . so you had those discussions. Obviously the CT scan was quite an important thing in terms of what you were expecting because that was the plan, wasn't it? If you did well, the CT scan showed you had done well – you were going to go on to the next step, which was surgery. That sounds like quite a big thing during that particular hospital admission – did you feel like . . . Did you have other discussions? Did you meet with the consultant and have any conversations with them, or was it just with the registrars?

P2: No, just with the registrars.

JR: Just with the registrars, but you have got an appointment this week to follow up on some of that?

P2: Yeah, with Oncology on Thursday morning.

JR: Will you see M there or will there be another consultant?

P2: I think it will be M, I hope it's M. It should be either M or the consultant anyway, but he did say he would see me in clinic so . . .

JR: So you have seen him all the way through?

P2: Yeah, except once when he was sick and that was when I saw the consultant.

JR: Whose your consultant?

P2: KC.

JR: Oh right, you mentioned K. So thinking about the time that you were in hospital for that week, was there anything specific that you found particularly distressing? I mean, obviously there was some uncertainty around your scan, which I'm picking up was quite, was a little bit distressing – actually quite distressing for you.

P2: It was only distressing because, well, it was actually distressing because of what it might show, of course.

JR: Bit of that unknown.

P2: So yeah, sorry, I interrupted you.

JR: So was there anything else during that hospital . . . that seemed like a big thing to me.

P2: It was a huge thing for me because it all hinges on . . .

JR: It feels like a big thing, yeah.

P2: But no, as I say there was nothing that the doctors and nurses would do.

JR: Just that waiting, wondering about the scan . . . because when we talked, you talked about the scan – you were worried about the drink you had to have.

P2: Yeah, I didn't know whether you would ask about that. . . . But I'm just so . . . I get so nervous, I get so worked up about it and . . . but actually, it wasn't as bad as what I was making it out to be. I mean, I was shaking like anything, but I'd had something before and I thought that was the same fluid I was going to have. But it wasn't – it was a different liquid. I didn't manage to drink all of it but I think we was supposed to drink 600 and I think I got to 480.

JR: That's pretty good.

P2: I think it was 480 because they didn't . . . That was another thing – they didn't wake me up at the time. They should have woken me up and it was one of the nights I slept, and I didn't often sleep there for various reasons. But it was one of the nights I did sleep and I think I should have started drinking at 07:20 because the ambulance was coming at 8 o'clock so I had to start drinking.

JR: Because you had your scan at Greenlane?

P2: Yeah, I went in an ambulance and it so, it was a bit of a rush, so I had to take it in a . . . in the ambulance in a jug and my daughter came with me and she was carrying this jug (*laughing*), so it – I didn't actually – it wasn't that I couldn't finish it, it wasn't all that much, 600, but trying to get ready in case the ambulance came and trying to drink this, it was a bit of a farce really.

JR: So the other thing you mentioned was the Clexane injections.

P2: Oh, yeah.

JR: Are you still on the Clexane?

P2: Six months I've got to do it for.

JR: Really? Are you managing those alright?

P2: Yeah, it's a head thing with me this because the actual injection Clexane, I mean, I have done it so often to other people, and you don't realise but actually putting the needle in and putting the solution in it doesn't hurt. It's not – it's just those two or three minutes afterwards but I'm getting my head around it. I know I have to do it, so I'm doing it.

JR: It's one thing injecting other people – it's another thing injecting yourself.

P2: I know I'm a real wimp. . . . I'm terrible.

JR: So you mentioned sleeping was quite difficult at times when you were in hospital?

P2: I struck a bad patch. The first, my first admission, I had three lovely people and they all turned the lights off at 9 or 10 o'clock, you know. But it was bad this time and I don't want to . . . you know. . . I don't want to . . .

JR: No, it's not an uncommon thing for people to have problems sleeping because hospitals are noisy and being in a four-bedded room is . . .

P2: The thing I found difficult, I had two people who were very sick and . . . but what I found really hard this time was that they all . . . I had a space around the corner as you go into the ward just around the corner, and what I found really hard this time [was that] nobody drew their curtains at all. So I never got to look out the window the whole week; everybody had their curtains drawn. And what I found more disconcerting was that there were these signs up saying: *Visiting, please leave the ward by 8.15*. And there were people next to my bed – they brought children in at a quarter past 12 at night, and they all sat there reading the Bible. And I just . . . I was so really upset about. . .

JR: No, no it's fine.

P2: I was so upset and I kept saying to the nurses, "Can you please turn the light off," and one of them said to me, "Well, we can't yet until they have finished what they were doing or the whānau and then we have got to clean her up", and, you know . . . I found it so distressing.

JR: Did you? So that was just because people were there late and it was noisy?

P2: Yeah, it was that late. I can understand it when people are really sick and they want their family, but not with little kids at that time of night. It's not fair on the families, you know.

JR: And you were talking about the curtains were always closed around everybody the whole time?

P2: I never saw anybody. The last morning the day I was leaving – the last morning, two people left and the cleaners came in and opened all the curtains and it was just lovely.

JR: So that must make it feel very dark.

P2: Yeah, it's claustrophobic, I hated to say. . . . I don't usually complain. I'm not a complainer, you know. . . . I hated that admission.

JR: A lot of people . . . I think in four-bedded rooms a lot of people keep curtains closed around them a lot, and I often think . . . particularly in those . . . because you were in the room onto the atrium rather than on the street side, weren't you?

P2: No, I got moved, no they moved me.

JR: Did you?

P2: Yeah, I was only there for one . . . two nights, then I got moved down to the street side, but I couldn't see anything.

JR: So you moved bed spaces. No, thank you for that because I think understanding the limitations of the physical environment is really important, so I appreciate you sharing that because . . .

P2: It's not a complaint.

JR: No, it's not a complaint and this isn't about complaining. This is about trying to understand because the physical environment of a hospital has quite severe limitations and understanding what those limitations are for people is really important for us to understand, particularly for people like you who are struggling with quite a lot of stuff because of your illness. So when you are in an environment that you can't get quiet, or privacy, or whatever, or even daylight. . . .

P2: Well, it was a daylight thing for me. I just it was so claustrophobic but I . . . when we moved into that bed space on the . . . I think it was the second night, and you know there was people in the next . . . you know they were fine. And fair enough, you know, and they got to about half past nine and ten o'clock, and I said to the nurse, "I didn't realise you had open visiting on this ward". And she says, "No", she says, "We don't", she says. But that's a big problem here you know, and I kept thinking they would go and then they stayed and then they would read their Bible and the preacher would come and pray with them and . . .

JR: And pulling curtains doesn't dampen the noise, does it?

P2: No, I mean you are two feet away you know.

JR: I know, it's strange isn't it? We shut all the curtains and think no one can hear us.

P2: And there was a nice lady across from me I would have liked to have talked to, but curtains shut all the time. . . . Anyway, that's probably enough of that.

JR: No, thank you for that. So we have talked about the things that perhaps were quite challenging about being in the hospital, and I'm wondering if you could perhaps reflect on what you found useful about being in hospital. So coming out and thinking well, that was a useful thing about being in hospital. What's some good stuff that came out of it that you think that was well worth going in for? . . .

P2: It was definitely well worth going in for because of the help that they gave me – I mean, particularly with the graseby pump.

JR: So stopping your vomiting.

P2: Stopping the vomiting and not taking the pills, and I didn't have to think about it. I just didn't have the pain and I didn't have the vomiting. They treated all the symptoms I had, you know, and they reassured me about my leg. They did say it was a common thing to happen – did you know that?

JR: Yeah, it is, it is very common.

P2: I didn't recognise it for what it was in the beginning. I wish I had have known so. . . . No, it was very worthwhile. I couldn't have stayed at home anyway.

JR: So you feel you came out of the hospital feeling better?

P2: Definitely feeling better.

JR: So there was some value in going in?

P2: I've only got four pills now in the morning.

JR: Well done – that must be a relief?

P2: And I can sort my pills myself now whereas before I thought I had to take all of these things, you know, to come right.

JR: So during the time you were there they obviously rationalised your medications a bit, or changed it, so that you have got a lot less and that feels . . .

P2: And they came around every day. I mean, someone came around every day and I could talk about it, you know.

JR: Somebody from the?

P2: From the medical team, I mean.

JR: So you could check in with what was happening.

P2: And even the nurses . . . (*hesitates and looks at the digital recorder*)

JR: Go on, it's confidential, and honestly and you will just be one of many people.

P2: I found this quite funny, although my daughter didn't. . . . but anyway (*laughs*). There was a little girl, she was a junior nurse and I could tell she was a junior nurse, you know, and she came around and every day and she would tell me exactly what my pills were and you know, bless her, but the funny thing was I came off my graseby on the Thursday so they could just see how I coped, you know. . . . and while I had been on the graseby my nausea one, the Maxolon, I had been having 60mg over 24 hours.

JR: In the pump?

P2: In the pump. . . . Well, she, this little girl, brought me my tablets, bless her, and she said “. . . and this is this, and this is this, and this is your 60mg of Maxolon”. And I says, “No, I don't think so” (*laughs*) . . . Because she tipped them all out, and there is six of those, and I said, “Look, you know – don't take this the wrong way – but just go and check with the doctor and see if this is what” . . . You know.

JR: She must have been mortified.

P2: Yes, she didn't realise, you know. I mean . . . and the funny thing was one of the consultants who is a friend of mine from my ward was, you know . . . had just come in and . . . (*laughing*)

JR: I can see why your daughter didn't think it was funny.

P2: Oh, she didn't. . . . And she asked the consultant afterwards: "If mum had taken those, if she hadn't realised, what would have happened"? and this consultant says, "Well, she might have gone a bit clonic", she said, but she said it would have worn off. . . . (laughing)

JR: So obviously it didn't bother you that it had happened?

P2: No, it didn't bother me 'cos I knew exactly that the doctor had not crossed off . . . he had not done it, you know, or charted it right.

JR: But also you were able to . . . you have got enough knowledge that you could see that it wasn't right.

P2: I know, but anyone else, any other drug it could have been quite disastrous. If it hadn't been the Maxolon it would have been you know . . .

JR: It could have been . . .

P2: It could have been anything. . . .

JR: It could have been morphine, even.

P2: Anyway, bless her.

JR: Is there any reason that you think you might have to go back to hospital again?

P2: Oh, well, apart from the surgery.

JR: Apart from the surgery, yeah.

P2: That's another thing that bothers me – I mean, if I have to go, well, I will have some more chemo if this is successful, and I just sort of wonder about complications again but . . .

JR: From the chemo?

P2: Yeah, I mean I have had so many. . . . I had the pneumonia and then I had this happen and I just sort of wonder.

JR: Yeah, it knocks you about a bit.

P2: But it's not, it doesn't bother me unduly, it's just a thing that if it happens it happens.

JR: So if there was a way of managing some of these things at home would you take that option or would you prefer to go back into hospital?

P2: What sort of things are you thinking of?

JR: Things like the nausea and vomiting – if they could manage it at home, if there was a way . . .

P2: What if I had a pump at home, that sort of thing?

JR: Yeah, if things could be managed at home where you could get the help you needed, would you prefer to stay at home or would you prefer to be in hospital?

P2: Well, before this admission I would have stayed. . . . It's a hard one that because I actually felt quite confident about going in again and I needed to go in. But it depends whether it's for something like a graseby I could manage that at home.

JR: But maybe the experience of going in hospital this time wasn't quite as positive as the last?

P2: It wasn't, but it was just the one-off. It doesn't mean to say it's going to happen again.

JR: So you are not . . .

P2: I'm not put off hospitals. . . . I think there are times when you have to be there and . . .

JR: But it's nice being home.

P2: Oh, it's nice being home and in my own bed.

JR: I think it's like being at home and feeling well and being at home and feeling sick is different, isn't it?

P2: It is different and once you understand the reasoning behind why these things happen and that you know. I mean, this is not actually not my home – I have sold my house so . . . this is my daughter's house. So I have to think about buying another house once I've sort of . . .

JR: Did you have a house around here or?

P2: No, I lived in Hillsborough, so I will have to think about buying something else really.

JR: That's a big thing too, isn't it? So how do you think, you mentioned your family are perhaps dealing with your illness in a different way to you. How do you think they would feel about you going back into hospital again?

P2: I think they would be happier if I was in hospital rather than at home.

JR: Do you? Tell me why you think that?

P2: Well, we have differing things about my tablets for a start-off. K is not quite sure that I can manage, you know. Like she will come in in the morning and she will put out all my pills, you know, in neat little containers and if there is still some there when she comes home at night: "Why haven't you taken this, Mum? And why haven't . . .," you know. . . . She feels a lot more confident in the doctors than in me.

JR: Do you think she is taking quite a lot of responsibly around the caregiving aspect?

P2: Yes, she is Now she's worrying about the surgery and, you know, district nurses and things like that.

JR: Does she work full time?

P2: Yeah, and she can't take any more time off and we have got an 11-year-old granddaughter as well. I remember her saying to me: "Oh Mum, when you first started being

sick” – and I was quite sick in the beginning with nausea – she was saying, “I thought I [would] have to give up my job”, she said, “And then we would lose the house”. So it’s . . .

JR: Worrying about the big things, isn’t it, as well?

P2: Yeah, and she probably would have if I had been really ill, you know. So there is a lot to it, isn’t there?

JR: So your family are probably relieved when you go to hospital when you are not feeling 100%?

P2: I have a good friend though who I go stay with after I have chemo and she is retired. She is a retired nurse as well.

JR: Really? That’s great.

P2: I will probably go and stay with her after my surgery so then K won’t have to worry.

JR: Retired nurses together, that’s great.

P2: Yeah.

JR: So in terms of you going back to hospital, I mean, obviously you have talked a little bit about the fact that you are in between homes. And you know the issue around if you needed more care than what you could manage on your own – that would be a difficulty as well.

[Are] there any other difficulties that you can think of that if you wanted to stay at home around those times, when you are not feeling quite as well, and bringing some interventions in to make you feel better – is there anything else that you would need, do you think? Or that you would . . . you have got a young family so . . .

P2: If it was just for minor things I could stay at home.

JR: So if you were feeling like you felt last Sunday, and the care that you needed, that you got in hospital was able to be brought in here, for argument’s sake, would you have stayed here or would you have preferred to have gone to hospital?

P2: I think I would have preferred to have gone to hospital at that stage mainly because I didn’t know my . . . this thing about my leg was bothering me. If it’s just a question of controlling nausea and things, and I understand and I had the tools . . . I probably would prefer to stay at home.

JR: This might be a question that you may not be able to answer, but I was just wondering whether you have ever talked to your family about the issues around care if you weren’t, like after your surgery, you are in between your houses. I mean, you have obviously have had quite open conversations with your family around what your preferences would be?

P2: We haven’t really talked about that at the moment. I mean, we are only seeing the surgeon tomorrow, so I don’t really know a lot of the questions or answers. I haven’t talked

to my family about should I become seriously ill – that's not cropped up, the practicalities of it.

JR: Feels too hard perhaps at the moment, do you think?

P2: I don't have enough information at the moment, I don't think, to discuss this with them. And I think K, particularly, would get too upset. I think she would, but I really can't say about that.

JR: Well, I think that's it really.

P2: Is that enough for you?

JR: It's great, it's really good.

