Palliative Care In Hospital: Perceptions of Care.

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Sarah Waghorn

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Abstract

In New Zealand, as in many other developed countries, a large number of people die in a hospital setting (Broad, Gott & Boyd, 2013). Based on New Zealand's growing and aging population, this number is expected to increase (Ministry of Health, 2001). Previous studies have investigated how family members perceive palliative care, but there is still a lack of understanding of how families perceive this care in hospital and in particular in a New Zealand context. This research investigated how family members experienced a patient's palliative care in a medical ward in a New Zealand hospital.

Seven participants who were next-of-kin/contact person for an individual who had passed away while on a medical ward in a New Zealand hospital three to 12 months prior took part in semi-structured interviews which were analysed using thematic analysis. As a result of the analysis, five themes were identified: Physical environment, interactions with staff, communication regarding palliative care, identifying and accepting death, and care after death.

These results have implications for the way in which palliative care is provided in New Zealand hospitals. Through the consideration of these factors, the experience of next-of-kin/contact people can be improved.

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Chapter One: What is Palliative Care

Palliative care is an approach to care that originated in the 1960's. It is an approach to the medical care of an individual which is focused on providing relief from the symptoms of a serious illness, without the intention of providing a cure. Palliative care originated within the hospice environment and is well understood within this context, however with more deaths worldwide occurring in hospitals, it is important to understand how palliative care is used in the acute hospital setting. The core belief of palliative care is that the patient and the family are treated with respect throughout the dying process in order to allow the patient a "good death".

Previous research has defined the concept of a good death as one in which there is acceptance, awareness, and preparation for death (Hart, Sainsbury & Short, 1998). The need to understand the role palliative care plays in the dying experience of a patient is important as it will allow health professionals to ensure they are providing the best possible care to palliative patients.

It has been difficult in the past to assess palliative care as often patients are too unwell to take part in research during the time they are under palliative care. Researchers have thus used family members as proxies for the patients. Family members are often deeply involved in the care of a patient, spending a significant amount of time with the patient in the

months and days leading up to their death, developing their own understanding of the palliative care which the patient receives (Williams, Woodby, Bailey & Burgio, 2008).

The following chapters will provide an overview of palliative care, its definition and its implementation in New Zealand, discuss the location of deaths and the importance of high quality palliative care in hospitals, define and discuss the concept of a good death and examine the ways in which care can be assessed from the view of a family member.

Palliative Care

Palliative care is an approach to care that began to gain momentum in Europe in the early 1960s (Duffin, 2014). Palliative care is believed to have originated as a result of the work of Dame Cicely Saunders who opened the St.Christopher's Hospice in London in 1967 (Duffin, 2014; Clark, 1998). Dame Saunders was one of the first medical professionals to recognise the importance of the multi-dimensional approach to care and the need to incorporate emotional and psychological support to the patient and to the family.

In North America, Dr Balfour Mount was a driver of the palliative care movement and was one of the first to coin the term "palliative care". The use of this term originated due to his concern that people would avoid hospice care as a result of its negative association with death and he felt that palliative care was a better way of describing the approach to care whereby the suffering of the patient would be alleviated (Bruce, 2006).

Palliative care in New Zealand was not a major focus of the Ministry of Health until 1999 when, as a response to a number of issues raised by palliative care providers the Ministry of Health and Health Funding Authority initiated a five-ten year strategy for palliative care services (Ministry of Health, 2001).

The World Health Organisation's (WHO) original definition of palliative care was focused on patients who were not responding to treatment and was seen as a final stage of care when medical staff would aim to alleviate the symptoms of an illness without the expectation of a cure (Sepulveda, Marlin, Yoshida & Ullrich, 2002). This led to a focus of care on the patient and their physical needs as they approach death. A different approach to palliative care is now taken, with the WHO broadening its definition to incorporate the spiritual and emotional aspects of well-being and to consider the needs of the family who are facing bereavement.

The WHO now defines palliative care for adults as "an approach 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, n.d)

 Palliative care aims to:
- "provide relief from pain and other distressing symptoms;
- affirm life and regard dying as a normal process;
- intend neither to hasten or postpone death;

- integrate the psychological and spiritual aspects of patient care;

- offer a support system to help patients live as actively as possible until death;

- offer a support system to help the family cope during the patient's illness and in their own bereavement;

- use a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;

- enhance quality of life, and may also positively influence the course of illness;

- be applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications" (WHO, n.d)

It is now accepted that the best practice for the treatment of an individual under palliative care involves prioritising the comfort of the patient, but also providing support to the family and caregivers throughout the illness and after the death.

Palliative Care in New Zealand

Palliative care practice in New Zealand hospitals is guided by the Palliative Care Strategy (Ministry of Health, 2001), a document which is the result of the identification of an increasing number of problems in providing palliative care to patients by care providers.

The vision of this strategy is that "all people who are dying and their family/whanau who could benefit from palliative care services have

timely access to quality palliative care services that are culturally appropriate and are provided in a co-ordinated way" (Ministry of Health, 2001, p.7).

The palliative care strategy recognises the need for improved delivery of palliative care in New Zealand, in particular in relation to Māori and Pacific peoples. This document identifies that Māori and Pacific peoples in particular have specific needs when it comes to palliative care. It is important to understand the specific needs and practices that exist within these cultures around death and dying and ensure that care providers are equipped to meet these needs. Through the implementation of models such as whanau-centred nursing and Te Whare Tapa Wha, palliative care providers will be better equipped to meet the needs of these groups (Moeke-Maxwell, 2014; Rochford, 2004)

End-of- life care

In medical terminology, the end-of-life is seen as the period prior to natural death during which medical care is unlikely to prevent death (Lamont, 2005). During this time period, care should be supportive and focused on controlling symptoms rather than invasive care focused on extending life. Watson (2005), describes end-of-life care as an aspect of palliative care, referring to the period of time (often days or weeks) in which it is clear that the individual is in a developing state of decline. Once it has been identified that death is approaching, often the patient is placed on a specific care pathway and the patient and friends/family are made aware of the changes to treatment that will take place.

Russell, 2015 and Hui et al. (2014) have discussed the difficulties with defining palliative care and the terms associated with this area. Often terms such as end-of-life care and palliative care are used interchangeably and are not clearly defined. This can be challenging for both researchers and for family members who may struggle to understand the care the patient is receiving. For the purposes of this research, we have focussed specifically on the period of time in which the patient is seen to be at the end-of-life due to an admission to hospital with a treatment focus on support and control of symptoms rather than cure. The term palliative care was used throughout interviews and analysis as this was the way in which medical staff at this hospital referred to the care the patient received and thus the participants understood the care in this way.

Where do deaths occur
Studies on place of death around the world have shown that many individuals under palliative care show a preference for dying in their home or in a hospice setting rather than in a hospital (Evans, Finucane, Vanhegan, Arnold, & Oxenham, 2014; Holdsworth, & Fisher, 2010). Patients with advanced illness who have spent time in a hospice previously often show a preference for death to occur there, perhaps due to familiarity with staff and the environment, and they may be distressed at the thought of passing away in an unfamiliar environment (Evans et al., 2014). The hospital environment is perceived by some family members to be an inadequate atmosphere in which to provide palliative care due to the general focus on life saving, an inability to identify the palliative needs of a patient and the clinical atmosphere (Brereton et al.,

2011; Reyniers, Houttekier, Cohen, Pasman & Deliens, 2014; Witkamp, van Zuylen, Borsboom, van der Rijt & Heida, 2015). Similar studies in New Zealand have found that in a clinical setting it is not always easy to predict death and a focus on the active treatment of patients and eventual cure may lead to a difficulty in staff providing quality palliative care to a patient and their family (Sheward, Clark, Marshall and Allan, 2011; Gott et al.,2013).

Despite a hospital not being the preferred place of death for the majority of the population, with the proportion of the population over 65 years expected to double within the next 50 years (Ministry of Health, 2001) it is expected that the demands on hospitals to provide high-quality palliative care will increase. Currently, the majority of deaths worldwide are occurring in hospital and this is only expected to increase. Broad et al. (2013) found in an analysis of place of death across 40 countries that on average 54% of deaths occurred in hospital, 12% in residential aged care and 32% in other locations. 78% of deaths in Japan occurred in hospital, 58% of deaths in England, 47% of deaths in the USA, 54% of deaths in Australia and 34% of deaths in New Zealand occurred in hospitals. These statistics are in line with those presented by the Palliative Care Council of New Zealand (2014) who reported that in New Zealand between 2000 and 2010 34.2% of all deaths occurred in hospital, 30.7% of deaths occurred in residential aged care, 22.3% in a private residence, 6% in a hospice inpatient unit and 6.7% in other locations.

This shows a clear need for high-quality palliative care to be provided throughout hospitals in New Zealand. While The New Zealand Palliative Care Strategy (Ministry of Health, 2001) outlines ways in which care should be provided, due to a lack of research in this area it is unclear if the currently provided care is meeting the standard.

Chapter Two: How do we assess care?

Having defined palliative care and recognised the need for high quality services to be available in hospitals in particular, it is now necessary to consider the ways in which the quality of palliative care services in hospitals can be assessed.

The Liverpool Care Pathway (LCP) is a palliative care pathway that has been adapted for use in New Zealand hospitals to guide staff through treating patients who fall under palliative care services. This pathway is designed to facilitate staff discussion with both the patient and the family members and is a process which creates a detailed record of the care given. By considering the use of the LCP in care, it is possible to identify the most important aspects of palliative care and assess how these are received by the patient and family.

A good death is defined by Hart et al. (1998) as a death in which there is acceptance, awareness and preparation for death and in which the death itself is peaceful and dignified. This concept has been used in prior research to define the essential aspects of a good death, and then to assess family and patient experiences in order to determine if the patient was afforded a good death (Aleksandrova-Yankulovska & ten Have, 2015; Cipolletta & Oprandi, 2014; Vig, Davenport & Pearlman, 2002).

Finally, family member's perceptions of care have also been used in previous research to identify both the aspects of care that are being well attended too and those which require further attention (Robinson, Gott and Ingleton, 2014). The family member's perceptions are seen in the literature

to be extremely important, as the surviving family members are in a position to offer a unique insight into not only the quality of care the patient received at the end-of-life, but the services and facilities that are available for families at this time (Addington-Hall & McPherson, 2001; Williams et al., 2008)

Liverpool Care Pathway

The LCP was developed by the Marie Curie Hospice and the Royal Liverpool University Hospital following the identification of poor nursing care and a lack of support in the final stages of a terminal illness when the patient was in hospital (Chojnacka, 2012). The intention of the LCP was to take the fundamentals of best practice in palliative care from the hospice setting and apply them in an acute hospital setting. The hospice model of care was thus adapted to create the LCP which intended to improve the care of the patient and ensure they were afforded a good death, regardless of the care setting (Becker, 2013; Chojnacka, 2012; Neuberger et al., 2013).