Appendix 3 Phase 2 Study Documentation

Appendix 3.1 Integration of Data

Question	Source
Circumstances surrounding the hospital admission	
WHAT CAUSED THE ADMISSION TO HOSPITAL?	
Worsening pain Uncontrolled nausea and vomiting Difficulty breathing Fatigue and exhaustion Had a temperature Constipation An infection Family not coping	Reasons for admission were considered in the literature review (see Chapter 4) and policy review (see Chapter 2) as being a major focus for identifying potentially avoidable hospital admissions, prompting recommendations to increase community resources to support patients at home. (Robinson et al., 2016; Robinson, Gott, et al., 2014)
WHAT WERE THEIR PREFERENCES FOR PLACE OF CARE WHEN THEY BECAME UNWELL AT HOME?	
Preference to come to hospital this time	Evidence from the literature (see Chapter 1.2) and policy review (see Chapter 2) suggests that hospital is rarely chosen as the preferred place of care. (Robinson et al., 2016)
WHAT IS MOST IMPORTANT FOR PATIENTS ON THE DAY OF ADMISSION?	
Stay at home Get help from health professionals Stay with family Get treatment for the illness Relief from symptoms Information about why they are unwell Get tests and investigations Avoid being a burden on family	Priorities at the time of being admitted to hospital may influence preferences for place of care (see Chapter 1.2). Indeed, patient priorities may well be aligned more with what the hospital can offer rather than the elements described in the “good death” (see Chapter 2.2), such as being with family and staying at home. Instead Phase 1 (see Chapter 7) showed that patients’ priorities at the time of admission were more aligned with the technology and expertise that the hospital could offer. (Robinson, 2015)

DO COMMUNITY SERVICES (including the nature of the relationship with GP) INFLUENCE THE DECISION TO COME TO HOSPITAL?	
Making the decision to come to hospital Services involved and contact made prior to the admission? Having a good relationship with their GP – trust and listening	There is increasing focus in policy (see chapter 2) and practice to increase resourcing to community services in order to reduce or prevent admissions and death in the hospital setting (see Chapter 1.3).
WHAT DO PARTICIPANTS THINK THEY NEED TO ENABLE THEM TO REMAIN AT HOME RATHER THAN COME TO HOSPITAL?	
Could a home visit from the GP enable patients to remain at home? Do family carers who know what to do during a period of acute illness enable patients to remain at home? Does access to equipment at home enable patients to remain at home? Does a home visit from hospice enable patients to remain at home? Was there anything that could have enabled them to remain at home?	Timely access to care, including care which is provided by family and services such as hospice and the general practitioner, are considered as essential to support people at home. Caring for people in their own home as they near the end of their life is a key element to achieving “good dying” (see Chapter 2.2).
DOES A PATIENT’S UNDERSTANDING OF THEIR ILLNESS OR LEVEL OF FUNCTION INFLUENCE THE DECISION TO COME TO HOSPITAL?	
What do patients understand about their illness? What is their current level of function?	
WHAT ARE PATIENTS’ PERCEPTIONS OF THE NECESSITY OR AVOIDABILITY OF THE HOSPITAL ADMISSION?	
Was the admission avoidable? Was the admission unnecessary?	Findings from the policy review showed that hospitals are positioned in palliative care using the “good death” (see Chapter 2.2) as a benchmark. Indeed, elements of a good death are used to support a focus on reducing or avoiding hospital admissions.
Preferences to return to hospital	
DOES THE LIVING SITUATION INFLUENCE A PERSON’S PREFERENCE TO RETURN TO HOSPITAL?	

<p>Who do they normally live with? Who do they rely on most to help them at home? What does this person help them with the most? How do they rate the health status of the carer? What is the deprivation of patients being admitted to hospital?</p>	<p>Living alone is considered to be one of the barriers to achieving the “good death” (see Chapter 2.2). Equally having an elderly carer with poor health may make remaining at home more difficult (see Chapter 1.3). These factors therefore may influence a person’s preference to return to hospital rather than remain at home.</p>
<p>DO THE BENEFITS OF BEING IN HOSPITAL INFLUENCE PATIENTS’ PREFERENCES TO RETURN TO HOSPITAL?</p>	
<p>Feeling safe Getting/feeling better Getting help to manage at home Talking to other patients</p>	<p>Data from Phase 1 revealed that the benefits of being in hospital extended beyond the treatment they received.(Robinson, Gott, Gardiner, et al., 2015) Participants identified a range of concepts related to benefits that were included in the Phase 2 questionnaire (see Chapter 7).</p>
<p>DOES FEELING SAFE IN HOSPITAL INFLUENCE PATIENTS PREFERENCES TO RETURN TO HOSPITAL?</p>	
<p>Being monitored and observed by staff Being cared for by health professionals Getting information about the illness make patients Getting help quickly when needed Do staff who appear busy make patients feel unsafe?</p>	<p>Feeling safe was identified in Phase 1(Robinson, Gott, Gardiner, et al., 2015) as being a major benefit of being in hospital (see Chapter 7). The concept feeling safe was explored in more detail using key concepts identified by participants. This was an opportunity to not only identify predictors related to “feeling safe” but to also explore substantiate the elements of the “feeling safe” concept, which participants had identified in Phase 1.</p>
<p>DO PATIENTS’ EXPERIENCES OF BURDENS INFLUENCE THEIR PREFERENCES TO RETURN TO HOSPITAL?</p>	
<p>Being away from family and friends Being in multi-bed rooms Sharing bathrooms with other patients Staff are busy Being around sick people Being bored and lonely</p>	<p>Phase 1 findings revealed that patients with palliative care needs experienced a range of difficulties being in hospital (see Chapter 7.4). A major theme identified from Phase 1 data were burdens related to the physical environment and cultural milieu of the hospital setting.(Robinson, Gott, Ingleton, et al., 2015) The questions listed here were</p>

<p>Can't leave the ward when I want to Not involved in the decisions regarding care Visitors coming and going all the time Cost of hospital parking Too noisy</p>	<p>developed from these findings.</p>
<p>WHEN DO PATIENTS EXPECT THEY WILL NEED TO RETURN TO HOSPITAL?</p>	
<p>When they can no longer care for themselves When their family can't care for them at home When their illness gets worse If their symptoms get worse When they become unwell again</p>	
<p>WHAT IMPORTANCE DO PATIENTS PLACE ON CHOOSING PLACE OF CARE AT THE END OF LIFE?</p>	
<p>Is it important to patients that they are able to choose their place of care? Where would patients prefer to be cared for at the end of their life?</p>	

Appendix 3.2 Study Protocol

(Included in Health and Disability Ethics Committees application)

Title: The role of the hospital in palliative care with a focus on the benefits and burdens of hospital admissions and their impact on preferences for place of care during a period of acute illness: Phase 2

Investigator: Jackie Robinson (JR), Palliative Care Nurse Practitioner, Auckland District Health Board (ADHB) and PhD Candidate, School of Nursing, University of Auckland

Supervisor: Professor Merryn Gott, Director of Research, School of Nursing, University of Auckland

Background

An integrative review of the literature has shown that there is significant burden associated with hospital admissions for patients with palliative care needs.(Robinson, Gott, et al., 2014) Factors such as poor communication with health professionals, symptom burden, and an inadequate environment are often a focus for patient and family dissatisfaction with palliative care in the hospital setting. However, there is a paucity of research exploring the benefits of hospital admissions for those with palliative care needs.

The first phase of this PhD study explored the benefits and burdens of hospital admissions from the perspectives of patients with palliative care needs(Robinson, Gott, Gardiner, et al., 2015) admitted to an acute hospital. Participants identified a number of benefits that extended beyond the treatment they received including a sense of being cared for and feeling safe, receiving care to manage at home, relief for family, and a feeling of “getting better” and “feeling better”. Furthermore, while most participants expressed some level of burden associated with being in hospital, most reported their preference to come to hospital even if they had been able to access the care they received in hospital at home.

The findings from Phase 1 began to challenge the practice norms that underpin palliative care and informed a review of national policy in palliative care. The findings from this review identified a number of factors associated with the problematization of a “good death”, which drives the development of policy and informs much of the research agenda in palliative care. The assumption that a good death is not achievable in a hospital setting, nor the preferred place of care or place of death for patients, impacts on policy recommendations, many of which are designed to avoid hospital admissions. It has been suggested that without a better understanding of patient priorities and preferences at the end of life, there is a risk that the model of palliative care outlined in policy will be applied “blanket-fashion” and prove to be ineffective and inequitable.(Lloyd, 2011) Ideals such as patient choice and patient preferences with a focus on home as the ideal place of care and place of death, combined with the pressure to avoid hospitalisation and reduce hospital costs by avoiding unnecessary admissions, is evident throughout palliative care policy.

Accepting that a core role of the hospital is to care for those with a life limiting illness, death in hospital is likely to remain relatively high. However, the ongoing emphasis on patient

preferences for place of care and place of death, along with a focus on the inadequacies of the hospital environment to provide good palliative care with little attention to the benefits of being in hospital, risks creating inequities for patients with a life limiting illness accessing hospital level care when needed.

Aim

The aim of this study is to investigate the role of the acute hospital with a focus on benefits and burdens of hospital admissions and how these influence preferences for place of care during a period of acute illness.

Questions

1. Does the patient's living situation influence a decision to come to hospital during a period of acute illness?
2. Does a patient's understanding of their illness influence the way in which they perceive the role of the hospital during a period of acute illness?
3. How do community services influence the need to be admitted to hospital during a period of acute illness?
4. How accessible and effective is the General Practitioner in providing care at home and does this impact on the perceived role of the hospital?
5. What do participants believe they need in terms of service support to enable them to remain at home during a period of acute illness?
6. Does the reason for admission influence patients' perceptions of needing to come to hospital during a period of acute illness?
7. What is most important for patients during a period of acute illness at home?
8. What are the perceived benefits of being in hospital and do they influence patients' preferences for place of care and place of death?
9. Does feeling safe in hospital during a period of acute illness influence patients' preferences for place of care and place of death?
10. Do patients' experiences of the social environment of a hospital influence their preferences for place of care and place of death?
11. What are patients' perceptions of the necessity of admission to hospital during a period of acute illness?
12. When and why do patients expect they will need to return to hospital as their illness progresses?

Study Design

Non-experimental study designs are used to measure the relationship between two or more variables. (Robson, 2011) Using a non-experimental fixed design, this study will use a questionnaire survey to collect data. Questionnaires vary in a number of ways including the method of contacting people, the vehicle of delivery, and the way in which they are administered. This study will use a face-to-face delivery of the questionnaire. Response rates for interviewer delivered questionnaires are considered to be one of the strengths of the face-to-face mode of delivery. (Robson, 2011) The questionnaire has been developed using the findings from Phase 1 and informed by the results of the policy review.

Validity and reliability

A pilot study testing the survey tool will be carried out with 20 participants to examine validity and reliability. Content validity examines the extent to which the study concepts are represented by the items in the questionnaire. A number of factors need to be considered in order to achieve content validity, including an outline of the measurement aim, target population, concepts to be considered, interpretability of items, and development of the tool. Details of item selection and reduction as a result of the pilot study will be documented for content validity.

Reliability relates to the consistency of a measure. Correlation coefficient testing will be carried out for internal consistency of the questionnaire results. Equivalence through inter-rater reliability testing will be carried out to test the relevance of each item on the questionnaire. The process and results of this will be documented and included in the findings.

Sampling

Quantitative research uses a statistical approach to decide on an adequate sample size and samples are usually much larger than that of qualitative studies. The population needs to be large enough to meet the requirements of statistical tests. For the purposes of this research a stratified sampling method will be used, selecting the sample based on a series of characteristics identified during the first phase of the study. These parameters are based on diagnosis (cancer and non-cancer), age (<65 years or not), prognosis (death within six months or not), length of stay in hospital (<4 days or not), and living situation (lives alone or not). These characteristics have been known to have an impact on a patient's experiences of palliative care and their preferences for place of care. After discussion with a statistician and a review of the required statistical testing, a sample size of 120 will be recruited.

Sampling frame

A non-randomised approach to sampling will be used. The target population consists of patients with palliative care needs who meet one of the Gold Standards Framework Prognostic Indicators for palliative care need who have been in hospital for longer than 72 hours. General Medicine and Oncology were the two services that the majority of participants were recruited from in Phase 1, therefore sampling will be limited to patients from these services. Participants identified as likely to be discharged within the next 24 hours will be invited to participate in the study.

AMENDMENT: recruitment will be extended to include all adult wards throughout Auckland City Hospital (ACH). This is to increase the sampling frame of participants with a non-cancer diagnosis, particularly those with end-stage respiratory disease.

Auckland City Hospital experienced 123,996 discharges over a 12-month period from 1st July 2013 to 30th June 2014. General Medicine made up 10% (12,674) and Oncology nearly 3% (3,503) of the total number of hospital discharges. A previous census study of hospital inpatients at Auckland City Hospital showed that 31% of patients on the General Medical wards and 66% of patients on the Oncology ward met one of the Gold Standard Prognostic Indicators for palliative care need. Those patients readmitted during the recruitment period will not be surveyed again. Data related to readmissions in this specific group of patients is

currently unknown. In addition, recruitment will be limited to those patients discharged between Monday and Friday although the majority of discharges occur during business hours.

The potential sampling frame therefore is estimated to be made up of approximately 3,000 discharges during the six-month recruitment period. Factors that may impact on the size of the sampling frame are patient readmissions (participants will only be surveyed once) and length of stay (participants in hospital less than 72 hours will be excluded). A total of 120 participants will be recruited to the study over a six-month period between 31st August and 31st May 2016.

Recruitment

A daily list of admissions to all adult wards at ACH will be screened for eligibility by JR using the computer-based clinical systems to review clinical notes (CONCERTO and 3MView). Using the Gold Standards Framework Prognostic Indicator Guide patients with palliative care needs will be identified. To ensure patient confidentiality no data will be collected during the screening process. JR is a hospital employee and works under the staff confidentiality agreement.

A morning visit to each ward will be carried out and patients who meet the GSFPIG who are being discharged that day will be identified through discussion with the Charge Nurse or one of the General Medicine Clinical Nurse Specialists. The nurse responsible for the care of the patient will approach the patient to see if they are interested in participating in the study and written participant information. One of the six Clinical Nurse Specialists from the Hospital Palliative Care Team or JR will obtain written consent prior to the survey.

Data collection

The questionnaire will be delivered face-to-face with participants by JR or one of the CNSs from the Hospital Palliative Care Team (HPCT). All researchers are also employed as nurses in the HPCT. To avoid role conflict any nurse involved in the care of the patient during the study admission will not also be involved in data collection for that particular participant. Baseline data such as date of admission, date of discharge, diagnosis and age will be collected directly from the clinical notes. All those involved in collecting clinical data will be ADHB employees working under a confidentiality employment contract. Data will be cleaned and coded into an SPSS database.

Data analysis

The independent samples *t*-test will be used to compare sample means from two independent groups for an interval-scale variable (such as age) when the distribution is approximately normal. Where the independent group uses an ordinal scale (such as a Likert scale) or where the *t*-test assumptions (normalised) are not met with interval-scale variables, the Mann-Whitney test will be used to compare two independent samples. The study design and development of the questionnaire has been reviewed by a statistician for quality and applicability in answering the research questions.

Ethics

Informed consent – Before the questionnaire survey starts the study will be discussed fully and written information provided. Opportunities to withdraw from the study without

explanation will be provided to each participant. Written consent to participate in the study will be obtained prior to the survey. Due to the deterioration of physical health in the study population, a fluctuating level of cognition is not uncommon. As a result, obtaining informed consent can be a challenge. This issue will be addressed by periodic checking of the patient's ability to participate throughout the interview.

Confidentiality – The privacy of participants will be maintained at all times. Any data collected will not identify individual participants. In addition, the way in which results are reported will not identify individual participants. Storage of paper documentation will be securely stored at the School of Nursing (UoA). Electronic data will be password protected. Access to the data will be limited to the researchers.

Access to clinical information will be limited to JR who as an ADHB employee will be working under the ADHB Confidentiality Agreement. During the survey participant's privacy will be maintained by keeping curtains pulled around bed spaces during the interview and where possible and practical interviews will take place in a private meeting room on the ward.

Rights to withdraw – The participant's right to withdraw will be highlighted during the consent process. Participants will be reminded that the survey can be discontinued at any time.

Role conflict – The researcher (JR) and the CNSs involved in data collection are employed by the Auckland District Board. Some participants may have been referred to the HPCT during the study admission. A conflict of interest arises as a result of the researcher having a dual role: as researcher and as a health professional involved in the participant's care during the study admission. This could result in the patient feeling pressured into consenting for fear that their care may be compromised if they decline to participate. Furthermore, participants may provide inaccurate information about their experiences knowing that the researcher is also a hospital employed health professional.

The risk of conflict in roles will be mitigated by the researcher explaining the intentions of each visit to the patient and clarifying their role. Those who have been involved in the care of the patient in their capacity as a member of the HPCT during the study admission will NOT be involved in the data collection process.

Vulnerability of study population – In view of deteriorating physical health, along with the presence of symptoms that may be causing some discomfort, involving patients with a life limiting illness in research can be tiring for participants. Conversations exploring participants feelings about the impact of hospitalisations on themselves and their family may raise sensitive issues related to the knowledge that time may be short. For some people this may be distressing. Furthermore exploring patient's experiences of care in hospital may cause distress particularly if the experience has not been positive.

The researchers will use their skills and knowledge in palliative care to ensure participants are well supported throughout the study period. They all have well developed communication skills and are experienced in dealing with sensitive issues and will ensure that participants are well supported during the interviews. If participants are seen to be tiring or becoming upset during the interview, the researcher will offer to discontinue the interview. When necessary they will be offered referrals to participants that may benefit from ongoing emotional or practical support.

Māori participants

Using the guiding Treaty principles of partnership, participation and protection the rights of Māori will be respected throughout the research project by:

Partnership – recognition of Māori as partners in research and respect for their cultural knowledge, values and beliefs. This will be particularly important when interviews are being held in a participant’s home. Involving whānau as a support to participants during the interview will be offered.

Participation – a Māori advisor has been consulted to ensure the research design is appropriate for Māori. For example, using face-to-face interviews is suggested to be more appropriate for Māori participants.

Protection – this project is relevant to improving Māori health outcomes. Despite the fact that Māori are over represented in the incidence of cancer and chronic diseases, they continue to be under represented in referrals to palliative care services. Exploring the experiences of hospital admissions for Māori patients who have a life limiting illness will contribute to a better understanding of why this inequity currently exists in palliative care.

Consultation with the ADHB Māori Ethics Advisor (Helen Wihongi) was made during Phase 2. Māori participants will be offered the opportunity to have Kaumātua present during the interview if one is available. Participants will be given the opportunity to withdraw from the study if Kaumātua are unavailable and their preference is to have one present. Participants will be given the opportunity to have whānau present during the interview.

Table 1

Inclusion Criteria

Inclusion criteria
Meets one of the GSF prognostic indicators
Aged over 18 years
Speaks English
Within 24 hours of discharge

Appendix 3.3 Ethics Approval and Amendment



Health and Disability Ethics Committees
Ministry of Health
Freyberg Building
20 Aitken Street
PO Box 5013
Wellington
6011

0800 4 ETHICS
hdec@moh.govt.nz

21 August 2015

Mrs Jackie Robinson
University of Auckland
Faculty of Medical and Health Science
School of Nursing
Park Road
Grafton, Auckland 1142

Dear Mrs Robinson

Re:	Ethics ref:	15/CEN/109
	Study title:	A mixed methods study exploring the role of the hospital in palliative care with a focus on the benefits and burdens of hospital admissions for patients with palliative care needs and its impact on their preferences for place of care.

I am pleased to advise that this application has been approved by the Central Health and Disability Ethics Committee. This decision was made through the HDEC-Expedited Review pathway.

Conditions of HDEC approval

HDEC approval for this study is subject to the following conditions being met prior to the commencement of the study in New Zealand. It is your responsibility, and that of the study's sponsor, to ensure that these conditions are met. No further review by the Central Health and Disability Ethics Committee is required.

Standard conditions:

1. Before the study commences at *any* locality in New Zealand, all relevant regulatory approvals must be obtained.
2. Before the study commences at *a given* locality in New Zealand, it must be authorised by that locality in Online Forms. Locality authorisation confirms that the locality is suitable for the safe and effective conduct of the study, and that local research governance issues have been addressed.

Non-standard conditions:

1. The addition of the version number and document date to footer of the PIS/CF is required.
2. Please include Maori support contact details to the PIS/CF.

Appendix 3.4 Participant Information Sheet



The University of Auckland
School of Nursing
Level 2
Building 505
85 Park Road

The role of the hospital in the care of patients with a serious illness

*For any further information or questions, please contact: Jackie Robinson, ph: (09) 3074949 extn 23918
Professor Merryn Gott, ph: (09) 923 1655 extn 81655*

Participant Information Sheet

You are invited to take part in a study which explores your beliefs about the role of the hospital in caring for you when you are unwell. Whether or not you take part is your choice. If you don't want to take part, you don't have to give a reason, and it won't affect the care you receive. If you do want to take part now, but change your mind later, you can pull out of the study at any time.

This Participant Information Sheet will help you decide if you'd like to take part. It sets out why we are doing the study, what your participation would involve, what the benefits and risks to you might be, and what would happen after the study ends. We will go through this information with you and answer any questions you may have. You do not have to decide right now whether or not you will participate in this study. Before you decide you may want to talk about the study with other people, such as family, whānau, friends or healthcare providers. Feel free to do this.

If you agree to take part in this study you will be asked to sign the Consent Form on the last page of this document. You will be given a copy of both the Participant Information Sheet and the Consent Form to keep. This document is four pages long, including the Consent Form. Please make sure you have read and understood all the pages.

What is the purpose of the study?

The purpose of this study is to explore your beliefs about the role of the hospital in caring for you during a period when you have been unwell. The findings from this study will help us to understand the benefits and burdens of being in hospital for patients with illnesses like yours. This is a PhD study being undertaken by Jackie Robinson who is also a palliative care nurse at Auckland Hospital. This study has been approved by the Health and Disability Ethics Committees and the Auckland District Health Board Research Office.

What will my participation in this study involve?

If you choose to participate in this study you will be asked to complete a questionnaire survey with assistance from a researcher who is also a palliative care nurse in the hospital. You have been chosen because you have recently been in hospital with a serious illness. During the survey you will be asked questions about your recent experience of being unwell at home,

what it was like being in hospital and your preferences regarding place of care. The survey should take about 30 minutes to complete and will take place on the ward on or near the day you are being discharged from hospital. In addition, information about you and your illness will be collected from your clinical notes.

What are the possible benefits and risks of this study?

There are no specific risks associated with taking part in this study however some people may find it distressing answering questions about their illness. If needed, the researchers can talk to you about referrals to services that can support you and your family. If you find the questions upsetting, you can stop the interview without giving a reason. Participating in this study will give you the opportunity to express your views about being in hospital. Your participation may also help to inform the care that other people receive in the future.

Who pays for the study?

There is no cost to you being involved in this study.

What are my rights?

Being involved in this study is your choice. You are free to decline to participate or withdraw from the study at any time, without needing to provide a reason. This will not affect the care you receive. You have the right to access information about yourself, which has been collected as part of the study.

What happens after the study or if I change my mind?

The answers you provide to the questions will be recorded by the researcher on the survey form. Results from the study will be reported in a way that you will not be identifiable. All completed surveys and other information will be stored in a locked cupboard and on a password protected computer at the University of Auckland for 10 years after which all files will be destroyed. The findings will be reported in a range of professional journals and conferences. It will also be written into a report (thesis) for completion of the researcher's PhD study. A summary of the findings will be made available to you upon request.

Who do I contact for more information or if I have any concerns?

If you have any questions, concerns or complaints about the study at any stage, you can contact:

- Principal Investigator: Jackie Robinson (09) 3074949 extn 23917 or email j.robinson@auckland.ac.nz
- PhD Supervisor: Professor Merryn Gott (09) 923 1655 extn 81655
- Head of School of Nursing: Associate Professor Judy Kilpatrick 09 373 2897

For Māori support please contact:

- He Kamaka Wairoa – ADHB Māori Health: Patrick Taylor (09) 3074949

If you want to talk to someone who isn't involved with the study, you can contact an independent health and disability advocate on:

Phone: 0800 555 050
Fax: 0800 2 SUPPORT (0800 2787 7678)
Email: advocacy@hdc.org.nz

You can also contact the Health and Disability Ethics Committee (HDEC) that approved this study on:

Phone: 0800 4 ETHICS
Email: hdecs@moh.govt.nz

Consent Form

This form will be kept for a period of 6 years

Project title: “The role of the hospital in the care of patients with a serious illness”

Names of Researchers: Jackie Robinson j.robinson@auckland.ac.nz and Professor Merryn Gott m.gott@auckland.ac.nz

Please tick to indicate you consent to the following

I have read, and I understand, the Participant Information Sheet.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I have been given sufficient time to consider whether or not to participate in this study.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I have had the opportunity to use a legal representative, whānau / family support or a friend to help me ask questions and understand the study.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I am satisfied with the answers I have been given regarding the study and I have a copy of this consent form and information sheet.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time without this affecting my medical care.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I consent to the research staff collecting and processing my information, including information about my health.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
If I decide to withdraw from the study, I agree that the information collected about me up to the point when I withdraw may continue to be processed.	Yes <input type="checkbox"/>	No <input type="checkbox"/>
I agree to an approved auditor appointed by the New Zealand Health and Disability Ethics Committees, or any relevant regulatory authority or their approved representative, reviewing my relevant medical records for the sole purpose of checking the accuracy of the information recorded for the study.	Yes <input type="checkbox"/>	No <input type="checkbox"/>

I understand that my participation in this study is confidential and that no material, which could identify me personally, will be used in any reports on this study. Yes No

I know who to contact if I have any questions about the study in general. Yes No

I understand my responsibilities as a study participant. Yes No

I wish to receive a summary of the results from the study. Yes No

Declaration by participant:

I hereby consent to take part in this study.

Participant's name: _____

Signature: _____

Date: _____

Declaration by member of research team:

I have given a verbal explanation of the research project to the participant, and have answered the participant's questions about it.

I believe that the participant understands the study and has given informed consent to participate.

Researcher's name: _____

Signature: _____

Date: _____

Appendix 3.5 Questionnaire Survey

Pre Survey data to be completed by interviewer

Interviewer's initials.....

Date survey completed.....

Male Female

Patient identifier

Date of birth.....

Age in years.....

Residential address.....

NZDep2013 (office use only).....

Ethnicity: NZ European Māori Cook Island Māori Pacific Island Chinese Indian Other (state)

.....

Admitting Service: Radiation Oncology Medical Oncology General Medicine

Diagnosis:	Cancer	<input type="checkbox"/>	Non-cancer (GSF)	<input type="checkbox"/>	Co-morbidities	Yes/No	<input type="checkbox"/>
Primary:	Lung	<input type="checkbox"/>	Heart disease	<input type="checkbox"/>	Cardiac		<input type="checkbox"/>
	Breast	<input type="checkbox"/>	COPD	<input type="checkbox"/>	Respiratory disease		<input type="checkbox"/>
	Prostate	<input type="checkbox"/>	Renal disease	<input type="checkbox"/>	Stroke		<input type="checkbox"/>
	Colorectal	<input type="checkbox"/>	Parkinson's	<input type="checkbox"/>	Cancer		<input type="checkbox"/>
	Melanoma	<input type="checkbox"/>	MS	<input type="checkbox"/>	Diabetes		<input type="checkbox"/>
	UGI	<input type="checkbox"/>	Dementia	<input type="checkbox"/>	PVD		<input type="checkbox"/>
	Gynae	<input type="checkbox"/>	Stroke	<input type="checkbox"/>	CVD		<input type="checkbox"/>
	Other	<input type="checkbox"/>	Other	<input type="checkbox"/>	Mental health		<input type="checkbox"/>
					Dementia		<input type="checkbox"/>
					Chronic liver disease		<input type="checkbox"/>
					Musculo-skeletal disorders		<input type="checkbox"/>
					Substance abuse		<input type="checkbox"/>
					Chronic renal disease		<input type="checkbox"/>

Entry to hospital via: Emergency department	<input type="checkbox"/>	Palliative Care Alert: None	<input type="checkbox"/>
Assessment and Planning Unit	<input type="checkbox"/>		S <input type="checkbox"/>
Outpatient clinic	<input type="checkbox"/>		C <input type="checkbox"/>
Oncology day stay	<input type="checkbox"/>		N <input type="checkbox"/>
Other	<input type="checkbox"/>		H <input type="checkbox"/>
			W <input type="checkbox"/>

Date and time of presentation to hospital (CMS).....

Primary presenting complaint as recorded in admission notes (multi select)			
Gastrointestinal problems* <input type="checkbox"/>	Lung problems** <input type="checkbox"/>	Pain <input type="checkbox"/>	Reduced performance status <input type="checkbox"/>
Disease progression <input type="checkbox"/>	Dehydration <input type="checkbox"/>	Infections <input type="checkbox"/>	Social causes/unmet care needs <input type="checkbox"/>
Kidney failure <input type="checkbox"/>	Heart problems*** <input type="checkbox"/>	Frailty**** <input type="checkbox"/>	
*includes nausea/vomiting, diarrhoea, constipation and bowel obstruction			
**includes dyspnoea, pleural effusion, pneumonia, PE			
***includes angina, decompensated heart failure			
****includes fractures, falls, (frailty)			

Karnofsky Score at time of survey (please circle) 0 10 20 30 40 50 60 70 80 90 100

Proposed management plan as recorded in admission notes			
IV Hydration <input type="checkbox"/>	Change of analgesics <input type="checkbox"/>	IV antibiotics <input type="checkbox"/>	Oxygen therapy <input type="checkbox"/>
Urinary catheterisation <input type="checkbox"/>	Blood transfusion <input type="checkbox"/>	Nutrition (NG/TPN) <input type="checkbox"/>	Thoracentesis <input type="checkbox"/>
Paracentesis <input type="checkbox"/>	Surgery <input type="checkbox"/>	Stenting <input type="checkbox"/>	Change in medication (other) <input type="checkbox"/>
Investigations* <input type="checkbox"/>	Radiotherapy <input type="checkbox"/>	Chemotherapy <input type="checkbox"/>	Bisphosphonates <input type="checkbox"/>
*includes imaging, biopsy, gastroscopy, colonoscopy, blood tests etc			
Hjermstad, et al., (2013)			

Study Title: What is the role of the hospital in the care of patients with a life limiting illness?

Researcher: Jackie Robinson, PhD Student at the School of Nursing, University of Auckland and Nurse Practitioner at Auckland City Hospital

Supervisor: Professor Merryn Gott, Director of Research at the School of Nursing, University of Auckland

The aim of this questionnaire survey is to look at your beliefs about the role of the hospital in your care and management of your illness. You will be assisted to complete the survey by a nurse who works at the hospital and it should take about 20 minutes to complete. The nurse will ask you questions about how you felt before you came into hospital, your thoughts about your recent hospital admission and a few questions related to possible admissions to hospital in the future.

Your responses will be treated in confidence and the findings will be presented in such a way that your identity cannot be identified.

Participating in this survey will **not** affect your care in hospital now or during any subsequent admissions to hospital.

Please try to answer every question that you can. There are no right or wrong answers. Your response to the questions is unique to you and reflects your personal experiences about being in hospital. We hope that the findings from this research will help to improve healthcare services for people with illnesses just like yours.

1. Where were you staying prior to this admission?

- a. Home
- b. Hospice
- c. Aged care facility
- d. Another hospital
- e. Other (please specify).....

2. If you could have, would you have preferred to stay where you were or come to hospital?

- a. Stay where I was
- b. Go to hospital
- c. Not sure

3. Who do you normally live with? (multi-select)

- a. I live on my own
- b. I live with my parents
- c. I live with my spouse/partner
- d. I live with my children
- e. I live with someone else (please state).....

4. Who do you rely on the most to help you at home?

- a. My spouse/partner
- b. My parents
- c. My children
- d. I live in a care facility
- e. No-one, I can look after myself

5. What do they help you with the most?

- a. Household tasks such as shopping, meal preparation, cleaning, transport
- b. Personal cares such as washing, toileting, dressing and medications
- c. Emotional support
- d. Financial assistance
- e. Something else (specify).....
- f. I don't need any help

6. Thinking about the person who helps you the most at home what is the state of their health with 0 being poor health and 5 being excellent health. (please circle the answer on the scale below)

0	1	2	3	4	5	N/A
Poor						Excellent

7. What is your understanding of your current health?

- a. It will get better eventually
- b. It will never get better and in time will get worse
- c. It will stay the same
- d. I don't know

8. Who decided that you should come to hospital this time?

- a. I did
- b. My family
- c. General Practitioner
- d. Hospice nurse/doctor
- e. Ambulance crew
- f. Care facility nursing staff (if came from aged care facility or hospice)
- g. Other (please specify)

.....