The LCP is primarily a tool for medical staff to follow which creates a structured record of the patient's care and can be particularly helpful for hospital staff without palliative care expertise; it is a holistic model which takes into account the emotional, social and spiritual needs not only of the patient but of the friends and family. Once on this pathway the patient will not be subjected to unnecessary tests or treatments, with the focus on maintaining comfort and dignity (Clark, Sheward, Marshall & Allan, 2012; Neuberger et al., 2013).

The LCP involves three stages: initial assessment, ongoing assessment and care after death (Becker, 2013). During initial assessment the patients current needs are identified, this includes identification of symptoms and pain which will be managed and any existing medical treatments the patient is receiving. During ongoing assessment, the staff consider pain management and symptom management in order to ensure that the patient is comfortable. The staff also consider the psychological wellbeing of both the patient and the patient's family members. Care after death requires the staff to verify the death, and provide support and practical information for the family regarding the next steps they should take (Becker, 2013). Each of these stages involves interaction and communication with the patient and the patient's family members and documentation of the communication and the next steps and goals in the care of the patient.

The LCP allows us to identify some important aspects of palliative care which can be used to assess the quality of the care a patient receives. The LCP identifies pain and symptom management, communication and family care as important aspects of palliative care (Chojnacka, 2012; Clark et al., 2012; Constantini et al., 2014; Duffy, Payne & Timmins, 2011).

The LCP has been found by Constantini et al. (2014) and Clark et al. (2012) to have a positive effect on the staff member's confidence and knowledge of palliative care. Staff who used the LCP reported feeling more confident providing pain and symptom relief to patients. Chojnacka, (2012) identifies the importance of a pain free death for both the patient, and the family who can become distressed when seeing a family member in pain. Here the LCP can be used in a positive manner to facilitate a better dying experience for

not only the patient and the patient's family but also a better care experience for the medical staff who are involved in providing the care.

Following the implementation of the LCP, it was found that there was an increase in the attention paid to the family member's emotional and spiritual needs, the family member's self-efficacy improved and the family felt the patient was treated with greater dignity and kindness (Constantini et al., 2014). This is an important factor to consider in the quality of care, as family members who feel they have been well supported may be more likely to report positive experiences of care, both for themselves and for the patient.

Communication between staff and the patient and the patient's family is the final important aspect of palliative care that the LCP identifies. Clark et al. (2012) found that staff members felt using the LCP led to improved end-of-life care and assisted with staff communication regarding death. Effective and successful communication is a vital part of end-of-life care and can be challenging for both family members and staff members (Chojnacka, 2012). The LCP assists staff in identifying how best to communicate with the patients and their family members to ensure that they clearly receive the necessary information and are given the opportunity to discuss any concerns they may have with the medical staff (Chojnacka, 2012). Communication can be seen to be an important factor to consider when assessing the quality of care as it can impact greatly on the experience of the family members.

Dying a good death

The concept of a good death is important in palliative care and is one of the main outcomes that health professionals try to achieve. However this term can be difficult to define given the large number of factors which can influence a death, and the individualistic nature of death, what is seen as a good death by one may be seen as a bad death by another (Cipolletta & Oprandi, 2014). Although there is no clear cut definition of what constitutes a good death, previous studies agree on the concept of a good death being broadly defined as one in which there is acceptance, awareness, and preparation for death (Hart, Sainsbury & Short, 1998). Factors such as comfort and pain control, place of death, maintaining dignity, dying quickly and without pain, and feeling one has lived their life to the full are factors which many individuals, their families and health professionals identify as being an important aspect of a good death (Aleksandrova-Yankulovska & ten Have, 2015; Cipolletta & Oprandi, 2014; Granda-Cameron & Houldin, 2012; Vig et al., 2002).

Comfort and pain control. Borbasi, Wotton, Reddon & Chapman, (2005) identified the importance of managing the patients pain and symptoms. A lack of managing the patient's pain and symptoms is aligned with a bad death as nurses feel they have not fulfilled the patient's needs.

The patient can be concerned about the pain associated with dying, and frightened of the symptoms associated with imminent death such as struggling to breathe (Gott, Small, Barnes, Payne & Seamark, 2008). Holdsworth, (2015) found that patients who did not experience good symptom management and pain control were more distressed in the last

days of life and were more likely to express a wish for euthanasia/ assisted dying as a result of the pain they were feeling and their fear of death.

Place of Death. The place of death has been identified as an important factor which affects the concept of a good death, however it varies in importance from individual to individual. While many view a good death as one which occurs in their own home, others prefer the more clinical atmosphere of the hospital.

Those who feel dying at home contributes to a good death feel that in this environment they are the most relaxed and it is the natural way to die compared to what is described as the clinical experience of dying in a hospital. Even those patients who express a desire to spend their final days at home or to die at home express some concern about the burden this places on their family members (Gott et al., 2008, Cipolletta & Oprandi, 2014; Paddy, 2011).

Some patients express a wish to die in a more clinical atmosphere such as a hospital, this is often due to the patients wish to not be a burden on family members or a desire to maintain their dignity for as long as possible. For patients who no longer have family members to be with them, dying in hospital alleviates their fear of dying alone (Gott et al., 2008, Cipolletta & Oprandi, 2014; Paddy, 2011).

Maintaining Dignity. The importance of maintaining dignity in patients at the end-of-life is also seen as another important aspect of a good death. Miyashita et al. (2008) found that having a private room for the patient at the end-of-life was positively correlated with an enhancement in

the patient's dignity. Having a private space in which to spend their last days was reported as enabling patients to maintain a feeling of self-worth and meant they did not have to worry about other patients seeing them in pain or dying.

Factors such as deterioration in appearance, becoming a burden to others, and needing assistance with things such as toileting and bathing were all factors that contributed to a patient's lack of dignity (Cipolletta & Oprandi, 2014). While Cipolletta and Oprandi, (2014) acknowledge that there is not a vast amount of research into this aspect of a good death, they suggest that maintaining the patients dignity through clear and open communication around their needs can enable a greater sense of dignity.

Dying quickly and without pain. Aleksandrova-Yankulovska & ten Have, (2015) found dying without pain and suffering to be the most common factor in a good death. Patients express a wish to die without pain, and for some this means a wish to die in their sleep. Patients see dying in their sleep as a way to achieve a good death as they perceive dying in this way to be fast and without pain.

Others see a death from an event such as a heart attack as a good death as there is not a period of prolonged illness before the death (Vig et al., 2002) while death from a terminal illness such as cancer is seen as a bad death as there is a period of pain and suffering leading up to the death.

Feeling of living life to the full. The concept of living life to the full, also incorporates the patients need to acknowledge that death is imminent. When this is the case, the patients feel more at ease as they are

able to put in place measures to support their families, and have ample opportunity to say the important goodbyes that they feel are necessary (Holdsworth, 2015). Miyashita et al. (2008) found that the patient's age was related to the concept of a good death, with the deaths of the older patients being viewed as a good death. This could be due to the belief that at an older age, the patient has lived a full life and therefore has earned the right to die which a younger life has not.

Families perceptions of palliative care in hospital

When considering the concept of a good death, it is important to consider it from the viewpoint of the family members. Family members are often deeply involved in the care of a patient, spending a significant amount of time with the patient in the months and days leading up to their death and developing their own understanding of the palliative care which the patient receives (Williams et al., 2008). This means that not only are the family members uniquely situated to offer an insight into the care of a patient, but they are deeply involved in their care. The memory of a loved one's death stays with an individual for a lifetime and a bad experience can be detrimental to the wellbeing of the family member who will continue to relive the experience in the years to come (Marco, Buderer & Thum, 2005). The importance of the family is seen in the WHO definition of palliative care which identifies the physical, psychological and emotional needs of the family members as a priority for care providers.

The current international literature on family or next-of-kin views on palliative care in hospitals has led to the identification of factors which

family members believe affect the quality of care. These factors are varied and were synthesised by Robinson et al. (2014) into five primary themes: symptom control and burden, communication with health professionals, decision making related to patient care and management, inadequate hospital environment and interpersonal relationships with health professionals. The current literature on family views of palliative care in hospital will be discussed under the five common headings identified by Robinson et al. (2014)

Hospital environment. One of the common themes amongst the literature (Bird, Candy, O'Malley, and Maden-Jenkins, 2011; Caswell, Pollock, Harwood & Porock, 2015; Slatyer, Pienaar, Williams, Proctor & Hewitt, 2015) was the negative impact the hospital environment can have on the dying experience and the need for a private space in which the patient could die comfortably and with dignity. Having a private space in which their family member could die comfortably is of utmost importance to relatives (Bird et al., 2011; Caswell et al., 2015; Slatyer et al., 2015). Through the provision of a dedicated space separate from the main hospital ward, families feel more at ease and able to spend time with their loved ones before their death. By creating a space which is larger and more private from the main ward, family members are able to take part in physical cares for the patient and they feel there is a decrease in the clinical atmosphere that is felt in a standard hospital ward. The private room is also better suited for families to conduct traditional cultural practices associated with dying which they may not be able to conduct in a shared room. Providing a private room for patients at the end-of-life can also make discussions with medical

staff and the delivery of bad news an easier task for the staff and for family members who may feel uncomfortable asking questions or expressing emotion while in a shared room.

General hospital wards have been identified by family members as busy, clinical environments in which the focus of care is cure rather than comfort. By providing private spaces for patients who are receiving palliative care, these barriers to quality care are removed and both patients and families feel more at ease.

Communication. Communication is identified as being of great importance to family members when evaluating the care that the patient received. Communicating with the family gives them an opportunity to ask questions and raise concerns regarding the care of the patient, it acts as a form of support for the family, and allows the family to better prepare for the death as they are aware of what is going on (Bussman et al., 2015; Heyland et al., 2006; Marco et al., 2005; Steinhauser, Voils, Bosworth & Yulsky, 2015). Family members have been found to perceive hospital staff as too busy to answer their questions, they use medical jargon which makes it hard for the family members to understand what is being said, and fail to communicate effectively that the patient is being treated under palliative care. This has a negative impact on the family members who feel that the staff are unwilling to talk to them about their relative's status, and they are ill prepared for the death that will occur.

Decision making. Decision making in regard to patient care and management is closely linked with communication. Family members who

are involved by medical staff in the treatment and care of the patient tend to be more satisfied with the quality of care the patient receives (Baker et al., 2000; Young, Dent & Addington-Hall, 2009). Involving the family in the decision making process ensures they feel more comfortable and that their opinions matter. Family members perceive themselves as the voice of the patient who may be unable to communicate and thus they feel that it is their job to ensure that care is provided the way the patient would want. Families who are not involved in the decision making process often lack knowledge of the patient's condition and may be ill prepared when death occurs.

Symptom control. In order for families to feel the patient has been afforded a good death, symptom control and burden must be well managed. The literature currently shows this as one of the most important aspects of good quality palliaitive care, yet it is also the factor which most families report dissatisfaction with (Robinson et al., 2014). It is considered important for family members that the patient die without pain, and it is distressing for the family if they perceive the patient to be in pain during the final days of hours of their life (Bussman et al., 2015). Family members who perceive that the patients pain levels and other symptoms are well managed describe the death as peaceful and the quality of care as high (Steinhauser et al., 2015).

Relationships with staff. The final factor which families perceive affects the quality of care is the interpersonal relationships with health professionals. Families felt reassured by medical staff that went out of their way to care for the patient or for the family (Spichiger, 2009). This was often by staff bending the rules to allow the family to stay longer with the

patient, taking the time to sit and talk with the family, making cups of tea etc. By exhibiting qualities such as kindness and empathy the staff were better able to connect with the families which allowed for easier communication and clarity around the care of the patient (Bussman et al., 2015). Medical staff who appear to be too busy or uninterested in the care of the patient have a negative impact on the families perception of care with family members feeling that the staff lack respect for the patient and their needs (Steinhauser et al., 2015).

Previous research has identified five overarching themes which are perceived by family members as having an impact on the quality of care received by the patient. These five themes: symptom control and burden, communication with health professionals, decision making related to patient care and management, inadequate hospital environment and interpersonal relationships with health professionals are not an exhaustive list but do provide a general insight into the essential factors that the family perceive to affect the quality of palliative care in hospitals.

Chapter Three: Approach to research

Following the previous review of the literature, a number of important

factors in the quality of palliative care were identified. The importance of

assessing quality of care in order to ensure hospitals provide a high level

of palliative care to patients and their families has been discussed and the

factors which influence quality of palliative care have been discussed.

However, Robinson et al., (2014) review on palliative care in hospitals

has identified that there is a lack of information regarding family

experiences of palliative care in acute care situations. Furthermore, there

is to date no research available which specifically investigates the view

of family members on palliative care in hospitals in New Zealand. In

order to address this lack of research on palliative care in New Zealand

hospitals, the following research aim and goals were developed.

How do family members experience a patient's palliative care on a medical

ward in a New Zealand hospital?

From this primary question three more specific research goals were

developed:

- Investigate how family members experience a patient's palliative
  care in the hospital setting.
- Identify ways in which their experience of care could be changed to
  make it an easier and more manageable time for the family
  members.

- Identify what effect the hospital environment has on the family member's experience.

The intention of this thesis was to explore family member's views and experiences of the palliaitive care that an individual received while in hospital in order to contribute to the current literature regarding palliative care in hospitals.

Methodology

To answer the research questions, qualitative research methods have been used in this study. This approach was adopted due to the nature of these questions which are focused on the individual's experience, and thus cannot be adequately explored without considering the context in which the event took place and the meaning which the individual brings to it (Crowe, Inder, & Porter, 2015). As we were interested in investigating the experience of the individual, qualitative methods allowed the researcher to gain an in-depth look at the participants experience and the personal meaning which they have associated with the experience. This cannot be represented in the same detail by numerical quantitative methods (Pistrang & Barker, 2012). While it is possible to undertake qualitative research from a number of theoretical stances, this research employs a realist theoretical framework which follows the belief that there is a real world, which can be accurately described through the investigation of an individual's experience. Therefore an individual's experience and the meaning which accompanies it can be reported by the researcher (Braun & Clarke, 2006; Pistrang & Barker, 2012).

Chapter Four: Method

Summary of study

This research explored the palliative care received by patients on a medical ward in a New Zealand hospital. In order to gain an insight into the palliative care that a patient receives while in hospital the views of the family members of a person who passed away in hospital were examined. Semi-structured interviews were carried out with individuals who were listed as next-of-kin or as primary contact person on the patients' medical records. The interview data was then transcribed and analysed using thematic analysis.

Hospital context

This study focused on the families of individuals who received palliative care while on a medical ward within a hospital in New Zealand. The hospital has 350 beds in total and provides care for a population catchment of 160,000 people. The specific ward in which this study was conducted is an acute medical ward for patients who require acute medical care. The ward has 32 beds, six of which are in single rooms. The ward also has a family room. The family room was created in 2013 as a direct response to staff concern regarding the lack of single rooms and the conditions of these existing single rooms which the staff felt did not have adequate space for family to support the dying person and are a very clinical environment.

The family room, as it is known, is larger than a standard single room and has a kitchenette with a small fridge and microwave, a radio and CD player, 2 La-Z-Boy fold out chairs, and art work on the wall. Patients who have

been placed on the LCP or have signed a not for resuscitation form are prioritised for this room.

Participants

The intended participants in this study were the family members of a patient who had received palliative care as an acute inpatient within a medical ward in the hospital. In order to access these participants those who were listed as next-of-kin or as the contact person for an individual who had passed away while in the hospital were contacted. As a result of this, six participants were family members and one participant was the patient's power of attorney and long-time friend. These individuals were selected for this study as previous research has shown that family members and those close to an individual are able to act as a reliable proxy when it comes to evaluating the care the individual receives in hospital (Fowler, Coppola & Teno, 1999; Williams et al., 2008). A total of seven participants took part in this study. Their details are outlined in Table 1 below; all participants have been assigned pseudonyms in order to protect their true identity.

Table 1

Participant Characteristics

Pseudonym	Relationship to the deceased	Age	Ethnicity
Laura	Daughter	64	European
Billy	Son in law	63	European
Janet	Friend	82	British
Claire	Daughter	58	New Zealand European
Elizabeth	Wife	74	New Zealand European
Linda	Daughter	53	European Fijian
Mary	Wife	71	New Zealand European

Procedure

In order to identify potential participants, a third party from the hospital accessed patient mortality data from the medical ward within the hospital for the previous three to 12 month period which identified a total of 60 potential participants. Deaths that occurred between the Christmas period of 12 December 2014 and12 January 2015 (N=9) were excluded due to the significance of this time in many people's lives. Working retrospectively, the discharge summaries of patients were reviewed in clusters of 10 to avoid any unnecessary review of patient information and the discharge summaries were accessed in order to identify potential participants. To be sure that the participants would have a full experience of the palliative care in hospital individuals who did not have a complete discharge summary (N=5), whose death was unexpected (N=9), and who had been in hospital for less than 72

25

hours prior to death were excluded (N=13). Individuals who lived more than an hour's drive (N=4) from the location of the hospital were also excluded from the study due to the time restraints of the researcher. This resulted in 20 individuals meeting the participation criteria.

From the remaining discharge summaries the third party then identified next-of-kin or contact person details in the form of a contact phone number. The third party made initial contact with the next-of-kin or contact person to explain the purpose of the study and how their contact details had been obtained. They then enquired if it would be acceptable to send an introductory letter (Appendix One) and an information letter (Appendix Two) regarding the study from the researcher and if so a current postal address was obtained. Those who chose to receive the information were then sent an introductory letter from the third party on behalf of the hospital and an information sheet from the researcher regarding the study.

Participants were requested to reply to the researcher within two weeks using an enclosed postage paid envelope or through phoning an 0800 number to leave their contact details should they wish to participate. This procedure was repeated until all possible participants had been contacted. In total, four of the 20 individuals were unable to be contacted, and one declined the sending of information. A total of 15 letters were sent, with responses received from six individuals.

Interviews

Those who returned the contact form or rang the 0800 number were contacted by the researcher and invited to participate in an interview. They

were given the option of having this interview take place in their home or at Massey University. Two participants chose to be interviewed at Massey University while the remaining five were interviewed in their own homes. All participants were invited to have a support person with them for the duration of the interview. One individual chose to do so, and her husband subsequently became the seventh participant. The interviews were semi-structured and followed an interview schedule (Appendix Three) with guiding questions and prompts which were used as necessary by the researcher. Before the interview commenced, the researcher explained the purpose of the study and asked the participants if they had any questions, it was explained to the participants that the interview would be recorded and transcribed. The participants all signed a consent form (Appendix Four) and were given the option of having their transcripts returned to them prior to the analysis taking place. Four participants chose not to have their transcripts returned and signed an authority to release transcript form (Appendix Five) at the conclusion of the interview. Three participants chose to review their transcripts and a meeting was arranged following transcription during which the participant was able to review the transcript and make any changes. All participants were gifted a pot plant at the conclusion of the interview to thank them for taking part.

Data Analysis

Data was analysed using thematic analysis following the procedure outlined by Braun and Clarke (2006). The data was analysed using an inductive, semantic approach. Inductive thematic analysis means that the themes which result from the data are closely linked to the data itself, and the data

is coded without trying to fit it into a pre-existing set of codes or themes and as such it is not driven by the researcher's interest in the topic (Braun & Clarke, 2006). Taking a semantic approach to analysis means that the themes are identified from the explicit meaning of the data, the researcher does not look beyond what the participant has said and the themes represent a summary of the patterns from within the data and their meanings and implications (Braun and Clarke, 2006).

The data was transcribed verbatim by the researcher and the transcript was then checked against the original recording for accuracy. The transcripts were read numerous times to increase familiarity with the data. The data was then systematically coded to identify ideas and common language between the interviews. These were then grouped into similar ideas and synthesised into themes. These themes were consolidated into five final themes which the researcher felt gave an accurate portrayal of the ideas contained within the data set.

Ethical issues

Bereavement research often uses the next-of-kin or family members as a proxy to describe or evaluate the care received from the patient prior to their death. The next-of-kin or family member is able to share their view on the patient's palliative care experience which allows an evaluation of care and can assist in changes being made to the provision of care (Addington-Hall & McPherson, 2001; Bentley & O'Connor, 2015; Curtis et al., 2002; Williams et al., 2008). However it is important to ensure the participants in bereavement research have the capacity to provide informed consent, their

memory of the event is intact, that participating in the research is not distressing and that their confidentiality is maintained.

To ensure that the participants were able to give their full informed consent, the third party from the hospital discussed the research with them, and they were then given the option of being posted an information letter prior to taking part. The study was again explained to them by the researcher before the interview commenced. The participants were encouraged to ask any questions they may have before the interview or at any time during or after the interview. The participants all signed a consent form (Appendix 5) prior to the interview taking place.