9. Which services did you have supporting you at home prior to this admission to hospital? (circle as many as are applicable)

- a. General practitioner
- b. District nurses
- c. Hospice
- d. Home help
- e. I had no services supporting me at home
- f. I live in an aged care facility

10. Thinking about the week prior to this admission to hospital, which health care provider did you have contact with?

- a. General Practitioner
- b. District nursing
- c. Hospice
- d. Home help
- e. Ambulance
- f. Other (please specify)
- g. I had no contact from any health care provider

11. Which services did you have contact with on the day of admission to hospital?

- a) General practitioner
- b) District nursing
- c) Hospice
- d) Home help
- e) Ambulance
- f) Other (please specify).....
- g) I had no contact with any service

12. Are you registered with a General Practitioner?

Yes No (if you answered no to this question skip this page and move on to Question 14)

13. Thinking specifically about the service you receive from your General Practitioner, how much do you agree with the following statements?

a	My GP will do home visits if I need it	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
b	My GP is available for me out of hours including weekends	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
c	My GP costs too much money	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree

14. Thinking specifically about the relationship you have with your General Practitioner, how much do you agree with the following statements?

a	I have a very good relationship with my GP	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
b	My GP has a good understanding of my illness	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
b	I trust my GP will know what to do when I get sick at home	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
c	My GP listens and discusses everything with me fully	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree

15. Thinking about this recent hospital admission and what may have enabled you to stay at home (or aged care facility) instead of coming to hospital, how much do you agree or disagree with the following statements?

a	If my GP had visited me at home I could have stayed at home	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
b	If my family knew what to do to look after me I could have stayed at home	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
c	If I could have accessed equipment I could have stayed at home	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
d	If I could have accessed medication I could have stayed at home	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
e	If the hospice had visited me at home I could have stayed at home	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
f	Was there anything else that you think could have helped you stay at home?	Free text				

16. Thinking about the reasons why you came into hospital this time, how much do you agree or disagree with these statements?

a	I came to hospital because the pain got worse	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
b	I came to hospital because I was nauseous and vomiting	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
c	I came to hospital because I had trouble breathing	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
d	I came to hospital because I had	1	2	3	4	5

	no energy and was exhausted	Strongly disagree	Disagree	Neither	Agree	Strongly agree
e	I came to hospital because I had a temperature	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
f	I came to hospital because I was constipated	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
g	I came to hospital because I had an infection	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
h	I came to hospital because my family were not coping with me	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
i	Were there any other reasons why you came to hospital?	Free text				

17. Thinking about the day you came to hospital please rate the following statements. It was most important:

a	It was most important that I stayed at home (or ACF)	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
b	It was most important that I got help from health professionals	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
c	It was most important that I was with my family	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
d	It was most important that I got treatment for my illness	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
e	It was most important that I got treatment for the symptoms I had	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
f	It was most important that I got information from the hospital about why I was unwell	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
g	It was most important that I got tests and investigations to find out what was happening	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
h	It was most important that I was not a burden for my family	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
i	It was most important that I went to hospital	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree

18. Thinking about the benefits of being in hospital this time please circle the number that reflects how strongly you agree or disagree with each of the following statements. A benefit of being in hospital was that:

a	I got better while I was in hospital	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
b	I feel better now compared to when I was admitted to hospital	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
c	During this admission I got help to manage at home	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
d	During this admission I enjoyed talking to other patients on the ward	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
E	Where there any other benefits of being in hospital?	Free text				

* includes getting equipment, information about illness, education about managing illness, referrals to community services

19. Thinking how you felt when you were in hospital this time, how much do you agree with the following? Please circle the number that reflects how strongly you agree or disagree with each of the following statements:

A	Being monitored and observed by the ward staff makes me feel safe in hospital	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
B	Being looked after by doctors and nurses makes me feel safe in hospital	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
C	Getting information about what was happening to me made me feel safe in hospital	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
D	Getting help from staff quickly when I need it makes me feel safe in hospital	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
E	When the staff are busy it makes me feel unsafe in hospital	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
F	When staff don't check on me regularly I feel unsafe in hospital	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
G	When I can't get the help I need quickly from staff I feel unsafe in hospital	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
H	When I don't understand what is happening with my illness I feel unsafe	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree

20. Thinking now about some of the difficulties associated with being in hospital please circle the number that reflects how strongly you agree or disagree with each of the following statements:

A	I find it difficult being away from my family and friends	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
B	I find it difficult sharing a room with other patients	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
C	I find it difficult sharing a bathroom with other patients	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
D	I feel uncared for when the doctors and nurses are so busy	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
E	I find it difficult being around sick people while I am in hospital	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
F	I get bored when I am in hospital	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
G	I get lonely when I am in hospital	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
H	I find it difficult when I can't leave the ward whenever I want to	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
I	I would find it difficult if the doctors and nurses didn't involve me in decisions about my care	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
J	I find it difficult when visitors are coming and going all the time	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
K	I find the cost of parking makes it difficult for my family to visit	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
L	I find the hospital is too noisy for me	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree

M	Is there anything else you find difficult about being in hospital	Free text
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21. Thinking about how you feel overall about this particular admission to hospital, please circle the number that reflects how strongly you agree or disagree with the following statements:

A	I feel that this admission could have been avoided	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
B	I feel that this admission was unnecessary	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree

22. Thinking about the future how much do you agree or disagree with the following statements:

A	I would prefer to come back to hospital again if I can't manage at home	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
B	I would prefer to come back to hospital again if my family/friends can't look after me	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
C	I would prefer to come back to hospital if my illness gets worse	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
d	I would prefer to come back to hospital again if my symptoms get worse	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree

23. Thinking about if you were to become unwell again (but not at the end of your life) how much do you agree or disagree with the following statements:

A	I would prefer to stay at home if I become unwell again	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
B	I would prefer to go to the hospice if I become unwell again	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
C	I would prefer to go to an aged care facility if I become unwell again	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
D	I would prefer to come back to hospital if I become unwell again	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree
E	When I become unwell it is important that I get to choose where I am cared for	1 Strongly disagree	2 Disagree	3 Neither	4 Agree	5 Strongly agree

24. When I am at the end of my life I would like to be cared for at:

- a. Home
- b. Hospital
- c. Aged care facility
- d. Hospice
- e. Somewhere else (please state).....
- f. I don't mind where I am cared for
- g. Not sure

The following few questions are designed to identify people who have had special financial needs in the last 12 months. Although these questions may not apply directly to you, for completeness we need to ask them of everyone.

- 1. In the last 12 months have you personally been forced to buy cheaper food so that you could pay for other things you needed?**
Yes/No
- 2. In the last 12 months have you been out of work at any time for more than one month?** (NOTE: defined as “no” for those 65 and over, and for full time caregivers/home makers)
Yes/No
- 3. In the last 12 months ending today, did you yourself receive payments from any of these three benefits: Jobseeker Support (unemployment benefit), Sole Parent Support (Domestic Purposes Benefit) or Supported Living Payment (Sickness/Invalid Benefit)?**
Yes/No
- 4. In the last 12 months have you personally put up with feeling cold to save heating costs?**
Yes/No
- 5. In the last 12 months have you personally made use of special food grants or food banks because you did not have enough money for food?**
Yes/No
- 6. In the last 12 months have you personally continued wearing shoes with holes because you could not afford replacement?**
Yes/No
- 7. In the last 12 months have you personally gone without fresh fruit and vegetables, often, so that you could pay for other things you needed?**
Yes/No
- 8. In the last 12 months have you personally received help in the form of clothes or money from a community organisation (like the Salvation Army)?**

Yes/No

What is your highest education?

- a. Doctorate degree
- b. Master's degree
- c. Post graduate certificate/diploma
- d. Bachelor's degree
- e. Trade certificate
- f. Secondary school qualification
 - a. Level 3 (7th form Bursary/Scholarship)
 - b. Level 2 (6th form certificate/University Entrance)
 - c. Level 1 (5th form School Certificate)
- g. Other qualification.....
- h. No educational qualification

Thank you for your time.

Post questionnaire data to be completed by researcher

Date of admission.....Date of discharge.....

Length of stay (including day of admission and day of discharge).....

Discharge destination:Home
Aged care facility
Hospice
Other

Interventions during admission (from notes)

IV Hydration Change of analgesics IV antibiotics Oxygen therapy
Urinary catheterisation Blood transfusion Nutrition (NG/TPN) Thoracentesis
Paracentesis Surgery Stenting Change in medication (other)
Bisphosphonates Investigations* Radiotherapy Chemotherapy

* includes imaging, biopsy, gastroscopy, colonoscopy, blood tests etc

Referrals during admission (from notes)

Referral to social worker Referral to physio Referral to dietician Referral to NASC
Referral to other medical specialty Referral to HPCT Referral to Hospice Referral to DN Referral to OT
Referral to other community provider

Other

Number of hospice inpatient admissions in the previous 6 months.....

Date of death..... follow up 6/12 post survey dates)

References

- Abel, J., Rich, A., Griffin, T. and Purdy, S. (2009) End of life care in hospital: a descriptive study of all in patient deaths in 1 year. *Palliative Medicine*, 23(7): 616-622
- Addington-Hall, J. (2002). Research sensitivities to palliative care patients. *European Journal of Cancer Care*, 11, 220–224.
- Addington-Hall, J., & O’Callaghan, A. (2009). A comparison of the quality of care provided to cancer patients in the UK in the last three months of life in inpatient hospices compared with hospitals, from the perspective of bereaved relatives: Results from a survey using the VOICES questionnaire. *Palliative Medicine*, 23(3), 190–197.
- Agar, M., Currow, D., Shelby-James, T., Plummer, J., Sanderson, C., & Abernethy, A. (2008). Preference for place of care and place of death in palliative care: Are these different questions? *Palliative Medicine*, 22, 787–795.
- Ahearn, D., Nidh, N., Kallat, A., Adenwala, Y., & Varman, S. (2013). Offering older hospitalised patients the choice to die in their preferred place. *Postgraduate Medical Journal*, 89(1047), 20–24.
- Almaawiy, U., Sussman, J., Brazil, K., & Seow, H. (2014). Are family physician visits and continuity of care associated with acute care use at end-of-life? A population-based cohort study of homecare cancer patients. *Palliative Medicine*, 28(2), 176 –183.
- Appelin, G., & Bertero, C. (2004). Patients’ experiences of palliative care in the home. *Cancer Nursing*, 27(1), 65–70.
- Aries, P. (1981). *The hour of our death*. London, England: Allen Lane.
- Arnold, B. (2011). Mapping hospice patients’ perception and verbal communication of end-of-life needs: An exploratory mixed methods inquiry. *BMC Supportive and Palliative Care*, 10(1), 1–10.
- Arnold, E., Finucane, A., & Oxenham, D. (2013). Preferred place of death for patients referred to a specialist palliative care service. *BMJ Supportive and Palliative Care*, 13(4). doi:10.1136/bmjspcare-2012-000338
- Atkinson, J., Salmond, C., & Crampton, P. (2014). *NZDep2013 Index of Deprivation*. University of Otago, Wellington, New Zealand.
- Auckland District Health Board. (2014). About the Auckland DHB. Retrieved from http://www.adhb.govt.nz/about/about_adhb.htm
- Bacchi, C. (2012). Why study problematization? Making policies visible. *Open Journal of Political Science*, 2, 1–8. doi:10.4236/ojps.2012.21001
- Bailey, C., Hewison, A., Karasouli, K., Staniszevska, S., & Munday, D. (2016). Hospital care following emergency admission: A critical incident case study of the experiences of patients with advanced lung cancer and Chronic Obstructive Pulmonary Disease. *Journal of Clinical Nursing*, 25(15–16), 2168–2179.
- Baker, R., Wu, A. W., Teno, J. M., Kreling, B., Damiano, A. M., Rubin, H. R., . . . Wenger, N. S. (2000). Family satisfaction with end of life care in seriously ill hospitalized adults. *Journal of the American Geriatrics Society*, 48(5), S61–S69.
- Barbera, L., Paszat, L., & Chartier, C. (2006). Indicators of poor quality end of life cancer care in Ontario. *Journal of Palliative Care*, 22(1), 12–17.

- Barbera, L., Taylor, C., & Dudgeon, D. (2010). Why do patients with cancer visit the emergency department near the end of life? *Canadian Medical Association Journal*, *182*(6), 563–568.
- Bardsley, M., Goerghiou, T., Spence, R., & Billings, J. (2016). Factors associated with variation in hospital use at the end of life in England. *BMJ Supportive and Palliative Care*. doi:10.1136/bmjspcare-2015-000936
- Barnes, S., Gott, M., Payne, S., Parker, C., Seamark, D., Gariballa, S., & Small, N. (2006). Prevalence of symptoms in a community based sample of heart failure patients. *Journal of Pain and Symptom Management*, *32*(3), 208–216. doi:10.1016/j.jpainsymman.2006.04.005
- Beaton, D. E., Tarasuk, V., Katz, J. N., Wright, J. G., & Bombardier, C. (2001). “Are you better?” A qualitative study of the meaning of recovery. *Arthritis Care and Research*, *45*, 270–279.
- Beernaert, K., Deliens, L., De Vbleminck, A., Devroey, D., Partdon, K., Van Den Block, L., & Cohen, J. (2014). Early identification of palliative care needs by family physicians: A qualitative study of barriers and facilitators from the perspective of family physicians, community nurses, and patients. *Palliative Medicine*, *28*(6), 480–490.
- Belanger, E., Rodriguez, C., & Groleau, D. (2011). Shared decision making in palliative care: A systematic mixed studies review using narrative synthesis. *Palliative Medicine*, *25*(3), 242–261.
- Bell, C., Somogyi-Zalud, E., & Masaki, K. (2009). Methodological review: Measured and reported congruence between preferred and actual place of death. *Palliative Medicine*, *23*, 482–490.
- Bellamy, G., Gott, M., & Frey, R. (2011). “It’s my pleasure?”: The views of palliative care patients about being asked to participate in research. *Progress in Palliative Care*, *19*(4), 159–164.
- Benner, P. (1984). From novice to expert. *American Journal of Nursing*, *82*(3), 402–407.
- Beresford, M. J. (2010). Medical reductionism: Lessons from the great philosophers. *Quarterly Journal of Medicine*, *103*, 721–724.
- Berger, R. (2015). Now I see it, now I don’t: Researcher’s position and reflexivity in qualitative research. *Qualitative Research*, *15*(2), 219–234.
- Bhandari, A., & Wagner, T. (2006). Self-reported utilization of health care services: Improving measurement and accuracy. *Medical Care Research and Review*, *63*(2), 217–235.
- Biesta, G. (2010). Pragmatism and the philosophical foundations of mixed methods research. In A. Tashakkori & C. Teddlie (Eds.), *SAGE handbook of mixed methods in social and behavioural research* (2nd ed.) (pp. 95–118). London, England: SAGE.
- Billings, J. A., & Kolton, E. (1999). Family satisfaction and bereavement care following death in the hospital. *Journal of Palliative Medicine*, *2*(1), 33–50.
- Black, J. (2011). What are patients' priorities when facing the end of life? A critical review. *International Journal of Palliative Nursing*, *17*(6), 294–300.
- Boland, J., Martin, J., Wells, A. U., & Ross, J. R. (2013). Palliative care for people with non-malignant lung disease: Summary of current evidence and future direction. *Palliative Medicine*, *27*(9), 811–816.
- Borgstrom, E. (2015). Planning for an (un)certain future: Choice within English end-of-life care. *Current Sociology*, *65*(5), 700–713. doi:10.1177/0011392115590084

- Borum, M. L., Lynn, J., & Zhong, Z. (2000). The effects of patient race on outcomes in seriously ill patients in SUPPORT: An overview of economic impact, medical intervention and end of life decisions. *Journal of the American Geriatrics Society*, 48(5 Suppl.), S194–S198.
- Boston, P., Bruce, A., & Schrieber, R. (2011). Existential suffering in the palliative care setting: An integrated literature review. *Journal of Pain and Symptom Management*, 41(3), 604–618.
- Bowling, A., Illiffe, S., Kessel, A., & Higginson, I. (2010). Fear of dying in an ethnically diverse society: Cross sectional studies of people aged 65+ in Britain. *Postgraduate Medical Journal*, 86, 197–202.
- Bradbury, M. (2000). A good death? In D. Dickenson, M. Johnson, & J. S. Katz (Eds.), *Death, dying and bereavement*. London, England: SAGE.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3(2), 77–101. doi:10.1191/1478088706qp063oa
- Brazil, K., Howell, D., Bedard, M., Krueger, P., & Heidebrecht, C. (2005). Preferences for place of care and place of death among informal caregivers of the terminally ill. *Palliative Medicine*, 19(6), 492–499.
- Brereton, L., Gardiner, C., Gott, M., Ingleton, C., Barnes, S., & Carroll, C. (2012). The hospital environment for end of life care of older adults and their families: An integrative review. *Journal of Advanced Nursing*, 16(5), 961–1195.
- Bridges, J., Flateley, M., & Meyera, J. (2010). Older people's and relatives' experiences in acute care settings: Systematic review and synthesis of qualitative studies. *International Journal of Nursing Studies*, 47(1), 89–107.
- Broad, J. B., Gott, M., Kim, H., Boyd, M., Chen, H., & Connolly, M. J. (2013). Where do people die? An international comparison of the percentage of deaths occurring in hospital and residential aged care settings in 45 populations, using published and available statistics. *International Journal of Public Health*, 58(2), 257–267.
- Broom, A., & Cavenagh, J. (2010). Masculinity, moralities, and being cared for: An exploration of experiences of living and dying in a hospice. *Social Science & Medicine*, 71(5), 869–876.
- Bryman, A. (2006). Integrating quantitative and qualitative research: How is it done? *Qualitative Research*, 6(1), 97–113.
- Buck, H. G. (2012). Upstreaming palliative care for patients with end stage heart failure. *Journal of Cardiovascular Nursing*, 27(2), 147–153.
- Calman, L., Brunton, L., & Mollasiotis, A. (2013). Developing longitudinal qualitative designs: Lessons learned and recommendations for health services research. *BMC Medical Research Methodology*. doi:10.1186/1471-2288-13-14
- Campos-Calderon, C., Montoya-Juarez, R., Huseo-Montoro, C., Hernandez-Lopez, E., Ojeda-Virto, F., & Gardia-Caro, M. P. (2016). Interventions and decision-making at the end of life: The effect of establishing the terminal illness situation. *BMC Palliative Care*, 15(91). doi:10.1186/s12904-016-0162-z
- Canning, D., Yates, P. and Rosenberg, J.P. (2005) Competency standards for specialist palliative care nursing practice. Brisbane: Queensland University of Technology
- Cantor, J. C., Blustein, J., Carlson, M. J., & Gould, D. A. (2003). Next-of-kin perceptions of physician responsiveness to symptoms of hospitalized patients near death. *Journal of Palliative Medicine*, 6(4), 531–542.

- Care closer to home* (2014). Wellington: Ministry of Health. Retrieved from <http://www.health.govt.nz/publication/care-closer-home>.
- Carper, B. (1978). Fundamental patterns of knowing in nursing. *Advances in Nursing Science*, 1(1), 13–23.
- Centeno, C., Lynch, T., Garralda, E., J. M., Carrasco., Guillen-Grima, F., & Clark, D. (2016). Coverage and development of specialist palliative care services across the World Health Organization European Region (2005–2012): Results from a European Association for Palliative Care Task Force survey of 53 countries. *Palliative Medicine*, 30(4), 351–362.
- Chan, L. S., Macdonald, M. E., Carnevale, F., & Cohen, S. R. (2017). I'm only dealing with the acute issues: How medical ward “busyness” constrains care of the dying. *Health*, 1–18.
- Chan, W., Jackson, G., Winnard, D., & Anderson, P. (2011). Healthcare services funded by Counties Manukau District Health Board for people in the last year of life. *New Zealand Medical Journal*, 124(1225), 40–51.
- Charlton, C. C., Dearing, K. S., Berry, J. A., & Johnson, M. J. (2008). Nurse practitioners' communication styles and their impact on patient outcomes: An integrated literature review Authors. *Journal of the American Association of Nurse Practitioners*, 20(7), 382–388. doi:10.1111/j.1745-7599.2008.00336.x
- Charmaz, K. (1997). *Good days, bad days: The self in chronic illness and time*. New Jersey, USA: Rutgers University Press.
- Chitnis, X. A., Georghiou, T., Steventon, A., & Bardsley, M. J. (2014). Effect of a home based end-of-life nursing service on hospital use at the end of life and place of death: A study using administrative data and matched controls. *BMJ Supportive and Palliative Care*, 3(4), 422–430. doi:10.1136/bmjspcare-2012-000424
- Claessens, M. T., Lynn, J., Zhong, Z., Desbiens, N. A., Phillips, R. S. W., A W, Harrell, F. E. J., & Connors, A. F. J. (2000). Dying with lung cancer or chronic obstructive pulmonary disease: Insights from SUPPORT. *Journal of the American Geriatrics Society*, 48(5 Suppl), S146–153.
- Clark, D. (1998). Originating a movement: Cicely Saunders and the development of St Christopher's hospice, 1957–1967. *Mortality*, 13(1), 43–63.
- Clark, D. (2002). Between hope and acceptance: The medicalisation of dying. *British Medical Journal*, 324, 905–907. doi:10.1136/bmj.324.7342.905
- Clark, D. (2008a). From margins to centre: A review of the history of palliative care in cancer. *Lancet Oncology*, 8(5), 430–438. doi:10.1016/S1470-2045(07)70138-9
- Clark, D. (2008b). History and culture in the rise of palliative care. In S. Payne, J. Seymour, & C. Ingleton (Eds.), *Palliative care nursing: principles and evidence for practice* (pp. 39–54). Maidenhead, England: Open University Press.
- Clark, D. (2012). Cultural considerations in planning palliative and end of life care. *Palliative Medicine*, 26(3), 195–196.
- Clark, D., Armstrong, M., Allan, A., Graham, F., Carnon, A., & Isles, C. (2014). Imminence of death among hospital inpatients: Prevalent cohort study. *Palliative Medicine*, 28(6), 474–479.
- Clark, D., Graham, F., & Centeno, C. (2015). Changes in the world of palliative care. *Medicine*, 43(12), 696–698.
- Clark, D., Ingleton, C., & Seymour, J. (2000). Support and supervision in palliative care research. *Palliative Medicine*, 14(5), 441–446.

- Code of Conduct for Nurses*. (2012). Retrieved from Wellington, New Zealand: www.nursingcouncil.org.nz/Nurses/Code-of-conduct. Retrieved 22 November 2017
- Code of Health and Disability Services Consumers' Rights Regulations 1996*. (2014). Wellington, New Zealand.
- Cody, W. K. (2013). Values-based practice and evidence-based care: Pursuing fundamental questions in nursing philosophy and theory. In W. K. Cody (Ed.), *Philosophical and theoretical perspectives for advanced nursing practice* (5th ed.) (pp. 5–14). Burlington, MA: Jones and Bartlett Learning.
- Collier, A., Phillips, J. L., & Iedema, R. (2015a). The meaning of home at the end of life: A video reflexive ethnographic study. *Palliative Medicine*, 29(8), 695–702.
- Conner, A., Allport, S., Dixon, J., & Somerville, A. M. (2008). Patient perspective: What do palliative care patients think about their care? *International Journal of Palliative Nursing*, 14(11), 546–552.
- Costello, J. (2001). Nursing older dying patients: Findings from an ethnographic study of death and dying in elderly care wards. *Journal of Advanced Nursing*, 35(1), 59–68.
- Costello, J. (2006). Dying well: Nurses' experiences of "good and bad" deaths in hospital. *Journal of Advanced Nursing*, 54(5), 594–601.
- Costello, J. (2015). We seem to have the science right, now we need to work on the art of palliative care nursing. *International Journal of Palliative Nursing*, 21(12), 577–578.
- Cottrell, L., & Dugleby, W. (2016). The "good death": An integrative literature review. *Palliative & Supportive Care*, 14(6), 686–712.
- Cournane, S., Byrne, D., Conway, R., O'Riordan, S., Coveney, S., & Silke, B. (2015). Social deprivation and hospital admission rates, length of stay and readmissions in emergency medical admissions. *European Journal of Internal Medicine*, 26(10), 766–771.
- Cox, K., Bird, L., Arthur, A., Kennedy, S., Pollock, K., Kumar, A., . . . Seymour, J. (2001). Public attitudes to death and dying in the UK: A review of published literature. *BMJ Supportive and Palliative Care*, 33, 37–45. doi:10.1136/bmjspcare-2012-000203
- Coyne, I. T. (1997). Sampling in qualitative research. Purposeful and theoretical sampling; merging or clear boundaries. *Journal of Advanced Nursing*, 26(3), 623–630.
- Creswell, J. (2013). *Qualitative inquiry and research design: Choosing among five approaches* (3rd ed.). Thousand Oaks, CA: SAGE.
- Creswell, J., & Plano Clark, V. (2010). *Designing and conducting mixed methods research* (2nd ed.). Thousand Oaks, CA: SAGE.
- Creswell, J. W. (2014). *Research design: Qualitative, quantitative and mixed methods approaches* (4th ed.). New York, NY: SAGE.
- Creswell, J. (2009). *Research design: Qualitative, quantitative and mixed methods approaches* (3rd ed.). Thousand Oaks, CA: SAGE.
- Cull-Wilby, B. L., & Pepin, J. I. (1987). Towards a coexistence of paradigms in nursing knowledge development. *Journal of Advanced Nursing*, 12(4), 515–521.
- Dalkin, S. M., Lhussier, M., Philipson, P., Jones, D., & Cunningham, W. (2016). Reducing inequalities in care for patients with non-malignant diseases: Insights from a realist evaluation of integrated palliative care pathway. *Palliative Medicine*. doi:10.1177/0269216315626352
- De Korte-Verhoef, M. C., Pasman, H. R., Schweitzer, B. P., Francke, A. L., Onwuteaka-Philipsen, B. D., & Deliens, L. (2014). Reasons for hospitalisation at the end of life: Differences between cancer and non-cancer patients. *Supportive Care in Cancer*, 33(3), 645–625.

- De Roo, M. L., Miccinesi, G., Onwuegbuzie, B. D., Van Den Noortgate, N., Van den Block, L., Bonacchi, A., . . . Francke, A. (2014). Actual and preferred place of death of home dwelling patients in four European countries: Making sense of quality indicators.
- Department of Health (2008). End of life care strategy: Promoting high quality care for all adults at the end of life. Retrieved from <https://www.gov.uk/government/publications/end-of-life-care-strategy-promoting-high-quality-care-for-adults-at-the-end-of-their-life>
- Department of Health (2010). Supporting Australians to live well at the end of life. National Palliative Care Strategy. Retrieved from [https://www.health.gov.au/internet/main/publishing.nsf/Content/EF57056BDB047E2FCA257BF000206168/\\$File/NationalPalliativeCareStrategy.pdf](https://www.health.gov.au/internet/main/publishing.nsf/Content/EF57056BDB047E2FCA257BF000206168/$File/NationalPalliativeCareStrategy.pdf)
- Department of Health and Children (2001). Report of the National Advisory Committee on Palliative Care, Ireland. Retrieved from <http://health.gov.ie/wp-content/uploads/2014/03/nacpc.pdf>
- Desbiens, N., Norman, A., Wu, A. W., Broste, K., Wenger, N., Connors, A. F., . . . Fulkerson, W. (1996). Pain and satisfaction with pain control in seriously ill hospitalized adults: Findings from the SUPPORT research investigations. *Critical Care Medicine*, 24(12), 1953–1961.
- Desbiens, N. A., Mueller-Rizner, N., Connors, A. F., Wenger, N. S., & Lynn, J. (1999). The symptom burden of seriously ill hospitalized patients. *Journal of Pain and Symptom Management*, 17(4), 248–255.
- Dickinson, G. E., Clark, D., & Sque, M. (2008). Palliative care and end of life issues in UK pre-registration, undergraduate nursing programmes. *Nurse Education Today*, 28(2), 163–170.
- Dixon, J., King, D., Matosevic, T., Clark, M., & Knapp, M. (2015). *Equity in the provision of palliative care in the UK: Review of evidence*. <https://www.mariecurie.org.uk/globalassets/media/documents/policy/campaigns/equity-palliative-care-uk-report-full-lse.pdf>. Retrieved 22 November 2017
- Douglas, C. H., & Douglas, M. R. (2003). Patient friendly hospital environments: Exploring the patients' perspective. *Health Expectations*, 7(1), 61–73.
- Doyle, L., Brady, A., & Byrne, G. (2009). An overview of mixed methods research. *Journal of Nursing Research*, 14(2), 175–185.
- Du Boulay, S. (1984). *Cicely Saunders. The founder of the modern hospice movement*. London, England: Hodder and Stoughton.
- Duke, S., & Bennett, H. (2010). Review: A narrative review of the published ethical debates in palliative care research and an assessment of their adequacy to inform research governance. *Palliative Medicine*, 24(2), 111–126.
- Dumont, S., Jacobs, P., Fassbender, K., Anderson, D., Turcotte, V., & Harel, F. (2009). Costs associated with resource utilization during the palliative phase of care: A Canadian perspective. *Palliative Medicine*, 23(8), 708–717. doi:0.1177/0269216309346546
- Dunne, K., & Sullivan, K. (2000). Family experiences of palliative care in the acute hospital setting. *International Journal of Palliative Nursing*, 6(4), 170–178.
- Dying without dignity: Investigations by the Parliamentary and Health Service Ombudsman into complaints about end of life care. (2015). United Kingdom: Parliamentary and Health Service Ombudsman.
- Dzul-Church, V., Cimino, J. W., Adler, S. R., Wong, P., & Anderson, W. G. (2010). “I’m sitting here by myself . . .”: Experiences of patients with serious illness at an urban public hospital. *Journal of Palliative Medicine*, 13(6), 695–701.

- Ebrahimi, Z., Wilhelmson, K., Moore, C. D., & Jakobsson, A. (2012). Frail elders' experiences with and perceptions of health. *Qualitative Health Research, 22*(11), 1513–1523.
- Edwards, A., Pang, N., Shiu, V., Chan, C., & De Casterle, B. (2010). The understanding of spirituality and the potential role of spiritual care in end-of-life and palliative care: A meta-study of qualitative research. *Palliative Medicine, 24*(8), 753–770.
- Elwyn, G., Frosch, D., Thomson, R., Joseph-Williams, N., Lloyd, Kinnersley, A., . . . Barry, B. (2012). Shared decision making: A model for clinical practice. *Journal of General Internal Medicine, 27*(10), 1361–1367.
- Evans, W. G., Cutson, M. D., Steinhauser, K., & Tulsky, J. (2006). Is there no place like home? Caregivers recall reasons for and experience upon transfer from home hospice to inpatient facilities. *Journal of Palliative Medicine, 9*(1), 100–110.
- Farquhar, M., Ewing, G., & Booth, S. (2011). Using mixed methods to develop and evaluate complex interventions in palliative care research. *Palliative Medicine, 25*(8), 748–757.
- Federal Office of Public Health. (2009). National strategy for palliative care 2010–2012. Retrieved from <http://www.bag.admin.ch/themen/gesundheitspolitik/13764/index.html?lang=en>
- Fidelis, M., & Manolo, M. D. (2013). End-of-life decisions about withholding or withdrawing therapy: Medical, ethical, and religio-cultural considerations. *Palliative Care Research and Treatment, 7*, 1–5.
- Field, D., & McGaughey, J. (1998). An evaluation of palliative care services for cancer patients in the Southern Health and Social Services Board of Northern Ireland. *Palliative Medicine, 12*(2), 83–97.
- Finfgeld-Connett, D. (2007). Meta-synthesis of caring in nursing. *Journal of Clinical Nursing, 17*(2), 196–204. doi:0.1111/j.1365-2702.2006.01824.x
- Firn, J., Preston, N., & Walshe, C. (2016). What are the views of hospital-based generalist palliative care professionals on what facilitates or hinders collaboration with in-patient specialist palliative care teams? A systematically constructed narrative synthesis. *Palliative Medicine, 30*(3), 240–256. doi:10.1177/0269216315615483
- Floriani, C. A., & Rolland, F. (2012). Routinization and medicalization of palliative care: Losses, gains and challenges. *Palliative & Supportive Care, 10*(4), 295–303.
- Formiga, F., Olmedo, C., López-Soto, A., Navarro, M., & Culla, A. Pujol, R. (2007). Dying in hospital of terminal heart failure or severe dementia: The circumstances associated with death and the opinions of caregivers. *Palliative Medicine, 21*(1), 35–40.
- Frey, R. A., Gott, M., Raphael, D., O'Callaghan, A., Robinson, J., Boyd, M., . . . Snow, B. (2013). Clinical staff perceptions of palliative care-related quality of care, service access, education and training needs and delivery confidence in an acute hospital setting. *BMJ Supportive and Palliative Care*. doi:doi:10.1136/bmjspcare-2012-000346
- Gardiner, C., Brereton, L., Gott, M., Ingleton, C., & Barnes, S. (2012). Exploring the health professionals' views regarding the optimum physical environment for palliative and end of life care in the acute hospital setting: A qualitative study. *BMJ Supportive and Palliative Care, 1*(2), 162–166.