Williams et al. (2008) discuss the difficulty of balancing the time of recruitment with the wish to cause no distress to the participant and ensuring that taking part is not a burden. Contacting individuals post-bereavement can become difficult the more that time elapses as bereavements can lead to changes in living arrangements, while the time passing can also affect the individual's recall of the event. Likewise, if the individual is contacted too close to the bereavement they may not be in a position to give their full informed consent and may be at risk of harm. McPherson and Addington-Hall (2003) also discuss this issue and conclude that the shorter the time period between the event and the recollection the better the memory will be. However the shorter the time period the more likely the participant may be distressed by discussing the event.

 Bentley and O'Connor (2015) found that bereaved carers felt it was appropriate for research to take place within the first five months of

bereavement as they felt their memory of the event was clear and they would be able to recall details more accurately. Their participants also felt that talking about the experience was beneficial as it allowed them to reflect on the experience and it had a therapeutic effect for them personally.

To address this issue, a minimum time period of three months post-bereavement and a maximum of 12 months was decided on. It was felt that this would allow the research to decrease distress to the participants while also maximising the potential for complete memory recall. Contact was made initially through a phone call and secondly through a letter which left the decision to participate firmly in the hands of the individual. Participants were encouraged to contact their GP or bereavement support services if they found discussing the death traumatic.

It was important in this research to maintain the confidentiality of the participants and of the bereaved individual as well. This was managed by using a third party from the hospital as a go-between. The third party identified deaths which met the research criteria and then contacted the next-of-kin or patient contact person to explain the study and ask if they may be interested in receiving further information. This ensured that the researcher had no access to patient files or confidential information regarding the clinical care of the patient. The researcher only had contact with individuals who were interested in the study and thus chose to make contact.

Ethical approval for this study was sought and obtained from the Massey University Human Ethics Committee Southern A, Application 15/37

(Appendix Six). Organisational approval was also obtained from the

hospital (Appendix Seven).

Chapter Five: Results

In this chapter the themes that emerged from the data collected in this research project are described and supported with examples. These five themes were: Identifying and accepting death, physical environment, interactions with staff, communication regarding palliative care, and the death.

Identifying and accepting death

The participants in this study took time to reflect on the patients' health and well-being prior to the hospitalisation. The participants who could identify that the patient had been unwell for some time prior to their hospitalisation had an easier time identifying and accepting that the death was imminent. Most of the patients suffered from a number of co-morbidities and as such the hospitalisation did not come as a surprise. The knowledge that their loved one was unwell and had been for some time made it easier to identify that death was close to occurring and to accept the death of their loved one.

For Claire, whose father was hospitalised, she was aware that he had been un-well and that being admitted to hospital was not a good sign:

> "He had a had a lovely long life. For the last ahh maybe five years he had quite bad health and he had a heart condition…So we were sort of you know knowing that you know things weren't gonna you know probably end that well for him last year"

For her this was good as it allowed her and her family to recognise the approaching death and cope with it accordingly:

"I think it was really good because, I, we'd, realised straight away that you know what we were dealing with"

Elizabeth was aware of her husband's declining health:

"Well he was in and out uhm about the last 4 years he's been in and out he went over in the ambulance 3 or 4 times with respiratory failure"

While upset about the hospitalisation she recognised that he had been unwell for a long time and did not want to see him suffer:

"But uhm but he hadn't been well for a long time poor old fella. I could not wish him to carry on he just got worse…No as much as I didn't want to lose him I didn't want to see him suffering"

These participants found it easier to come to terms with their family member being hospitalised and treated under palliative care as they saw it as a natural progression and an alleviation of pain and suffering. There were however some participants who did not immediately recognise the gravity of the situation and as such had a harder time coming to terms with the reality that their loved one was going to die.

For Mary the hospitalisation of her husband was a shock as prior to the hospitalisation he had maintained good health which made it harder for her to accept his impending death as she initially expected him to make a full recovery:

"I was thinking Timothy would come home and I would be nursing him"

Linda's mother was hospitalised and although she had been unwell for a number of years prior there was a rapid decline in the health of her mother which lead to her hospitalisation and this came as a shock for her:

> *"She was extremely active and believed very much in the physical activity and she was instructed to just keep going and she did and she lived a very very full life and in fact bred dogs so she was very very busy uhm so that before she got sick she was just a fully active person although greatly disabled by that point and she had been becoming more and more frail and disabled towards that time when she died it was December last year uhm but it still came as quite a shock when she realised or she was told that she had an enlarged heart and at that point she was very very ill and only just managing to get through her day and very quickly she she found herself in hospital"*

While the initial hospitalisation was a shock to Linda, she quickly came to terms with it:

> *"She felt that she'd lived long enough and achieved all she felt she needed to achieve and uhm she had end stage heart failure and she knew that and basically she got to a point where she couldn't stand up and we kind of knew that was getting near the end"*

Janet was surprised by her friend's admission to hospital despite her previous illness:

> *"it was really odd the day before she went into hospital I'd had I'd taken in afternoon tea and we'd had it in her room ahhh so it I was*

amazed to have a very very early phone call the next day saying we've

just sent her off to hospital"

However, she quickly came to the understanding that she would not be
making a recovery due to a clear conversation with the medical staff:

"It was explained to us that it was no longer well she put in her will

that she no longer wanted to be resuscitated so that was that"

Physical Environment

The physical environment in the hospital greatly influenced the family
member's experiences. Two participants had a family member who was
initially in a shared room in which there are four beds separated by curtains
before being moved to the family room which is a private room with only
one bed. One participant's mother was in a shared room for the duration of
her time in hospital while the remaining four had family members in the
family room. The environment in each of these rooms differed, and the
change in environment contributed to the participants comfort in the
hospital setting and their perception of the hospital setting as a suitable
environment for palliative care.

The participants whose family member was cared for in the shared room felt
that the environment in the shared rooms created a lack of privacy which
left them unable to openly talk to their loved ones as death approached.
They also felt that by being cared for in a shared room, the patient was
negatively affected as they were unable to settle and relax due to disruptions
by the other patients in the room and visitors coming and going.

For Linda it was upsetting to be with her mother in a shared room once she understood that her mother was probably dying:

> *"Because we knew what was happening we were pretty aware we had spoken to a doctor and she had said well she might not get out of here and on that understanding was upsetting to know that she had to share"*

She felt her mother was distressed by the presence of other patients in the room and that there was a lack of privacy for her and other family members to say goodbye and spend time with their mother in her final days:

> *"From our point of view it was very hard not to be able to say special things to her and she was conscious and we managed to say the essential special things but there were other things that we would have liked to have talked about but we couldn't do that"*

Janet's friend was initially admitted into a shared room and later moved to the family room. She felt that being in the shared room was hard for her friend who had poor hearing and vision and was aware of people coming and going from the room but was unsure who they were:

> *"I think it would have been much harder on her with people coming in if she couldn't see them her sight was very poor hearing was very poor even if she couldn't see she would be agitated by the comings and goings"*

Mary's husband was also initially in a shared room and then shifted into the family room. She was unhappy while he was in the shared room due to the

lack of privacy this offered to the patients and the fact that there were both women and men in the same room:

> *"I think it's horrible especially when behind the curtain the woman was talking about her bowels all the time and you know the doctor and she was very upset about it all and ah and talking in a loud voice and it's not very nice....there were other men in the room and I think perhaps I'm old fashioned"*

The experience of the participants whose family member was cared for in the family room was quite a contrast. In general they described feeling at ease, able to have large numbers of visitors, felt no pressure to leave the hospital, and felt the patient was also a lot more comfortable due to the facilities available in the room which were not available in the shared room.

Claire's father was in the family room and this had a positive effect on her experience:

> *"It was great it was fantastic actually I didn't realise they had that and it made a huge difference…*
>
> *You know because we'd been in that situation on the other side because dad was in and out of hospital so often and we did have times when we were visiting him and somebody was actually dying the next bed and that is rough man that is horrible"*

The large room meant they were able to have a number of people in the room at any one time and the facilities meant they were able to comfortably stay overnight:

"We had different family members coming in all the time and yeah we had a nice space and we could have meals there and uhm could sleep there if we wanted to in the chairs it was perfectly fine"

Laura and Billy's mother was also in the family room and they felt the physical environment there provided all they needed:

"…we had it was like a double single room so two singles put together and that had a little kitchen and a fridge and a microwave and all the cutlery and crockery in there ahh it had 4 La-Z-Boy chairs in it and a couple of normal sitting chairs and hand basin and light dimmers uhm the atmosphere was really good. Mum thought it was heaven she said is this really a hospital?"

…So there was some pictures around the wall, there was a stereo, it was perfect. It covered everything for us, you don't need anything more than a La-Z-Boy to sleep in…the staff gave us all the blankets all the pillows everything we would need"

While Laura felt the family room suited their needs, she did identify that the lack of facilities available for showering were a downfall of the hospital environment. While she and her husband were able to return home as this was nearby she pointed out that for those traveling from further away there were no facilities for this:

"Seriously there needs to be a place where you can go and refresh where you can have a shower…. even if it's down on that ground floor

> *where the public toilets and that are there needs to be somewhere there*
> *where you can have a shower and freshen up"*

The environment in the family room was perceived as far better than the
environment in the shared room. The shared room with its radio and C.D
player, comfortable chairs and facilities to prepare hot drinks and food was
perceived by family members to have a positive influence on their
experience. Not only did this provide comfort for the participants but it was
perceived as a better environment for the patient. In particular, being able to
play music for the patient was seen as one important way of helping to calm
and relax them:

> *"And there was a radio with uhm cassettes so we were able to play her*
> *music which seemed to help calm her" (Janet)*

> *"That was good they had some suitable C.D's there but we brought*
> *our own C.D's up and put them on so that was quite good" (Mary)*

For Elizabeth having her husband in the family room meant that both she
and his brother were able to stay overnight as there were La-Z-Boy chairs in
the room. Elizabeth discussed the importance to her of being able to stay
with her husband and not leave his side in his final days. She felt that having
him cared for in the family room allowed her to spend this quality time with
him. She would have found it distressing if she had not been able to stay in
the room with him over night:

> *"We sat in the hard La-Z-Boy chairs and oh they were hard so yeah we*
> *just we stayed with him the night before he died we weren't leaving him*

even if the others had gone I wouldn't have left him I stayed there all night"

The size and location of the room was seen as a positive as this allowed other family members to be in the room and offered the family members privacy from other visitors coming and going from the same ward. For Elizabeth the larger room meant that when her husband passed away he was surrounded by family:

"Yeah it was quite a big room and there was about I'd say about 7, 8 of us there with him you know before he died or my brother and his wife came in just after uhm but the rest of us were all there. It'd be terrible for him to die alone"

Claire also felt that the physical location of the room on the ward was good as it meant they had more privacy and did not have to interact with other patients:

"And I mean the great thing about that too is about its physical location it's as you come into the ward you didn't have to walk through down the whole length of the corridor to get there I thought that was quite nice coz you don't really want to be up against a whole lots of other people"

Interestingly, one participant commented that while the hospital environment may be suitable for many, families from larger backgrounds or cultures may struggle with the hospital environment:

"If the hospital could ever consider having a whanau room or a block or just whether it's a little lounge that you can have with a washroom and that off it that would definitely help I don't know how a Māori family would get on when you might have a lot of them"

Three of the participants discussed the parking at the hospital as an aspect of the physical environment which affected their experience of care in the hospital. Elizabeth was surprised that there were not better parking facilities available for the families of patients. She felt that the cost of parking was a burden to her family and one which they should not have to worry about with a family member who was approaching the end-of-life:

"When your there a long time you'd think they'd have a place set aside for people that are there cost a fortune for parking... one night we were there the guy in the thingy there he only charged us 5 dollars and we'd been there nearly all day but uhm other than that you know you've gotta pay the hourly rate and it gets quite expensive"

Laura expressed concern that the cost of parking was a struggle for her brother and worried that as a result of this he may not be able to spend as much time there as he would have liked:

"The other thing was, minor but if you haven't got the funds the parking was horrendous...we'd been there since Friday so it was costing us I think 7 dollars maximum but for Billy and I was okay but for my brother it was probably becoming a struggle"

Mary refused to park in the paid hospital parks, but her motives behind this were not financial and were based on her belief that it was wrong to make visitors pay to see loved ones who were unwell:

> *"That parking's a big thing you know why should you pay to go and visit your loved ones in the you know the hospital, it's horrible, terrible, I refuse to park in the parking you know on principle"*

The hospital was able to offer Laura a swipe card to allow her access to free car parking, however while this could have been a solution to her concern with parking, the lack of communication around the use of the card was almost as distressing as the lack of a card:

> *"The knowledge that if you park in the wrong carpark, that card doesn't do anything"*

> *"The card does nothing because you've got to give that to the guards for them to clip it you can't put it into the mouth the thing and just have the gates open"*

This is an important aspect of the hospital environment to consider as it has clearly impacted on the participants perception of care within the hospital. If families were unable to afford the cost of parking then they may not be able to spend as much time as they would like with the patient and could be left with a negative impression of the hospital environment. While there are measures in place to support these families as Laura identified through the use of the scan card, this needs to be more clearly communicated to families.

Interactions with staff

The interactions between staff and the patient and between staff and the family affected the way in which the family members viewed the quality of care the patient received. There were a number of positive interactions mentioned by participants which had an uplifting effect and reassured the family that the patient was receiving the best care possible. There were some negative interactions with the staff and these had an impact on the way in which the family members viewed the care the patient was receiving. The family members were able to recognise that these interactions were not personalised to either themselves or the patient and felt that they were due to external pressures or miscommunication between themselves and the staff.

The participants felt the staff displayed empathy and compassion when dealing with the patients and greatly appreciated the time the staff took to engage, not only with the patient but with them:

> *"They were very gentle with you know dealing with her" (Janet)*

> *"The staff were just amazing they were really. really supportive" (Billy)*

> *"They were awesome they really. really were, they were they respected her dignity which I was deeply grateful for" (Linda)*

> *"If you asked them for anything they were just so willing to do it or help you" (Elizabeth)*

Claire felt that the medical staff included her in the care of her father and as a result she felt involved in the care and like she was part of a larger care team. The positive interactions she had with the staff built her confidence in

her view of the care and thus it was easier for her to speak out when she felt the care was not of an adequate standard:

> *"One of the night shift nurses was I didn't think uhm particularly sympathetic but you know we basically ignored her but and you know and she did withhold pain relief from him that wasn't good but you know I just went out and had a chat with somebody else on the ward and they just came in and did it"*

For Laura and Billy it was important for them to be involved in the care of their mother/mother in law. While they had no desire to take part in the medical cares, they felt it was their place to care for her as much as possible and felt privileged that they were able to do so:

> *"With most of the staff they were wonderful they would come in and they would do all the cares for her and we were more than happy to do the sponge down and care for her in any way that we could the professional nursing we felt was their place to do"(Laura)*

> *"It was a privilege to look after her and from a caring point of view it didn't really bother either of us how long it took if it had taken a couple of weeks, if it had taken a year it just that was just one of those things we were perfectly happy with that" (Billy)*

It was also reported by participants that the staff were concerned not only about the patient's well-being, but theirs as well. Simple acts such as bringing the family members cups of tea and checking in on them made the participants feel more at ease in the hospital setting:

> *"I felt that they were very kind considering that they are very busy people and you know we got offered cups of tea and there was always somebody there in the room anyway a medical staff member if my memory serves me correctly they had somebody stationed there and uhm I felt that if I needed anything I only needed to ask, they were fabulous they were all really awesome" (Linda)*

> *"we had the same person for basically 2 days so we kinda got to know her and we had some confidence in her" (Laura)*

Mary discussed a difficulty in obtaining information from the medical staff. She felt that there were too many different people involved in the care of her husband and that as a result each individual involved was not aware of what the other was doing. She felt that as a result of this each medical professional assumed the others had checked up on her and her understanding of the situation when in actual fact it was not made clear to her what was occurring:

> *"I think there's too many people involved I think that's what it was and I think probably one person was relying on the other person to do their bedside chat with me and perhaps it didn't really happen?"*

Elizabeth felt that the care her husband received was negatively impacted by the pressure the staff were under and that had there been more staff available the care her husband received would have been of a much higher quality:

> *"The only thing wrong with the care while he was in the wards was the nurses are so busy when they want to go to the toilet they've gotta wait for so long for someone to come and take them"*

Some participants also expressed concern that care over weekends and on public holidays was not as good as the care received during weekdays. Laura felt that the care her mother received differed greatly. While she was happy with the care and support during normal workdays, she felt the care over ANZAC weekend was below the expected standard and was concerned about this:

> *"And I think generally it comes down to the fact that it's a weekend, a long weekend which made it even worse and being ANZAC weekend uhm like nobody came to see us about palliative care until Tuesday and we'd gone in there on the Friday"*

Elizabeth also thought that there was less support available to her and her husband over the weekend and at night. This had a negative impact on her perception of care as she felt that the staff should be available to provide support and care at all hours of the day, not just during normal working hours:

> *"Palliative care is 24 hours I mean for families it's not between 9-5 Monday to Friday that's your final stages that you shouldn't even have to think about oh people go home. Oh it's a weekend no wonder"*

Claire also identified a change in care over the weekend compared to during the week but was quite understanding of this and it did not appear to impact her perception negatively:

> *"I think actually what happened was that I think dad was shifted in there on either the Friday or Saturday so that the first 2 days were a*

weekend and that quite different and I understand that very different

thing at the hospital there aren't just the same number of staff around

but certainly by the Monday uhm there were more people" (Claire)

Communication regarding palliative care

Communication with the participants regarding palliative care occurred in

one of three ways: through a conversation with the medical team, through a

conversation with the palliative care team, or through the reading of

pamphlets in the patient's room.

Mary did not have a clear conversation with the medical team regarding

palliative care and obtained her understanding of palliative care from the

pamphlet in her husband's room. She was not made aware of her husband's

prognosis by the medical staff and as a result of this she relied heavily on

this pamphlet to understand his condition:

> *"I was wondering what the prognosis would be and what was really*
>
> *happening and well it was only because of this book on the wall that I*
>
> *could read that helped me a lot"*

Mary also discussed how she attempted to initiate a conversation with some

of the medical staff about her husband's condition but felt that no one was

willing to discuss this with her. The lack of open communication from the

medical staff left her with a negative perception of the care her husband

received:

> *"There seemed to be a sort of a miscommunicate- no no no that's not*
>
> *right not miscommunication but strange that one person had that*

department and another person had this department and if you asked

somebody about the other department they sort of really weren't happy

to tell you"

Linda, Janet, Claire and Elizabeth all had discussions with doctors or
medical staff who explained to them the nature of palliative care and what it
would entail for their family member. Linda had a clear conversation with
one of her mother's doctors regarding palliative care and the LCP. During
this conversation, she felt that her opinion was valued, and the doctor
genuinely cared for Linda's well-being as well as for her understanding of
her mother's care. As a result of this conversation, Linda was more
accepting of her mother's declining condition and felt the medical staff were
doing the best they could for both her mother and for herself:

> *"her doctor was with her or came on at that time and she said Linda*
>
> *you understand what has happened that your mother is on the Liverpool*
>
> *care pathway now and mum was sleeping or something and she said*
>
> *she did actually ask me how did I feel about that and I felt that at that*
>
> *point if I had objected then something might have happened uhm which*
>
> *I deeply respect because I didn't have the ultimate say but it was*
>
> *important to the medical team as I understand it that everybody was*
>
> *okay you know they were they were coming to accepting it and that they*
>
> *just had that opportunity to say"*

Claire also had a conversation with her father's medical team about the care
he would be receiving soon after he was admitted to hospital. They
discussed with her palliative care and the LCP and this lead to a better

understanding of the care that was being provided to her father and why the medical team was doing things in a certain manner:

> *"The nursing staff I think it was or maybe even one of the registrars told us you know fairly soon after we got there about the programme they were the I can't remember what it was called…. So we sort of knew you know that's what they were using so that was great because we could understand it and they gave us some information on it and so you know I thought it was well done done really well"*

For both Linda and Claire, the clear communication regarding palliative care and the LCP was important to them and helped them to understand the care that was being given to their family member. The naming of the care practices and pathway that was being used by the medical staff was important to them as it helped to contribute towards their understanding of the care their family member was receiving.

Interestingly, Janet and Elizabeth also felt reassured by their conversation with the doctor's, although palliative care and the LCP were not explicitly named or discussed. What was important for these participants was being aware of the fact that their loved one would not be returning home and that the doctors showed compassion and understanding towards them at this time.