- Gardiner, C., Cobb, M., Gott, M., & Ingleton, C. (2010). Barriers to providing palliative care for older people in acute hospitals. *Age & Ageing*, *40*(2), 233–238.
- Gardiner, C., Gott, M., & Ingleton, C. (2012). Factors supporting good partnership working between generalist and specialist palliative care services: A systematic review. *British Journal of General Practice*, *62*(598), e353–362.
- Gardiner, C., Gott, M., Ingleton, C., Seymour, J., Cobb, M., Noble, B., . . . Ryan, T. (2012). Extent of palliative care need in the acute hospital setting: A survey of two acute hospitals in the UK. *Palliative Medicine*, *27*(1): 76–83.
- Gardiner, C., Gott, M., Payne, S., Small, N., Barnes, S., Haplin, D., . . . Seamark, D. (2010). Exploring the care needs of patients with advanced COPD: An overview of the literature. *Respiratory Medicine*, *104*(2), 159–165.
- Gardiner, C., Gott, M., Small, N., Payne, S., Seamark, D., Barnes, S., . . . Ruse, C. (2009). Living with advanced chronic obstructive pulmonary disease: Patients concerns regarding death and dying. *Palliative Medicine*, *23*(8), 691–697.
- Gardiner, C., Ward, S., Gott, M., & Ingleton, C. (2014). Economic impact of hospitalisations among patients in the last year of life: An observational study. *Palliative Medicine*, *28*(5), 422–429.
- Gerrard, R., Campbell, J., Minton, O., Moback, B., Skinner, C., McGowan, C., & Stone, C. (2011). Achieving the preferred place of care for hospitalized patients at the end of life. *Palliative Medicine*, *25*(4), 333–336. doi:10.1177/0269216310387459
- Giddings, L., & Grant, B. (2006). Mixed methods research for the novice researcher. *Contemporary Nurse: A Journal for the Australian Nursing Profession*, *23*(1), 3–11.
- Gillick, M. R. (2009). Potential burdens of low-tech interventions near the end of life. *Journal of Pain & Symptom Management*, *37*(3), 429–432. doi:10.1016/j.jpainsymman.2009.01.001
- Global Atlas of Palliative Care at the End of Life*. (2014). Worldwide palliative care alliance and World Health Organisation.
- Gold Standards Framework. www.goldstandardsframework.org.uk Retrieved 22 November 2017
- Goldsbury, D. E., O’Connell, D. L., Girgis, A., Wilkinson, A., Phillips, J. L., Davidson, P. M., & Ingham, J. M. (2015). Acute hospital-based services used by adults during the last year of life in New South Wales, Australia: A population-based retrospective cohort study. *BMC Health Services Research*. doi:10.1186/s12913-015-1202-8
- Gomes, B., Calanzani, N., & Higginson, I. (2011). *Local preferences and place of death in regions within England*. www.endoflifecare-intelligence.org.uk/resources/publications/lp_and_place_of_death. Retrieved: 22 November 2017
- Gomes, B., & Higginson, I. (2006). Factors influencing death at home in terminally ill patients with cancer: Systematic review. *British Medical Journal*. doi: <https://doi.org/10.1136/bmj.38740.614954.55>
- Gomes, B., & Higginson, I. (2008). Where people die (1974–2030): Past trends, future projections and implications for care. *Palliative Medicine*, *22*(1), 33–41.
- Gomes, B., Higginson, I., Calanzani, N., Cohen, J., Deliens, L., Daveson, B., . . . Harding, R. (2012). Preferences for place of death if faced with advanced cancer: A population survey in England, Flanders, Germany, Italy, the Netherlands, Portugal and Spain. *Annals of Oncology Advance Access*, *23*(8):2006–2015

- Gott, M. (2014). Avoidable for whom? Hospital use at the end of life. *Palliative Medicine*, 28(7), 917–918. doi:DOI: 10.1177/0269216314534807
- Gott, M., Ahmedzai, S. H., & Wood, C. (2001). How many inpatients at an acute hospital have palliative care needs? Comparing the perspectives of medical and nursing staff. *Palliative Medicine*, 15(6), 451–460.
- Gott, M., Allen, R., Moeke-Maxwell, T., Gardiner, C., & Robinson, J. (2015). ‘No matter what the cost’: A qualitative study of the financial costs faced by family and whanau caregivers within a palliative care context. *Palliative Medicine*. Epub ahead of print. doi:269216315569337
- Gott, M., Frey, R., Raphael, D., O’Callaghan, A., Robinson, J., & Boyd, M. (2012). Palliative care need and management in the acute hospital setting: A census of one New Zealand hospital. *BMC Palliative Care*, 12(15). doi:10.1186/1472-684X-12-15
- Gott, M., Frey, R., Robinson, J., Boyd, M., O’Callaghan, A., Richards, N., & Snow, B. (2013). The nature of, and reasons for, ‘inappropriate’ hospitalisations among patients with palliative care needs: A qualitative exploration of the views of generalist palliative care providers. *Palliative Medicine*, 27(8), 747–756. doi:10.1177/0269216312469263
- Gott, M., Gardiner, C., Ingleton, C., Cobb, M., Noble, B., Bennett, M., & Seymour, J. (2013). What is the extent of potentially avoidable admissions amongst hospital inpatients with palliative care needs? *BMC Palliative Care*, 12(9). doi:10.1186/1472-684X-12-9
- Gott, M., Ingleton, C., Bennett, M. I., & Gardiner, C. (2011). Transitions to palliative care in acute hospitals in England: Qualitative study. *BMJ Supportive and Palliative Care*, 42–48. doi:10.1136/bmj.d1773
- Gott, M., Seymour, J., Bellamy, G., Clark, D., & Ahmedzai, S. H. (2004). Older people’s views about home as a place of care at the end of life. *Palliative Medicine*, 18(5), 460–467. doi:10.1191/0269216304pm889oa
- Gott, M., Seymour, J., Ingleton, C., & Bellamy, G. (2012). ‘That’s part of everybody’s job’: The perspectives of health care staff in England and New Zealand on the meaning and remit of palliative care. *Palliative Medicine*, 26(3), 232–241.
- Gott, M., Small, N., Barnes, S., Payne, S., & Seamark, D. (2008). Older people’s views of a good death in heart failure: Implications for palliative care provision. *Social Science and Medicine*, 67(7), 1113–1121.
- Gott, M., Williams, L., & Moeke-Maxwell, T. (2015). The paradoxes of ‘home’ within a palliative care context. In M. Roche, J. Mansvelt, R. Prince, & A. Gallgher (Eds.), *Engaging geographies: Landscapes, lifecourses and mobilities* (pp. 137–154). Newcastle upon Tyne, England: Cambridge Scholars Publishing.
- Grainger, K. (2015, February 2). I want my legacy to be that the NHS treats all patients with compassion. *The Guardian*. Retrieved from <http://www.theguardian.com/healthcare-network/2014/may/21/friendly-introduction-transform-patient-experience>
- Greene, J. (2008). Is mixed methods social inquiry a distinctive methodology? *Journal of Mixed Methods Research*, 2(1), 7–22.
- Groeneveld, E. I., Cassel, J. B., Bausewein, C., Csikos, A., Krajnik, M., Ryan, K. M., . . . Murtagh, F. E. (2017). Funding models in palliative care: Lessons learned from international experience. *Palliative Medicine*, 31(4), 296–305.
- Guba, E. G. (1981). Criteria for assessing the trustworthiness of naturalistic inquiries. *Educational Communication and Technology*, 29(2), 79–91.

- Hall, S., Petkova, H., Tsouros, A., Costantini, M., & Higginson, I. (2010). Palliative care for older people: Better practice. Retrieved from http://www.euro.who.int/__data/assets/pdf_file/0017/143153/e95052.pdf
- Hart, B., Sainsbury, P., & Short, S. (1998). Whose dying? A sociological critique of the 'good death'. *Mortality*, 3(1), 65–77.
- Harwood, L., & Clark, A. (2012). Understanding health decisions using critical realism: Home-dialysis decision-making during chronic kidney disease. *Nursing Inquiry*, 19(1), 29–38.
- Hawley, M. P. (2000). Nurse comforting strategies: Perceptions of emergency department patients. *Clinical Nursing Research*, 9(4), 441–459.
- Hay-Smith, E. J. C., Brown, M., Anderson, A., & Treharne, G. J. (2016). Once a clinician, always a clinician: A systematic review to develop a typology of clinician-researcher dual-role experiences in health research with patient-participants. *BMC Medical Research Methodology*, 16(95). doi:10.1186/s12874-016-0203-6
- Heale, R., & Twycross, A. (2015). Validity and reliability in quantitative research. *Evidence Based Nursing*, 18(3), 66–67.
- Health Canada. (2007). Canadian strategy on palliative and end-of-life care: Final report of the coordinating committee. December 2002 to March 2007. Retrieved from <http://healthycanadians.gc.ca/publications/health-system-systeme-sante/strategy-palliative-strategie-palliatifs/index-eng.php>
- Herd, E. B. (1990). Terminal care in a semi rural area. *British Journal of General Practice*, 40(335), 248–251.
- Hertzog, M. A. (2008). Considerations in determining samples size for pilot studies. *Research in Nursing and Health*, 31(2), 180–191.
- Heyland, D., Groll, D., Rocker, G., Dodek, P., Gafni, A., Tranmer, J., . . . Shortt, S. (2005). End of life care in acute hospitals in Canada: A quality finish? *Journal of Palliative Care*, 21(3), 142–150.
- Higginson, I., & Sen-Gupta, G. J. A. (2000). Place of care in advanced cancer: A qualitative systematic literature review of patient preferences. *Journal of Palliative Medicine*, 3(3), 287–300.
- Higginson, I., Wade, A., & McCarthy, M. (1990). Palliative care: Views of patients and their families. *British Medical Journal*, 301, 277–281.
- Horrocks, S., Anderson, E., & Salisbury, C. (2002). Systematic review of whether nurse practitioners working in primary care can provide equivalent care to doctors. *British Medical Journal*, 324(819). doi:<https://doi.org/10.1136/bmj.324.7341.819>
- Hosie, A., Davidson, P. M., Agar, M., Sanderson, C. R., & Phillips, J. (2012). Delirium prevalence, incidence, and implications for screening in specialist palliative care inpatient settings: A systematic review. *Palliative Medicine*, 27(6), 486–98.
- Hospice Friendly Hospices (2014) Irish Hospice Foundation. Retrieved 11 November 2017 <https://www.hospicefoundation.ie/healthcare-programmes/hospice-friendly-hospitals>
- Hulme, C., Carmichael, F., & Meads, D. (2014). What about informal carers and families? In J. Round (Ed.), *What about care at the end of life? An economic perspective* (pp. 167–176). Switzerland: Springer International Publishing.
- Ingleton, C., & Larkin, P. J. (2015). *Palliative care nursing at a glance*. United Kingdom: Wiley-Blackwell.
- Jacobs, L. G., Bonuck, K., Burton, W., & Mulvihill, M. (2002). Hospital care at the end of life: An institutional assessment. *Journal of Pain and Symptom Management*, 24(3), 291–298.

- Jiang, N., & Pacheco. (2014). *Demand in New Zealand hospitals: Expect the unexpected?* Retrieved from Auckland, New Zealand: https://www.aut.ac.nz/_data/assets/pdf_file/0005/
- Johansson, C. M., Axelsson, B., & Danielson, E. (2006). Living with incurable cancer at the end of life: Patients' perceptions on quality of life. *Cancer Nursing, 29*(5), 391–399.
- Johnson, R., & Onwuegbuzie, A. (2004). Mixed methods research: A research paradigm whose time has come. *Educational Researcher, 33*(7), 14–26.
- Johnson, R., Onwuegbuzie, A., & Turner, L. (2007). Toward a definition of mixed methods research. *Journal of Mixed Methods Research, 1*(2), 112–133.
- Johnstone, M., & Kanitsaki, O. (2009). Ethics and advance care planning in a culturally diverse society. *Journal of Transcultural Nursing, 20*(4), 405–416.
- Judkins-Cohn, T. M., Kielwasser-Withrow, K., Owen, M., & Ward, J. (2014). Ethical principles of informed consent: Exploring nurses dual role of care provider and researcher. *Journal of Continuing Education, 45*(1), 35–42.
- Karlawish, J. (2003). Conducting research that involves subjects at the end of life who are unable to give consent. *Journal of Pain and Symptom Management, 25*(3), S14–S24.
- Kellehear, A. (1990). *Dying of cancer: The final year of life*. Melbourne, Australia: Harwood Academic Publishers.
- Kellehear, A. (1999). Health-promoting palliative care: Developing a social model for practice. *Mortality, 4*(1), 75–82.
- Kellehear, A. (2007). *A social history of dying*. Cambridge, England: Cambridge University Press.
- Kennedy, C. (1998). Ways of knowing in palliative nursing. *International Journal of Palliative Nursing, 4*(5), 240–245.
- Koffman, J., & Higginson, I. (2004). Dying to be home? Preferred location of death of first generation black Caribbean and native-born white patients in the United Kingdom. *Journal of Palliative Medicine, 7*(5), 628–636.
- Koffman, J., & Higginson, I. J. (2001). Accounts of carers' satisfaction with health care at the end of life: A comparison of first generation black Caribbeans and white patients with advanced disease. *Palliative Medicine, 15*(4), 337–345.
- Kubler-Ross, E. (1969). *On death and dying*. New York, NY: Macmillan.
- Kvale, S., & Brinkmann, S. (2009). *Interviews: Learning the craft of qualitative research interviewing* (2nd ed.). Thousand Oaks, CA: SAGE.
- Lagman, R., Rivera, N., Walsh, D., LeGrand, S., & Davis, M. (2007). Acute inpatient palliative medicine in a cancer center: Clinical problems and medical interventions: A prospective study. *American Journal of Hospice & Palliative Care, 24*(1), 20–28.
- Langton, J. M., Blanch, B., Drew, A. K., Haas, M., Ingham, J. M., & Pearson, S. (2014). Retrospective studies of end of life resource utilization and costs in cancer care using health administrative data: A systematic review. *Palliative Medicine*. doi: 10.1177/0269216314533813
- Le, B. H. C., & Watt, J. N. (2010). Care of the dying in Australia's busiest hospital: Benefits of palliative care consultation and methods to enhance access. *Journal of Palliative Medicine, 13*(7), 855–860.