Janet also felt that the conversation she had with the doctor was clear and open and that he communicated with her clearly that her friend would not be recovering. She felt that he did this in a way which was respectful and understanding of the difficult time she was going through;

"The young fellow who was the doctor he he pointed out to both of us
he talked to both of us that it you know life and death they're all natural
things well we all know that uhm but he was very pleasant and he did a
good job"

Elizabeth felt the doctors communicated clearly to her that her husband
would not be recovering and returning home, and was aware that the
treatment he would be receiving for his remaining time in hospital would be
focused on comfort rather than cure:

"They just said that you know he had so much going wrong with him
that there was nothing that they could do to help him all they could do
was just keep him comfortable this uhm doctor he sat on the bed he
explained to his brother and I you know that there was nothing… we
realised that because, you know, we could see him going downhill"

Laura's experience differed to that of the other participants. When her
mother was admitted to hospital initially she had a very negative view of
palliative care and what it would mean for her mother's care while she was
in hospital:

"It was a shock to us in ED to suddenly understand that palliative care
means you're the last in the line and it makes sense its logic and
emergency departments are all about emergency it's all about people
who need to live and she'd chosen not to live at that point and so we
accepted that"

Once her mother was admitted to the ward the family were able to sit down and discuss with the doctor and her mother what palliative care was and what it would mean for her mother if she was treated in this manner. Both Laura's mother and Laura were able to voice any concerns they had regarding this approach to care and Laura felt that following this talk she had a better understanding of what palliative care would look like for her mother and was happy for her mother to be cared for in this way:

> *"She asked the doctors quite blunt things and so okay what's going to happen to me and when she got told well actually you can never go home and live alone again and uhm your heart is right at the end and there's nothing we can do to make that better we can give you your drugs that you've had and make you more comfortable or you can stop them all together and that's called palliative care where you don't have any drugs like that but we will give you comfort drugs so you won't be in any pain and won't be anxious"*

Laura questioned her understanding of palliative care following an episode in which her mother became agitated and the staff did not rush to help them. This situation was distressing for Laura as although she understood that the focus of palliative care was to provide comfort for the patient, she did not understand why the staff did not come to help her mother immediately:

> *"I could see that she was in stress and I called for help and nobody came and nobody came and nobody came and when Bruce went to find somebody they still never came and we got her over that bit of anxiety and when they arrived we were quite clearly told that do you not*

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understand that for not for resuscitation means that we don't rush to

help you"

This lead to Laura questioning her initial understanding of palliative care, she felt that a lack of clarity from the medical staff during their discussion of palliative care was in part to blame. Meeting with the palliative care team resolved her concerns regarding her mother's care and she felt supported and understood by them. Following this meeting, Laura felt that she was aware of the palliative care process and the systems that were in place to support not only her mother but her family as well:

> *"And that support was fantastic just too actually meet people from the palliative care. They made us feel on top of the world. They made us feel like we were first class people again so yeah I don't know either that's just because we'd been up against a brick wall but certainly to have professional people come in and say we understand what you're going through and are there any question you've got and how can we help you yip no they were absolutely wonderful"*

This section has highlighted the varying ways in which medical staff communicate with patients and family regarding palliative care. It shows that there are a number of ways in which effective communication can occur and that what works well for one individual may not be the best form of communication for another. This analysis stresses the need for medical staff to carefully approach communication with families in a way that is mindful and respectful of the difficult time they are experiencing and to be very clear with them when communicating.

Care after death

It was important for family members to spend time with their loved one prior to death, to be there when the death occurred and to be able to spend time with them after the death to say their goodbyes. The participants felt that staff played a vital role in facilitating this time. They ensured that the participants were able to stay as long as they needed with the patient and were made aware of what would happen next. The participants felt that they were cared for and looked after by the staff during this time.

After Linda's mother passed away she was able to spend time with her and appreciated that hospital staff and doctors who had cared for her mother came in to pay their respects:

> *"Very very good and there was somebody I think he might have been a doctor who came in and was with me for quite a while just to make sure that I was ok"*

> *"Her own doctor came in as well they just spent time they were just so quiet and respectful and just it was just very nice and there was no rush"*

Janet was not with her friend when she passed away, but was able to spend time with her body the next day and this was an important act for her:

> *"Yes somebody helped us find the way because it was quite intricate and so left us there so I remember sitting beside her and lynn was standing she could have sat uhm and it was quite a strange thing*

because I found I was just quite gently rubbing her shoulder as I had

done in hospital when she was alive. …. I think it was really necessary"

Mary felt that not only was she was able to spend enough time with her

husband after he passed away but her family was able to come up and spend

time with him as well:

> *"It was very nice because the uhm the family came up with their*
>
> *children and ah that was all nice and they didn't rush us and ah we had*
>
> *time"*

Elizabeth and Claire felt that the staff were good at this time, allowing them

adequate time and offering support:

> *"So we stayed with him about half an hour and then they come and*
>
> *asked us you know had we had enough time because they wanted to you*
>
> *know you know what they do lay them out and all the rest of it so we*
>
> *said our goodbyes to him"(Elizabeth)*

> *"We didn't feel any pressure at all uhm to you know but we did actually*
>
> *uhm we did get the undertaker quite quickly but that was because that*
>
> *was what we wanted to do and we didn't feel any pressure from the*
>
> *nursing staff" (Claire)*

For Linda the staff also provided practical help with making arrangements

for the undertaker. This practical support was greatly appreciated by Linda

as she and her family had not considered what to do after the death:

> *"You do have to arrange something to happen with the body and it's*
>
> *like well we need a phone book for all of that your just not prepared*

you don't know who you are going to phone so your hanging over the reception desk and you've got a phone book can we borrow your phone book so funny it's sort of a strange place to sort of kind of organise all of that"

Billy was with his mother in law when she passed away and returned home to pick up his wife. They were able to return to the hospital and spend time with their mother before she was taken to the mortuary and they felt that the staff were particularly kind and caring to them at this time

"It didn't take long at all maybe half an hour and within that time they had tidied her up made the bed etc and just left her there Paul was there and we spent as much time as what Laura wanted"

"When we said we were ready to go the nurse came in and explained to us fully what they were going to do with her which was really nice you know they were she was really good where she was going to take her to that she would prepare her for the funeral director etc and where she was going and all that she was really good and that was fine you know what I mean and they did she did make a point of stating that to us so that we understood what was the next step"

Chapter Six: Discussion

The aim of this research was to investigate how family members experience a patient's palliative care in a medical ward in a New Zealand hospital. More specifically this research aimed to: investigate how family members experience a patient's palliative care in a New Zealand hospital setting; identify ways in which their experience of care could potentially be changed to make it an easier and more manageable time for the family members and identify what effect the hospital environment has on the family member's experience. This was the first time family member's views on palliative care in hospital had been investigated in New Zealand. Thus, the purpose of the study was to gain insight into the views currently held regarding palliative care in hospitals and the factors which play a role in affecting these views. The present study confirmed previous findings in the international literature regarding the identification and acceptance of death, interactions with staff, communication regarding palliative care, the physical environment, and the care after death.

Identifying and accepting death was a major theme to result from this analysis and played an important role in the experience of the family members. Previous research (Reyniers et al., 2014) has shown that while families may know the patient is terminally ill, admittance to hospital can lead to the belief that it is still possible for them to be treated successfully due to the curative nature of a hospital, which can result in a lack of identification of the approaching death. This was seen in the current research where one participant assumed that her husband's admittance and treatment in hospital meant he would recover and return home. This made it

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harder for her to accept his terminal prognosis and she struggled to come to terms with the fact that he was dying.

This finding is in contrast to other research (Bussman et al., 2014), which has shown that families do not wish to see their loved one's life prolonged if they are in pain. In this study, participants saw that as the individual's illness progressed, they lost the ability to take part in their day-to-day activities and their independence. This, coupled with the family members' desire to not see the patient suffering or in pain, helped the individuals to accept the impending death of their loved one.

The findings of this study show that the physical environment has an effect on the family member's experience of care in hospital. The findings support the current literature which has found that noise in hospitals, lack of privacy and inability to spend time with the patient are barriers to care for families (Hawker et al., 2006; Bird et al., 2011). These factors were all found in this analysis to have a negative impact on the experience for the family members. The participants whose family member was cared for in a shared room felt they were unable to spend quality time with the patient and that due to the environmental factors the patient was unable to relax and rest peacefully. This was not the case for the family members of the patients in the family room who felt that the different environment enabled them to spend quality time with their loved one before they passed away.

Having a space in which the family can come together privately for the final days of the patients life is extremely important. A private space allows them to stay overnight, prepare food and drink, and spend time caring for the

patient. Slatyer et al. (2015) examined the specific effect of a dedicated space within a hospital ward for patients who require palliative care and found that this is an effective way of addressing the barriers to palliative care which exist in hospitals. The results from this study draw the same conclusions, that those individuals whose family member was in the family room of the ward during their hospitalisation felt this room gave a more private and welcoming atmosphere which was better suited for patients under palliative care. Being able to play music for the dying individual, spend quality time with them, and have family and friends present during this time made the experience a more positive one for the participants.

These results indicate that the general hospital environment is unsuitable for care at the end-of-life. However, the use of a family room; a private room with facilities such as La-Z-Boy chairs, a sink, fridge, and CD player helps the family to feel more comfortable and at ease. This environment has a positive effect on their experience of care.

In previous research, interactions with hospital staff have been found to greatly influence the families' perceptions of the quality of care (Hawker et al., 2006; Spichiger, 2008; Steinhauser et al., 2015). Staff are perceived by the family as a constant factor and can help them feel less confused and helpless in the situation. As such, they have a direct effect on the perceived quality of care the families feel the patient receives. Staff who are sensitive to the needs of the patient, who display respect for the patient, who involve the family in the care and who also exhibit signs of caring for the wellbeing of the family through acts such as making cups of tea are seen as an

extremely important aspect of the care. The family find it easier to connect to those who are empathetic and communicate clearly with both the patient and the family as they work.

The results from this study concur with these findings that staff who interacted with the family and took what was perceived as a genuine interest in the patient were viewed in a positive light and the family members felt it made the whole process easier. Families appreciated the time that the nursing staff took to ensure they were looked after as well. Other studies have found that patients under palliative care in hospitals often feel the staff are too busy to provide adequate care. This was reflected by some of the participants in this study who felt that the staffing levels over weekends and public holidays meant that the staff were too busy to provide adequate care and support to both the patient and the family. This could be due to the smaller nature of this hospital compared to the international hospitals that have been used in other studies, or could be due to the fact that the majority of patients in this study received care in the family room which has been designed for patients who are receiving palliative care.

Previous research has focused on the emotional and psychological support of the families at this time, and while this is important it is also worth considering that families may need help with practical arrangements. At the hospital where this research was conducted, visitors are required to pay for parking. The lack of clarity around which car parks are available for visitors and having to pay for parking caused distress for participants who felt that this was something they should not need to be concerned with when visiting

a patient who was receiving palliative care. This is an area which the hospital could potentially address that would have a positive effect on the families' experience. Previous research has found that providing families with free and easily accessible parking has a positive effect on their experience (Hawker et al., 2006).

Participants in this study also identified that care on weekdays was different to that provided on weekends and public holidays. They felt that the care received over weekends and public holidays was not always as good as that received during the weekdays due to the difference in staffing. One family struggled with receiving knowledge of palliative care until the palliative care team returned to work following the long weekend and this had a negative impact on their experience. Sherwood et al. (2011) found that outside of regular hours, there were delays in the decision-making process due to the inability to contact the primary consulting team, but other studies have not found this to be a factor affecting care in hospitals. This suggests the need for a focus in future research on palliative care after-hours as this was found to have a negative effect on the family members experience of care in hospital.

Communication regarding the care patients receive at the end-of-life is extremely important and can play a pivotal role in the experience of the family member's. The current literature suggests that families appreciate information on the dying process, the changes they can expect in the patient, honest and open communication from staff and they welcome the opportunity to have these discussions (Marco et al., 2005). The findings of

this study confirm that family member's want to have a clear understanding of the process the patient was going through so that they are well prepared and able to help as much as possible. For one participant who did not initially understand the nature of palliative care, the lack of communication was distressing as she felt the care her mother was receiving was substandard. Following communication with the medical staff, she had a better understanding of palliative care and was comfortable with the process her mother was undergoing.

Not all families are ready or prepared to hear this information and the timing of communication regarding palliative care must be carefully managed by the medical staff (Steinhauser et al., 2015). In some situations, leaflets or pamphlets outlining palliative care have been successfully used to educate families. Due to the sensitive and often uncomfortable nature of the discussion, staff may find it difficult to communicate and explain to family's the palliative care issues the patient faces. The use of written material is one way of facilitating a discussion between the families and medical staff (Steinhauser et al., 2015; Bussman et al., 2015). In this study, families found the written material regarding palliative care was helpful, but they identified the need to discuss and raise any queries that resulted from reading the pamphlets with medical staff.

Research has found that when there is open and honest communication between staff and families, the families feel empowered, have a clear understanding of what palliative care entails and have a more positive experience (Spichiger, 2008). The findings from this study support this, with participants who were able to communicate with the medical staff

feeling reassured, showing more trust in the staff and the care they were providing and feeling more accepting about the whole experience.

Research has shown that not only do medical staff need to be aware of when to discuss palliative care issues with families, they must be aware of how to talk to families (Caswell et al., 2015). Marco et al. (2005) found that while medical staff may be reluctant to discuss palliative care, the opportunity to discuss these issues was in fact welcomed by the family members. Similarly to this, Spichiger, (2008) and Bussman et al. (2015) found that family members appreciated the staff who were able to communicate clearly with both the patient and themselves. Family members expressed the need for clear understandable and transparent communication. This was seen in this study, where the participants appreciated the medical staff speaking to them about the nature of palliative care and what it would mean for the patient. However when this communication was not open and clear, it had a negative impact on the participants perception of care. While the use of pamphlets in patient rooms may act as a way to facilitate a conversation with the family, this study has highlighted the importance of face to face communication with the medical staff. In contrast to the participants who had a conversation with the medical team regarding palliative care, the one participant who relied only on pamphlets felt ill-informed regarding the care of the patient and expressed the wish to discuss the care of the patient with the medical team.

Steinhauser et al. (2015) found that care after death is extremely important to family members. Medical staff can ensure the family is prepared to see the body, assist with post-mortem cares, and allow the family to have

sufficient time to grieve with the body. These actions by the staff help to contribute to a positive experience for the family and can contribute to their positive perception of care.

It was interesting to note the prevalence of after-death care as a theme in this study, when previous research has focused on the care and experiences of the family up until the death. It was also interesting that the experience did not stop with the death of the patient, and the factors which were important prior to the death such as communication and interactions with the staff continued to be important and affect the experience of the family member after the death had occurred. Participants in this study identified the importance of spending time with the body after death had occurred. This was seen as a time of closure and presented an opportunity for the family to say their goodbyes. At this time, the staff played a pivotal role in providing support for the bereaved both emotionally and practically through sitting with them, preparing the body and providing information and resources for what was required to happen next.

This is an important aspect of palliative care in hospitals that has received little focus in the current literature. To the participants in this study it was a vital aspect that influenced the overall experience of palliative care in hospitals. This represents an area which future studies could address in order to increase the knowledge and understanding of the role after death care plays in palliative care.

Limitations

This study aimed to examine the family member's perceptions of care in the context of a New Zealand hospital. It is worth noting that Table 1 shows that there were no participants who identified as Māori in this study. Māori have been identified as a group within the wider population who lack knowledge about palliative care and there is concern about the provision of culturally appropriate palliative care for Māori in New Zealand (Ministry of Health, 2001) making it an important focus for future research. The lack of Māori participants in this study may be indicative of the difficulties Māori currently face in New Zealand when accessing palliative care services. It is interesting to note that while there were no participants in this study who identified as Māori, one participant did comment on the cultural appropriateness of the family room and the hospital environment and expressed concern that it may not meet the needs of Māori people. This is one aspect of palliative care in New Zealand that warrants further investigation.

While the use of the family room has been shown to be beneficial to the family members experience in this study, in hospitals where there is not a family room or private room for patients who are being treated under palliative care, the hospital environment may not be suitable for palliative care. This is an important fact to consider as the family members in this study felt that the general hospital environment was not conducive to a high standard of care for the patient who was receiving palliative care. In hospitals without a family room, this experience may differ and should be considered in further research.

This study was qualitative in nature and had only seven participants. With a small number of participants it is worth noting that groups within the population can be excluded. In this case, only one male took part in the study. Men may have differing views on the quality of palliative care a family member receives while in hospital but this could not be determined in this study. This study has been useful in order to gain greater insight in to the detailed experiences of palliative care in a hospital setting but a study with a larger sample size would be beneficial in order to ensure all groups within a population are represented and that the result are generalizable to the wider population.

Conclusion

This study has provided an insight into the experiences of family members of patients who received palliative care while in a New Zealand hospital, more specifically, in a medical ward with a family room. It was the first study of its kind to be conducted in this country and provides an important starting point for further research in the New Zealand context. The physical environment of the hospital is a major factor in the experience of family members, and the importance of a private space for the patient and their family has been highlighted. The major themes of identifying and accepting death, interactions with staff, communication regarding palliative care and care after death are all factors which affect the experience of the family member's and can inform the way in which palliative care is provided in hospitals. Practical issues such as access to free parking and shower facilities have been identified as issues which affect the family members of those receiving palliative care in hospital and should be considered by the specific hospital. More research is required to further explore palliative care in hospitals which do not have a dedicated family room and to examine the views of the groups who were not represented by this research.

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Appendix One

MCH /letterhead

Address

Date

Dear *(name)*

My name is Jean Clark and I am a nurse working in the Palmerston North Hospital Palliative Care service. Firstly, I would like to convey my condolences, as I understand (name and relationship) recently passed away in Palmerston North Hospital.

Why am I being contacted?

As a member of staff at the Hospital I have, with organisational permission, obtained your contact details and recently made initial contact with you by telephone to seek permission to send this information to you on behalf of the hospital and a Masters student. Following our conversation, I am writing to invite you to consider participating in a research project to help us find out, from people identified as next-of-kin or as the main contact person, about their experience of the care provided in hospital for people at the end-of-life.

Description of the study

This study aims to investigate the care of patients at the end-of-life on a medical ward at Palmerston North Hospital. Palliative care (including end-of-life care) is an approach to care implemented to improve the quality of

life of patients and their families facing the problems associated with life-threatening illness. To deliver a high standard of palliative care, it is important to understand what factors patients and their families feel have the most impact on the quality of care they receive. In New Zealand, to date there has been no formal study conducted to gather family and next-of-kin's views on the end-of-life care received while in an acute care setting.

The research team

The research will be undertaken by Sarah Waghorn who is a Masters in Psychology student from Massey University. Sarah's research will be supervised by Professor Christine Stephens and Dr Don Baken. Sarah and her supervisors do not have access to any personal health information at MidCentral Health or any relationship with ward staff at the hospital who were involved with the care of the patient. The information Sarah obtains in this research project will be used to help us improve the care of patients, families and whānau.

What happens next?

Please find enclosed the information Sarah has prepared for you to consider. Sarah's letter outlines the study and how you may contact her in the next two weeks if you would like to share your thoughts and experiences with her, or if you have any questions regarding the research. Sarah will then contact you to answer any questions and explain what is involved so you can decide if you would feel comfortable taking part in the research project. If you choose to take part, Sarah will arrange a time to visit you in your home to talk with you about your experience. If you would prefer, you are

able to meet Sarah at the Massey University campus in Palmerston North for this conversation. ***If you choose not to contact Sarah, then you will receive no further information regarding this study.***

Thank you for considering this invitation.

Yours faithfully

Jean Clark

Jean Clark RN BA Hons PhD

Clinical Nurse Specialist Hospital Palliative Care Service

Palmerston North Hopsital

Education and Research Unit

Arohanui Hospice

Honorary Research Associate, School of Nursing, Massey University

Appendix Two

MASSEY UNIVERSITY
COLLEGE OF HUMANITIES
AND SOCIAL SCIENCES
TE KURA PŪKENGA TANGATA

End of Life Care in Hospital: Perceptions of care.

INFORMATION SHEET

Researcher(s) Introduction

My name is Sarah Waghorn and I am currently in my last year as a fulltime Master of Science in Psychology student. I will be conducting this research project and will be supervised by Professor Christine Stephens and Dr Don Baken from the Massey University School of Psychology and supported by the Palmerston North Hospital Palliative Care Service.

What is this research about?

This study aims to investigate the care of a patient in end of life care on a medical ward at Palmerston North hospital. Palliative care (including end of life care) is an approach to care implemented to improve the quality of life of patients and their families facing the problems associated with life-threatening illness. To deliver a high standard of palliative care, it is important to understand what factors patients and their families feel have the most impact on the quality of care they receive. In New Zealand, to date there has been no formal study conducted to gather family and next of kin's views on the end of life care received while in an acute care setting.

This research aims to:

- Investigate how family members or next of kin experience a patient's palliative care in the Palmerston North hospital setting.

- Identify what effect the hospital environment has on the family or next of kins' experience.

- Identify ways in which their experience of care could be changed to make it an easier and more manageable time for the family or next of kin.

Appendix 2

Why have I been chosen?

You have been contacted to take part in this research following a phone call between yourself and Dr Jean Clark, Clinical Nurse Specialist Lead-Palmerston North Hospital Palliative Care Services during which you indicated you would be interested in receiving more information on the research. Dr Clark contacted you as you have been listed as the next of kin or contact person for a patient who passed away on Ward 25 of Palmerston North Hospital during the time period of this research. Neither I nor my supervisors have had access to any personal health information and we will only receive your contact information should you return the enclosed form or call our contact number.