- Lee, S. F., Kristjanson, L. J., & Williams, A. M. (2009). Professional relationships in palliative care decision making. *Supportive Care in Cancer*, 17(4), 445–450.
- Leung, S. (2011). A comparison of psychometric properties and normality in 4-, 5-, 6-, and 11-point Likert scales. *Journal of Social Service Research*, 37(4), 412–442.
- Lewin, W. H., & Schaefer, K. G. (2017). Integrating new models of palliative care. *Heart Failure Review*. doi:10.1007/s10741-017-9599-2
- Lien Centre for Palliative Care. (2011). Report on the National Strategy for Palliative Care. Retrieved from https://www.duke-nus.edu.sg/sites/default/files/Report_on_National_Strategy_for_Palliative_Care%20Jan2012.pdf
- Llamas, K., Pickhaver, A., & Piller, N. (2001). Mainstreaming palliative care for cancer patients in the acute hospital setting. *Palliative Medicine*, 15(3), 207–212.
- Lloyd, L. (2011). *What do we know about the congruence between what older people prioritize at the end of life and policy and practices?* Oxford, England: Oxford University Press.
- Lynn, J., Teno, J., Phillips, R. S., Wu, A. W., Desbiens, N., Harrold, J., . . . Connors, A. F. (1997). Perceptions by family members of the dying experience of older and seriously ill patients. *Annals of Internal Medicine*, 126(2), 97–106.
- Macfarlane, M., & Carduff, E. (2016). Does place of death vary by deprivation for patients known to specialist palliative care services? *BMJ Supportive and Palliative Care*. doi:10.1136/bmjspcare-2016-001099
- Mantzoukas, S., & Watkinson, S. (2006). Review of advanced nursing practice: The international literature and developing the generic features. *Journal of Clinical Nursing*, 16, 28–37.
- Maxwell, J. A. and Mittapalli, K (2010). Realism as a stance for mixed methods research. In Tashakkori & Teddlie (Eds.), *Sage handbook of mixed methods in social and behavioural research*, (2nd ed., pp 145-168. Sage publications Inc., California.
- May, P., Hynes, G., McCallion, P., Payne, S., Larkin, P., & McCarron, M. (2014). Policy analysis: Palliative care in Ireland. *Health Policy*, 115(1), 68–74. doi:10.1016/j.healthpol.2013.07.016
- Mcall, K., & Johnston, B. (2007). Treatment options in end-of-life care: The role of palliative chemotherapy. *International Journal of Palliative Nursing*, 13(10), 486–488.
- McCabe, C. (2003). Nurse–patient communication: An exploration of patients’ experiences. *Journal of Clinical Nursing*, 13, 41–49.
- McCabe, M. (2004). The hospice movement in New Zealand: 25 years on. Retrieved from <http://www.nathaniel.org.nz/component/content/article/16-bioethical-issues/bioethics-at-the-end-of-life/114-the-hospice-movement-in-new-zealand-25-years-on>
- McEvoy, P., & Richards, D. (2006). A critical realist rationale for using a combination of quantitative and qualitative methods. *Journal of Research Nursing*, 11(1), 66–78.
- McLaughlin, L., & Braun, K. L. (1998). Asian and Pacific Islander cultural values. *Health and Social Work*, 23(2), 116–126. doi:10.1093/hsw/23.2.116
- Mcleod, H. (2016a). *Deaths in New Zealand: History and projections*. Retrieved from Wellington, New Zealand: palliativecare.hiirc.org.nz/

- McLeod, H. (2016b). *The need for palliative care in New Zealand*. Retrieved from Wellington, New Zealand: <https://tas.health.nz/assets/Health-of-Older-People/Technical-Report-Need-for-Palliative-Care-vF2-June-2016>
- McNamara, B. (2004). Good enough death: Autonomy and choice in Australian palliative care. *Social Science and Medicine*, 58(5), 92–938. doi:10.1016/j.socscimed.2003.10.042
- McNamara, B., Waddel, C., & Colvin, M. (1994). The institutionalization of the good death. *Social Science & Medicine*, 39(11), 1501–1508.
- McPherson, C., & Addington-Hall, J. (2003). Judging the quality of care at the end of life: Can proxies provide reliable information? *Social Science & Medicine*, 56(1), 95–109.
- McPherson, C., & Addington-Hall, J. (2004). How do proxies' perceptions of patients' pain, anxiety and depression change during the bereavement period? *Journal of Palliative Care*, 20(1), 12–19.
- Mehta, A., & Chan, L. S. (2008). Understanding of the concept of “Total Pain”: A prerequisite for pain control. *Journal of Hospice and Palliative Nursing*, 10(1), 26–32. doi:10.1097/01.NJH.0000306714.50539.1a
- Mercadante, S., Masedu, F., Marco, V., Mercadante, A., & Aielli, F. (2016). The characteristics of advanced cancer patients followed at home, but admitted to the hospital for the last days of life. *Internal and Emergency Medicine*, 11(5), 713–718.
- Ministry of Health, N. Z. (2001). *The New Zealand Palliative Care Strategy*. Wellington, New Zealand.
- Ministry of Health, N.Z. (2012). *The Resource and Capability Framework for Integrated Adult Palliative Care Services in New Zealand*. Wellington: NZ Ministry of Health.
- Ministry of Health, N. Z. (2015). *New Zealand Palliative Care Glossary*. Wellington, New Zealand.
- Ministry of Health, N. Z. (2017). *Palliative Care Action Plan*. Wellington, New Zealand. Retrieved from <https://www.health.govt.nz/publication/palliative-care-action-plan>
- Moher, D., Shamseer, L., Clarke, M., Ghersi, D., Liberati, A., Petticrew, M., . . . Group, P.-P. (2015). Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. *BMC Health Services Research*, 4(1). doi:10.1186/2046-4053-4-1
- Mollon, D. (2014). Feeling safe during an inpatient hospitalization: A concept analysis. *Journal of Advanced Nursing*, 70(8), 1727–1737.
- Morgan, D. (2007). Paradigms lost and pragmatism regained: Methodological implications of combining qualitative and quantitative methods. *Journal of Mixed Methods Research*, 1(1), 48–76.
- Morize, V., Nguyen, D., Lorente, C., & Desfosses, G. (1999). Descriptive epidemiological survey on a given day in all palliative care patients hospitalized in a French university hospital. *Palliative Medicine*, 13(2), 105–117.
- Morris, Z. S., Fyfe, M., Momen, N., Hoare, S., & Barclay, S. (2014). Understanding hospital Admissions Close to the End of Life (ACE) Study. *BMC Health Services Research*, 13(1). <https://doi.org/10.1186/1472-6963-13-89>
- Morrow, S. L. (2005). Quality and trustworthiness in qualitative research in counseling psychology. *Journal of Counseling Psychology*, 52(2), 250–260.
- Mount, B., Cohen, R., MacDonald, N., Bruera, E., & Dudgeon, D. J. (1995). Ethical issues in palliative care research revisited. *Palliative Medicine*, 9(2), 165–155.

- Murray, S. A., Kendall, M., Boyd, K., & Sheikh, A. (2005). Illness trajectories and palliative care. *British Medical Journal*, *330*, 1007–1011. doi:10.1136/bmj.330.7498.1007
- Murray, S. A., Kendall, M., Carduff, E., Worth, A., Harris, F., Lloyd, A., . . . Sheikh, A. (2009). Use of serial qualitative interviews to understand patients' evolving experiences and needs. *British Medical Journal*, *339*(b3702), 958–962.
- National health needs assessment for palliative care. Phase 2 report: Palliative care capacity and capability in New Zealand*. (2013). Wellington, New Zealand.
- A national professional development framework for palliative care nursing in Aotearoa New Zealand*. (2014). Wellington, New Zealand: Ministry of Health.
- National survey of bereaved people (VOICES): England, 2015*. (2016). Retrieved from England: <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/system/bulletins/nationalsurveyofbereavedpeoplevoices>.
- Nelson, J., Puntillo, K., Pronovost, P., Walker, A., McAdam, J., Ilaoa, D., & Penrod, J. (2010). In their own words: patients and families define high quality palliative care in the intensive care unit. *Critical Care Medicine*, *38*(3), 808-818.
- The New Zealand Health Strategy: Future Directions*. (2016). Wellington Retrieved from <http://www.health.govt.nz/publication/new-zealand-health-strategy-2016>, accessed September 2017.
- New Zealand palliative care: A working definition*. (2007). Wellington, New Zealand: Ministry of Health, New Zealand.
- Nicholson, C., Meyer, J., Flatley, M., & Holman, C. (2013). The experience of living at home with frailty in old age: A psychosocial qualitative study. *International Journal of Nursing Studies*, *50*(9), 1172–1179.
- Nutley, S. M., Davies, H. T. O., & Mannion, R. (2000). Organisational culture and quality of health care. *Quality in Health Care*, *9*, 111–119.
- O'Callaghan, A., Laking, G., Frey, R., Robinson, J., & Gott, M. (2014). Can we predict which hospitalised patients are in their last year of life? A prospective cross-sectional study of the Gold Standards Framework Prognostic Indicator Guidance as a screening tool in the acute hospital setting. *Palliative Medicine*. doi:pii: 0269216314536089
- O'Leary, N., & Tiernan, E. (2008). Survey of specialist palliative care services for noncancer patients in Ireland and perceived barriers. *Palliative Medicine*, *22*, 77–83.
- Ong, C.-K. (2005). Embracing Cicely Saunders's concept of total pain. *British Medical Journal*, *331*(7156), 576–577.
- Onwuegbuzie, A. J., & Leech, N. L. (2005). On becoming a pragmatic researcher: The importance of combining quantitative and qualitative research methodologies. *International Journal of Social Research Methodology*, *8*(5), 375–387.
- Orb, A., Eisenhauer, L., & Wynaden, D. (2000). Ethics in qualitative research. *Journal of Nursing Scholarship*, *33*(1), 93–96.
- The Ottawa Charter for Health Promotion. (1986). Retrieved from www.who.int/healthpromotion/conferences/previous/ottawa/en/
- Parker, C., Barnes, S., McKee, K., Morgan, K., Torrington, J., & Tregenza, P. (2004). Quality of life and building design in residential and nursing homes for older people. *Ageing and Society*, *24*(6), 941–962.
- Pastrana, T., Junger, S., Ostgathe, C., Elsner, F., & Radbruch, L. (2008). A matter of definition: Key elements identified in a discourse analysis of definitions of palliative care. *Palliative Medicine*, *22*(3), 222–232. doi:10.1177/0269216308089803.

- Patel, A., Dunmore-Griffith, J., Lutz, S., & Johnstone, P. (2014). Radiation therapy in the last month of life. *Reports of Practical Oncology and Radiotherapy, 19*(3), 191–194.
- Payne, S., Burton, C., Addington-Hall, J., & Jones, A. (2010). End-of-life issues in acute stroke care: A qualitative study of the experiences and preferences of patients and families. *Palliative Medicine, 24*(2), 146–153.
- Péus, D., Newcomb, N., & Hofer, S. (2013). Appraisal of the Karnofsky Performance Status and proposal of a simple algorithmic system for its evaluation. *BMC Medical Informatics and Decision Making, 13*(72). doi:10.1186/1472-6947-13-72
- Pinnock, H., Kendall, M., Murray, S. A., Worth, A., Levack, P., Porter, M., . . . Sheikh, A. (2011). Living and dying with severe chronic obstructive pulmonary disease: Multi-perspective longitudinal qualitative study. *British Medical Journal, 342*:d142, 1–10.
- Pitre, N., & Myrick, F. (2007). A view of nursing epistemology through reciprocal interdependence: Towards a reflexive way of knowing. *Nursing Philosophy, 8*, 73–84.
- Pivodic, L., Pardon, K., Miccinesi, G., Alonso, T. V., Moreels, S., Donker, G. A., . . . Van den Block, L. (2015). Hospitalisations at the end of life in four European countries: A population-based study via epidemiological surveillance networks. *Journal of Epidemiology and Community Health. doi:10.1136/jech-2015-206073*
- Powell, A. E., & Davies, H. T. O. (2012). The struggle to improve patient care in the face of professional boundaries *Social Science & Medicine, 75*, 807–812.
- Pringle, J., Johnston, B., & Buchanan, D. (2015). Dignity and patient-centred care for people with palliative care needs in the acute hospital setting: A systematic review. *Palliative Medicine, 29*(8), 675–694.
- Proot, I. M., Abu-Saad, H. H., Crebolder, H. F. J. M., Goldsteen, M., Luker, K. A., & Widdershoven, G. A. M. (2003). Vulnerability of family caregivers in terminal palliative care at home: Balancing between burden and capacity. *Scandinavian Journal of Caring Sciences, 17*(2), 113–121.
- Quill, T. E., & Abernethy, A. (2013). Generalist plus specialist palliative care: Creating a more sustainable model. *New England Journal of Medicine, 368*(13), 1173–1175. doi:10.1056/NEJMp1215620
- Randall, F., & Downie, R. (2010). *The philosophy of palliative care*. Oxford, England: Oxford University Press.
- Rattray, J., & Jones, M. C. (2007). Essential elements of questionnaire design and development. *Journal of Clinical Nursing, 16*(2), 234–243.
- Report of the national advisory committee on palliative care*. (2001). Retrieved from <http://health.gov.ie/wp-content/uploads/2014/03/nacpc.pdf>
- Review of adult palliative care services in New Zealand*. (2016). Wellington, New Zealand.
- Reyniers, T., Deliens, L., Pasman, H. R., Stichele, V., Sijnave, B., Cohen, J., & Houttekier, D. (2016). Reasons for end-of-life hospital admissions: Results of a survey among family physicians. *Journal of Pain and Symptom Management, 52*(4), 498–506.
- Reyniers, T., Houttekier, D., Cohen, J., Pasman, H., & Deliens, L. (2014). What justifies a hospital admission at the end of life? A focus group study on perspectives of family physicians and nurses. *Palliative Medicine. doi:10.1177/0269216314522317*
- Reyniers, T., Houttekier, D., Cohen, J., Pasman, H. R., & Deliens, L. (2014). The acute hospital setting as a place of death and final care: A qualitative study on perspectives of family physicians, nurses and family carers. *Health and Place, 27*, 77–83.

- Rigby, J., Payne, S., & Froggatt, K. (2010). What evidence is there about the specific environmental needs of older people who are near the end of life and are cared for in hospices or similar institutions? A literature review. *Palliative Medicine*, 24(3), 268–285.
- Robinson, J. (2015, September 2). Are there any benefits to hospital admissions for people with palliative care needs? [Blog post]. Retrieved from <https://eapcnet.wordpress.com/2015/09/02/are-there-any-benefits-to-hospital-admissions-for-people-with-palliative-care-needs/>
- Robinson, J., Boyd, M., O’Callaghan, A., Laking, G., Frey, R., Raphael, D., Snow, B. and Gott, M. (2014). The extent and cost of potentially avoidable admissions in hospital inpatients with palliative care needs: A cross-sectional study. *BMJ Supportive and Palliative Care*. doi:0.1136/bmjspcare-2014-000724
- Robinson, J., Gardiner, C., Gott, M., & Ingleton, C. (2017). Specialist palliative care nursing and the philosophy of palliative care: A critical discussion. *International Journal of Palliative Nursing*, 23(7), 352–358.
- Robinson, J., Gott, M., Frey, R., Gardiner, C., & Ingleton, C. (2017a). Circumstances surrounding hospital admissions in palliative care: A cross-sectional survey of patients admitted to an acute hospital with palliative care needs. *Palliative Medicine*. Under review.
- Robinson, J., Gott, M., Frey, R., Gardiner, C., & Ingleton, C. (2017b). Predictors of patient-related benefit, burden and feeling safe in relation to hospital admissions in palliative care: A cross-sectional survey *Palliative Medicine*. doi:10.1177/0269216317731991
- Robinson, J., Gott, M., Gardiner, C., & Ingleton, C. (2015c). A qualitative study exploring the benefits of hospital admissions from the perspectives of patients with palliative care needs. *Palliative Medicine*, 29(8), 703–710. doi:10.1177/0269216315575841
- Robinson, J., Gott, M., Gardiner, C., & Ingleton, C. (2016d). The ‘problematization’ of palliative care in hospital: An exploratory review of international palliative care policy in five countries. *BMC Palliative Care*, 15(64). doi:10.1186/s12904-016-0137-0
- Robinson, J., Gott, M., & Ingleton, C. (2014). Patient and family experiences of palliative care in hospital: What do we know? An integrative review. *Palliative Medicine*, 28(1), 18–33. doi:10.1177/0269216313487568
- Robinson, J., Gott, M., Ingleton, C., & Gardiner, C. (2015). The impact of the environment on experiences of hospital admissions from the perspectives of patients with palliative care needs. *BMJ Supportive and Palliative Care*, Under review.
- Robson, C. (2011). *Real world research: A resource for users of social research methods in applied settings* (3rd ed.). Chichester, England: Wiley and Sons.
- Rocker, G., Dodek, P., & Heyland, D. (2008). Toward optimal end-of-life care for patients with advanced chronic obstructive pulmonary disease: Insights from a multicentre study. *Canadian Respiratory Journal*, 15(5), 249–254.
- Rogers, A., Karlsen, S., & Addington-Hall, J. (2000). ‘All the services were excellent. It is when the human element comes in that things go wrong’: Dissatisfaction with hospital care in the last year of life. *Journal of Advanced Nursing*, 31(4), 768–774.
- Rolfe, G. (2006). Validity, trustworthiness and rigor: Quality and the idea of qualitative research. *Journal of Advanced Nursing*, 53(3), 304–310.
- Rosenwax, L., McNamara, B., Murray, K., McCabe, R., Aoun, S., & Currow, D. (2011). Hospital and emergency department use in the last year of life: A baseline for future modifications to end of life care. *Medical Journal of Australia*, 194, 1–4.