What would I be asked to do?

Participants in this study will be interviewed about their experiences of hospital palliative care, by me, in their home. If you do not wish the interview to take place in your home, then you are able to come to the Massey University School of Psychology to be interviewed. The interview will last approximately 1 hour. It will be audio recorded and transcribed for analysis. You will be able to see a copy of the transcript for comment if you wish, and to receive a summary of the results of the research.

Your participation in this research is your choice.

How can I participate?

If you choose to take part, please contact me in one of two ways:
1. Phone 0800 100 134 and leave your name and number.
2. Complete the enclosed contact sheet and return it to me in the freepost envelope provided (no stamp required).

Please respond in one of the above ways within two weeks should you wish to participate in the research.

Appendix 2

I will then contact you to arrange a time and place which is suitable for you to take part in an interview. You are welcome to have other family members or support people present if you wish.

Discussing the death of a loved can understandably be distressing. If you would like to seek additional support at any time the best first contact is your General Practitioner service. You can do this at any time.

What will happen to the information I provide?

All information provided will be kept confidential. Only the researcher and supervisors will have access to it. It will be stored in a secure location at Massey University School of Psychology and will be destroyed after five years. Each participant will be assigned a pseudonym and their identity will be kept confidential. The researchers will store your contact details separately and securely and will destroy them once we have sent you a summary of the results.

The findings of the research will be published in the form of a Master's thesis, a report to the hospital, and a summary of project findings which will be sent to you should you wish. Findings from this research may also be published in medical or psychological scientific journals.

Participants Rights

You are under no obligation to accept this invitation.
If you decide to participate, you have the right to:

- decline to answer any particular question;
- withdraw from the study at any time until the data is analysed;
- ask any questions about the study at any time during participation;
- provide information on the understanding that your name will not be used
- be given access to a summary of the project findings when it is concluded.
- ask for the recorder to be turned off at any time during the interview.

If at any stage of the research you have any further queries or wish to contact either myself or my supervisor for further information about the study, email and phone details are as below:

Sarah Waghorn   Christine Stephens

Phone: 0273008003   Phone: + 64 (06) 356 9099 ext. 85059

Email: haras_9@hotmail.com   Email: c.v.stephens@massey.ac.nz

Thank you for considering this information

Yours sincerely,

Sarah Waghorn

Committee Approval Statement

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern A, Application __/__ *(insert application number)*. If you have any concerns about the conduct of this research, please contact Mr Jeremy Hubbard, Acting Chair, Massey University Human Ethics Committee: Southern A, telephone 04 801 5799 x 63487, email humanethicsoutha@massey.ac.nz.

This project has been reviewed and approved by the Massey University Human Ethics Committee: Southern B, Application __/__ *(insert application number)*. If you have any concerns about the conduct of this research, please contact Prof John O'Neill, Acting Chair, Massey University Human Ethics Committee: Southern B, telephone 06 350 5799 x 84384, email humanethicsouthb@massey.ac.nz

Appendix Three

End-of-Life Care in Hospital: Perceptions of care.

Interview Schedule

Prior to beginning ensure participant has read information sheet and answer any questions, obtain written consent from participant.

Be aware of culture- Ask if participant would like to start with a karakia or prayer, take food/ drink to the interview.

1) **Introduction**

My name is Sarah Waghorn and I am a student researcher from Massey University.

I would like to start by saying that I am very sorry to hear of your loss, and thank you again for consenting to take part in this research. I would also like to remind you that all personal details will be kept confidential, and you may ask to withdraw from the study without offering explanation.

I will be recording this interview, it will be transcribed by me and a full copy of the transcription will be returned to you to check for proof reading and accuracy prior to analysis. You may ask at any time during the interview for the recorder to be turned off or take a break.

I have had no access to any patient files at the hospital and have no knowledge of the clinical care that was received.

2)

My name is Sarah Waghorn and I am a student researcher from Massey University.

I am very sorry to hear of your loss.

I would like to thank you again for consenting to take part in this research and remind you that all personal details will be kept confidential, and you may ask at any time to withdraw from the study without offering explanation.

I will be recording this interview, it will be transcribed by me and should you wish, a full copy of the transcription can be returned to you for proof reading and accuracy prior to analysis. (If they wish to have transcript returned obtain email or postal address). You may ask at any time during the interview for the recorder to be turned off.

I have had no access to any patient files at the hospital and have no knowledge of the clinical care that was received.

3) Background

Tell me about (Name of relative)'s time in hospital?

Prompts

What was your relationship?

What do you understand about their condition?

4) Care of patient

How would you describe the care of (Name of relative) while on Ward 25?

<u>Prompts</u>

Were there any interactions with staff members which stood out as being particularly good or bad?

Did staff talk to you about EoL care plans and treatment (eg Liverpool care pathway)?

Were you involved in decision making about the care of the patient?

Do you feel the patients symptoms were managed well?

Was there clear communication between staff and yourself?

Do you think that (relative) was well cared for?

Were all their needs met while on Ward 25?

5) Can you tell me about the facilities available to you at the hospital?

<u>Prompts</u>

Did you use them?

Were they easy to use and access?

Were there any missing facilities/things you wish were there?

If from out of town- where did you stay? What services were offered?

6) **What sort of support did you receive from the hospital**?

Prompts

Emotional/practical?

Doctors/nurse/chaplain/physio/social worker

Do you feel anymore could have been done to help you?

7) **After (name of relative) passed away, did you feel you had enough time with them on the ward?**

Prompts

Was there anything else at this time that would have been helpful to you or your family?

8) **This must have been a very hard and trying time for you, when you think about what happened, do you think anything would have made it an easier?**

9) **Is there anything else you would like to share with me about your experience**?

10) Conclusion

Thank you again for sharing your time and experience with me. Present koha to thank them, ask again if they would like a transcribed copy of the interview, and confirm method of sending.

Upon completion of the study, if you wish, you will be sent a

summary of findings (Confirm address for postage) and a link to the

full study should you wish to read.

Additional prompts will be used to guide and continue conversation on each

topic as it arises:

Then what happened?

Can you tell me more about that?

You said…….what do you mean by that?

Appendix Four

MASSEY UNIVERSITY
COLLEGE OF HUMANITIES
AND SOCIAL SCIENCES
TE KURA PŪKENGA TANGATA

End of Life Care in Hospital: Perceptions of care.

PARTICIPANT CONSENT FORM - INDIVIDUAL

I have read the Information Sheet and have had the details of the study explained to me. My questions have been answered to my satisfaction, and I understand that I may ask further questions at any time.

I agree/do not agree to the interview being sound recorded.

I wish/do not wish to have my recordings returned to me.

I agree to participate in this study under the conditions set out in the Information Sheet.

Signature: .... Date: ....

Full Name - printed ....

Appendix Five

MASSEY UNIVERSITY
COLLEGE OF HUMANITIES
AND SOCIAL SCIENCES
TE KURA PŪKENGA TANGATA

End of Life Care in Hospital: Perceptions of care.

AUTHORITY FOR THE RELEASE OF TRANSCRIPTS

I confirm that I have had the opportunity to read and amend the transcript of the interview(s) conducted with me.

I agree that the edited transcript and extracts from this may be used in reports and publications arising from the research.

Signature: .... Date: ....

Full Name - printed ....

Appendix Six

MASSEY UNIVERSITY
TE KUNENGA KI PŪREHUROA

17 July 2015

Sarah Waghorn
16 Seddon Street
FEILDING 4702

Dear Sarah

Re: HEC: Southern A Application – 15/37
**   End of life care in hospital: Perceptions of care**

Thank you for your letter dated 10 July 2015.

On behalf of the Massey University Human Ethics Committee: Southern A I am pleased to advise you that the ethics of your application are now approved. Approval is for three years. If this project has not been completed within three years from the date of this letter, reapproval must be requested.

If the nature, content, location, procedures or personnel of your approved application change, please advise the Secretary of the Committee.

Yours sincerely

Mr Jeremy Hubbard, Chair
Massey University Human Ethics Committee: Southern A

cc   Prof Chris Stephens   Dr Don Baken
     School of Psychology   School of Psychology
     PN320   **PN319**

     Prof James Liu, HoS
     School of Psychology
     PN320

Appendix Seven

MidCentral District Health Board
Te Pae Hauora o Ruahine o Tararua

Locality Assessment Sign Off for Approval of Research/Clinical Trials

Full project title:	End of life care in hospital: Perceptions of care
Short project title:	End of life care in hospital

1. Declaration by Principal Investigator

The information supplied in this application is, to the best of my knowledge and belief, accurate. I have considered the potential ethical, resource and cultural issues involved in this research and believe that I have adequately addressed them for this locality.

A formal letter of consultation was sent to the Maori Health Unit on the

Name of Principal Investigator (please print):	Sarah Waghorn
Signature of Principal Investigator:	*SarahW*
Date:	18/5/15.

2. Declaration by Clinical Leader of Service/Department in which the Principal Investigator is located

I have read the application, and it is appropriate for this research to be conducted in this department. I give my consent for this locality to be included in the ethics committee application.
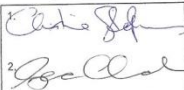
Name (please print):	Dee Hunter .	*Charlotte Lucas*	
Signature:	*Nthut* .	Institution:	Palmerston North Hospital/MCH
Date:	20/5/15 .	Designation:	Clin Trials Nurse Lead

- Where the Clinical Leader is also one of the investigators, the Clinical Leader declaration must be signed by the Clinical Executive Director.

MidCentral District Health Board
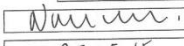Te Pae Hauora o Ruahine o Tararua

3. If the application is for a student project, the supervisor should sign the declaration.

I have read the application, and it is appropriate for this research to be conducted under my supervision. I give my consent for this locality to be included in the ethics committee application.

Name (please print):	1. Professor Christine Stephens 2. Dr Jean Clark Clinical Nurse Specialist Hospital palliative care service		
Signature:		Institution:	1. Massey University 2. MidCentral Health, Arohanui Hospice and Honorary research fellow School of Nursing Massey University.
Date:	1. 18/05/2015 2. 18/05/2015	Designation:	1. First Supervisor 2. Field supervisor

4. Declaration by relevant Operations Director

I have read the application, and it is appropriate for this research to be conducted in this department. I give my consent for this locality to be included in the ethics committee application.

Name (please print):	Mr Nicholas Glubb		
Signature:		Institution:	Palmerston North Hospital/MCH
Date:	22.5.15	Designation:	~~Group Manager~~

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