- Rosenwax, L., Spilsbury, K., McNamara, B., & Semmens, J. (2016). A retrospective population based cohort study of access to specialist palliative care in the last year of life: Who is still missing out a decade on? *BMC Palliative Care*, *15*(46). <https://doi.org/10.1186/s12904-016-0119-2>
- Rowland, C., Hanratty, B., Pilling, M., van den Berg, B., & Grande, G. (2017). The contributions of family care-giving at end-of-life: A national post-bereavement census survey of cancer carers' hours of care and expenditures. *Palliative Medicine*, *31*(4), 346–355.
- Rowlands, J., & Noble, S. (2008). How does the environment impact on the quality of life of advanced cancer patients? A qualitative study with implications for ward design. *Palliative Medicine*, *22*(6), 768–774.
- Russ, A., & Kaufman, S. (2005). Family perceptions of prognosis, silence and “suddenness” of death. *Culture, Medicine and Psychiatry*, *29*(1), 103–122.
- Rutty, J. (1998). The nature of philosophy of science, theory and knowledge related to nursing and professionalism. *Journal of Advanced Nursing*, *28*(2), 243–250.
- Sale, J. E. M., Lohfeld, L. H., & Brazil, K. (2002). Revisiting the quantitative–qualitative debate: Implications for mixed-methods research. *Quality and Quantity*, *36*(1), 43–53.
- Salisbury, H., Bosanquet, N., Wilkinson, E. K., Franks, P. J., Kite, S., Lorentzon, M., & Naysmith, A. (2009). The impact of different models of specialist palliative care on patients' quality of life: A systematic literature review. *Palliative Medicine*, *13*(1), 3–17.
- Sandelowski, M. (1986). The problem of rigor in qualitative research. *Advances in Nursing Science*, *8*(3), 27–37.
- Saunders, C. (1993). Hospice. *Mortality*, *1*(3), 317–321.
- Saunders, C., Summers, D. H., & Teller, N. (1981). *Hospice: the living idea*. London: Edward Arnold
- Schiller, C. (2016). Critical realism in nursing: An emerging approach. *Nursing Philosophy*, *17*(2), 88–102.
- Schofield, D. J., & Earnest, A. (2006). Demographic change and the future demand for public hospital care in Australia, 2005 to 2050. *Australian Health Review*, *30*(4), 507–515. doi:<http://dx.doi.org/10.1071/AH060507>
- Seale, C. (1995). Dying alone. *Sociology of Health & Illness*, *17*(3), 376–392.
- Seale, C. (1998). *Constructing death: The sociology of dying and bereavement*. Cambridge, England: Cambridge University Press.
- Seale, C., & Kelly, M. (1997). A comparison of hospice and hospital care for people who die: Views of the surviving spouse. *Palliative Medicine*, *11*(2), 93–100.
- Seale, C., & van der Geest, S. (2004). Good and bad death: introduction. *Social Science and Medicine*, *58*, 883–885.
- Seow, H., Brazil, K., Sussman, J., Pereira, J., Marshall, D., Austin, P. C., . . . Barbera, L. (2014). Impact of community based, specialist palliative care teams on hospitalisations and emergency department visits late in life and hospital deaths: A pooled analysis. *British Medical Journal*, *348*:g3496. doi:10.1136/bmj.g3496
- Seymour, J. (2012). Looking back, looking forward: The evolution of palliative and end of life care in England. *Mortality*, *17*(1), 1–17.
- Seymour, J., Clark, D., Hughes, P., Bath, P. A., Beech, N., Corner, J., . . . Webb, T. (2002). Clinical nurse specialists in palliative care. Part 3. Issues for the Macmillan Nurse role. *Palliative Medicine*, *16*(5), 386–394.

- Seymour, J., & Gott, M. (2011). The challenges of health technology for ageing and dying. In M. Gott & C. Ingleton (Eds.), *Living with ageing and dying* (pp. 42–51). Oxford, England: Oxford University Press.
- Seymour, J., Payne, S., Chapman, A., & Holloway, M. (2007). Hospice or home? Expectations of end-of-life care among white and Chinese older people in the UK. *Sociology of Health & Illness*, 29(6), 872–890.
- Shattell, M., Hogan, B., & Thomas, S. P. (2005). “It’s the people that make the environment good or bad”. The patient’s experience of the acute care hospital environment. *Advanced Critical Care*, 16(2), 159–169.
- Sheer, B., & Wong, F. (2008). The development of advanced nursing practice globally. *Journal of Nursing Scholarship*, 40(3), 204–211.
- Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for Information*, 22(2), 63–75.
- Sherman, D. W., Matzo, M., & Metheny, T. (2015). The interprofessional practice of palliative care nursing. In M. Matzo & D. W. Sherman (Eds.), *Palliative care nursing: quality care to the end of life* (4th ed.) (pp. 3–20). New York, NY: Springer Publishing Company.
- Simoens, S., Kutten, B., Keirse, E., Berghe, P. V., Beguin, C., Desmedt, M., . . . Menten, J. (2010). The costs of treating terminal patients. *Journal of Pain & Symptom Management*, 40(3), 436–448. doi:10.1016/j.jpainsymman.2009.12.022
- Sitzia, J., & Wood, N. (1997). Patient satisfaction: A review of issues and concepts. *Social Science & Medicine*, 45(12), 1829–1843.
- Sivell, S., Prout, H., Hopewell-Kelly, N., Baillie, J., Byrne, A., Edwards, M., . . . Nelson, A. (2015). Considerations and recommendations for conducting qualitative research interviews with palliative and end of life care patients in the home setting: A consensus paper. *BMJ Supportive and Palliative Care*. doi:10.1136/bmjspcare-2015-000892
- Skilbeck, J., & Seymour, J. (2002). Meeting complex needs: An analysis of Macmillan nurses’ work with patients. *International Journal of Palliative Nursing*, 8(12), 574–582.
- Skilbeck, J. K., Payne, S. A., Ingleton, M. C., Nolan, M., Carey, I., & Hanson, A. (2005). An exploration of family carers’ experience of respite services in one specialist palliative care unit. *Palliative Medicine*, 19(8), 610–618.
- Slyter, S., Pienaar, C., Williams, A. M., Proctor, K., & Hewitt, L. (2015). Finding privacy from a public death: A qualitative exploration of how a dedicated space for end-of-life care in an acute hospital impacts on dying patients and their families. *Journal of Clinical Nursing*, 24(15–16), 2164–2174.
- Sleeman, K. E., Davies, J. M., Verne, J., Gao, W., & Higginson, I. (2015). The changing demographics of inpatient hospice death: Population-based cross-sectional study in England, 1993–2012. *Palliative Medicine*. doi:10.1177/0269216315585064
- Solano, J. P., Gomes, B., & Higginson, I. J. (2006). A comparison of symptom prevalence in far advanced cancer, AIDS, heart disease, chronic obstructive pulmonary disease and renal disease. *Journal of Pain and Symptom Management*, 31(1), 58–69.
- Spichiger, E. (2008). Living with terminal illness: Patient and family experiences of hospital end-of-life care. *International Journal of Palliative Nursing*, 14(5), 220–228.
- Spichiger, E. (2009a). Being in the hospital: An interpretive phenomenological study of terminally ill cancer patients’ experiences. *European Journal of Oncology Nursing*, 13(1), 16–21. doi:10.1016/j.ejon.2008.10.001

- Spichiger, E. (2009b). Family experiences of hospital end-of-life care in Switzerland: An interpretive phenomenological study. *International Journal of Palliative Nursing*, 15(7), 332–337.
- Spilsbury, K., Rosenwax, L., Arendts, G., & Semmens, J. (2017). The association of community based palliative care with reduced emergency department visits in the last year of life varies by patient focus. *Annals of Emergency Medicine*, 69(4), 416–425.
- Stajduhar, K., Allan, D., Cohen, S., & Heyland, D. (2008). Preferences for location of death of seriously ill hospitalized patients: Perspectives from Canadian patients and their family caregivers. *Palliative Medicine*, 22, 85–88.
- Stajduhar, K. I., Martin, W. L., Barwhich, D., & Fyles, G. (2008). Factors influencing family caregivers' ability to cope with providing end of life cancer care at home. *Cancer Nursing*, 31(1), 77–85.
- Stjernsward, J., Foley, K. M., & Ferris, F. (2007). The public health strategy for palliative care. *Journal of Pain and Symptom Management*, 33(5), 486–493. doi:doi:10.1016/j.jpainsymman.2007.02.016
- Strategic plan for action on palliative and end of life care 2016–2021*. Retrieved from <http://www.gov.scot/Publications/2015/12/4053>
- Sykes, N., Pearson, S. E., & Chell Resea, S. (1992). Quality of care of the terminally ill: The carer's perspective. *Palliative Medicine*, 6, 227–236.
- Tanaka, A., Iwamoto, T., Kaneyasu, H., & Petrini, M. A. (1999). Thoughts and feelings of inpatients with advanced terminal cancer: Implications for terminal care improvement. *Nursing and Health Sciences*, 1(3), 189–193.
- Tang, S., & McCorkle, R. (2003). Determinants of congruence between the preferred and actual place of death for terminally ill cancer patients. *Journal of Palliative Care*, 19(4), 230–237.
- Tashakkori, A., & Teddlie, C. (2008). Quality of inferences in mixed methods research: Calling for an integrative framework. In M. M. Bergman (Ed.), *Advances in mixed methods research: Theories and applications* (pp. 101–119). London, England: SAGE.
- Tashakkori, A., & Teddlie, C. (2010). *Sage handbook of mixed methods in social and behavioural research* (Second ed.). Thousand Oaks, CA: SAGE.
- Temel, J. S., Greer, J. A., Muzilansky, A., Gallagher, E. R., Admane, S., Jackson, V. A., . . . Lynch, T. J. (2010). Early palliative care for patients with metastatic non-small-cell lung cancer. *The New England Journal of Medicine*, 363(8), 733–742.
- Teno, J., Clarridge, B., Welch, L., Wetle, T., Shield, R., & Mor, V. (2004). Family perspectives on end-of-life care at the last place of care. *Journal of the American Medical Association*, 29(1), 88–93.
- The SUPPORT Principal Investigators. (1995). A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). *Journal of American Medical Association*, 274(20), 1591–1598.
- Thomas, C., Morris, S., & Clark, D. (2004). Place of death: Preferences among cancer patients and their carers. *Social Science & Medicine*, 58(12), 2431–2444.
- To, T., Greene, A., Agar, M., & Currow, D. (2011). A point prevalence survey of hospital inpatients to define the proportion with palliation as the primary goal of care and the need for specialist palliative care. *Internal Medicine Journal*, 41(5), 430–433.

- Tong, A., Sainsbury, P., & Craig, J. (2007). Consolidated criteria for reporting qualitative research (COREQ): A 32 item checklist for interviews and focus groups. *International Journal of Quality in Health Care*, *19*(6), 349–357.
- Tsai, F.-C. (2008). Personhood and autonomy in multicultural health care settings. *American Medical Association Journal of Ethics*, *10*(3), 171–176.
- Turner, D. W. (2010). Qualitative interview design: A practical guide for novice investigators. *The Qualitative Report*, *15*(3), 754–760.
- van der Steen, J. T., Dekker, N. L., Gijssberts, M. H. E., Vermeulen, L. H., Mahler, M. M., & The, A. B. (2017). Palliative care for people with dementia in the terminal phase: A mixed methods qualitative study to inform service development. *BMC Palliative Care*, *16*(28). doi:10.1186/s12904-017-0201-4
- Wade, D. T., & Halligan, P. W. (2004). Do biomedical models of illness make for good healthcare systems? *British Medical Journal*, *329*(7479), 1398–1401.
- Waghorn, M., Young, H., & Davies, A. (2011). Opinions of patients with cancer on the relative importance of place of death in the context of a ‘good death’. *BMJ Supportive and Palliative Care*, *1*(3), 310–314. doi:10.1136/bmjspcare-2011-000041
- Wallace, E. M., Walsh, J., Conroy, M., Cooney, M. C., & Twomey, F. Why do palliative care patients present to the Emergency Department? Avoidable or unavoidable? *American Journal of Hospice and Palliative Medicine*. Retrieved from doi:10.1177/1049909112447285
- Wallace, M., Grossman, S., Campbell, S., Robert, T., Lange, J., & Shea, J. (2009). Integration of end of life care content in undergraduate nursing curricula: Student knowledge and perceptions. *Journal of Professional Nursing*, *25*(1), 50–56.
- Walling, A. M., Asch, S. M., Lorenz, K. A., Roth, C. P., Barry, T., Kahn, K. L., & Wenger, N. S. (2010). The quality of care provided to hospitalized patients at the end of life. *Archives of Internal Medicine*, *170*(12), 1057–1063.
- Walsh, B., & Laudicella, M. (2017). Disparities in cancer care and costs at the end of life: Evidence from England’s national health service. *Health Affairs*, *36*(7), 1218–1226.
- Walters, G. (2004). Is there such a thing as a good death? *Palliative Medicine*, *18*(5), 404–408.
- Ward, S., Gott, M., Gardiner, C., Cobb, M., Richards, N., & Ingleton, C. (2012). Economic analysis of potentially avoidable hospital admissions in patients with palliative care needs. *Progress in Palliative Care*, *20*(3), 147–153.
- Wassenaar, A., Schouten, J., & Schoonhoven, L. (2014). Factors promoting intensive care patients’ perception of feeling safe: A systematic review. *International Journal of Nursing Studies*, *51*(2), 261–273.
- Watson, J. (2003). Love and caring: Ethics of face and hand, an invitation to return to the heart and soul of nursing and our deep humanity. *Nursing Administration Quarterly*, *27*(3), 197–202.
- Watson, M. J. (1988). New dimensions of human caring theory. *Nursing Science Quarterly*, *1*(4), 175–181.
- Webb, P. T. (2014). Policy problematization. *International Journal of Qualitative Studies in Education*, *27*(3), 364–376. doi:10.1080/09518398.2012.762480
- Whittemore, R., & Knafl, K. (2005). The integrative review: Updated methodology. *Journal of Advanced Nursing*, *52*(5), 546–553.
- WHO definition of palliative care. (2015). Retrieved from <http://www.who.int/mediacentre/factsheets/fs402/en/>

- Wilkinson, E. K., Salisbury, H., Bosanquet, N., Franks, P. J., Kite, S., Lorentzon, M., & Naysmith, A. (1999). Patient and carer preference for, and satisfaction with, specialist models of palliative care: A systematic literature review. *Palliative Medicine*, *13*(3), 197–216.
- Williams, A. M. (2002). Changing geographies of care: Employing the concept of therapeutic landscapes as a framework in examining home space. *Social Science & Medicine*, *55*(1), 141–151.
- Williams, A. M., Dawson, S., & Kristjanson, L. (2008). Exploring the relationship between personal control and the hospital environment. *Journal of Clinical Nursing*, *17*(12), 1601–1609.
- Williams, C., & Gardiner, C. (2015). Preference for a single or shared room in a UK inpatient hospice: Patient, family and staff perspectives. *BMJ Supportive and Palliative Care*, *5*(2), 169–174.
- Wilson, F., Ingleton, C., Gott, M., & Gardiner, C. (2014). Autonomy and choice in palliative care: Time for a new model? *Journal of Advanced Nursing*, *70*(5), 1020–1029.
- Worth, A., Boyd, K., Kendall, M., Heaney, D., Macleod, U., Cormie, P., . . . Murray, S. (2006). Out of hours palliative care: A qualitative study of cancer patients, carers and professionals. *British Journal of General Practice*, *56*(522), 6–13.
- Young, A., Rogers, A., Dent, L., & Addington-Hall, J. (2009). Experiences of hospital care reported by bereaved relatives of patients after a stroke: A retrospective survey using the VOICES questionnaire. *Journal of Advanced Nursing*, *65*(10), 2164–2174.
- Zimmerman, C., & Rodin, G. (2004). The denial of death thesis: Sociological critique and implications for palliative care. *Palliative Medicine*, *18*(2), 121–128.