

THE IMPORTANT THING IS...:
PATIENT AND FAMILY VOICE IN PALLIATIVE
CARE

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The pounamu carving on the front cover is by Garth Wilson. It has many meanings but in this instance the two koru represent nursing and education and how they are both part of the same whole. They also represent the palliative care given to the participants in this research and the gift those participants gave back in participating, in order to benefit others.

Abstract

Dame Cicely Saunders created the hospice movement to be a voice for the voiceless. Those needing palliative care needed someone to speak for them and ensure they received the care they needed and deserved. Today, more than forty years later, the voice of the patient and family are in danger of being lost. This research aimed to discover what patients and their families thought were the most important priorities in palliative care. If hospices, and any other facility that cares for the dying, are to give the care that patients and their families need then the research in this thesis shows benefit to those patients and families if asked to identify what are their needs. If palliative care is to be truly holistic we need to find out from patients, and from their families, what they believe is important.

Using purposeful sampling, five patients and five family members were recruited from a hospice in-patient unit. In-depth interviews with open-ended questions were conducted with participants who were asked to share what had affected their care, or their relative's care, while admitted to the hospice. These interviews were recorded and transcribed in a qualitative descriptive study to identify and analyse what these participants described as the 'important thing' in palliative care. Specific, tangible detail was sought in order to define the 'essence' of palliative care as determined by those receiving it. Thematic analysis revealed four key themes and associated sub-themes relating to: the people who work in a hospice; the environment; philosophy and holistic care.

This research enables those caring for the dying in any context, to use the information shared by these individuals as guidance to enhance the care they offer to a dying person so that their final days may be more tolerable, even perhaps pleasurable: to help them 'live until they die'.

Glossary of Key Terms

End of Life Care: End-of-life care is the provision of supportive and palliative care in response to the assessed needs of the patient and family/whānau during the end of life phase. It focuses on preparing for an anticipated death and managing the end stage of a life-limiting or life-threatening condition. This includes care during and around the time of death, and immediately afterwards. It includes management of pain and other symptoms and provision of psychological, social, spiritual and practical support and support for the family. (NZ Palliative Care Council, 2012, p.5).

Family: In this research the term 'family' is used to refer to anybody that the patient considers significant. It is used in the broadest sense and may include close or distant relations as well as friends who the participant deems significant.

Hospice: Hospice is not only a building; it is a philosophy of care. The goal of Hospice care is to help people with life-limiting and life-threatening conditions make the most of their lives by providing high quality palliative and supportive care. Hospices provide care for the whole person, not just their physical needs but also their emotional, spiritual, and social needs. They also care for families and friends, both before and after a death (NZ Palliative Care Council, 2012, p.6).

Palliative Care: An approach that improves the quality of life of patients and their families facing the problems associated with life-limiting or life-threatening conditions, 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 (NZ Palliative Care Council, 2012, p.8).

Both the phrases 'hospice care' and 'palliative care' were used during the interview stage of this research. As people sometimes are accustomed to one or the other it was decided, for clarity, that both would be used by the interviewer so that interviewees could recognise and be familiar with either or both phrases.

Maori Language

There are instances of Maori language included in this document, along with their translation. Maori are the indigenous culture of New Zealand and the Maori language is recognised as an official language of New Zealand, therefore it is used in many New Zealand policy documents.

Key to Extracts from Transcriptions

The following is the key to the abbreviations used within the transcripts and therefore also in the presentation of results.

[] Information added or used to clarify context or meaning

(...) Words, phrases or sentences edited out

... Pause present within the interview or transcription

Italics Participants' quoted interview

Chapter 1: Introduction

1.1 Introduction

To be a voice for the voiceless was the reason Dame Cicely Saunders gave for creating the hospice movement (Oliviere, 2005). But are health professionals still giving that voice to palliative patients? Are patients being genuinely heard or are health professionals hearing only what they want to hear? Hospice care has become increasingly specialised as it has gained recognition by both health professionals and the general public. Randall and Downie (2006) suggest that, from their experience as Physician and ethicist “palliative care has become over-professionalized, too precious, and too busy” (p.vii). Their critique of palliative care supported my position in which I question whether the modern hospice movement has become so specialised, so medicalised, that it is moving away from the basics that Dame Cicely espoused. “The staff will not have acute emergencies to cope with, nor complicated treatments to prepare or carry out, but can spend their time making their patients comfortable” (Saunders, as cited in du Boulay, 1987, p.89). As treatments evolve over time, they can become increasingly complicated. It is vital that the basic care of making patients comfortable, advocated by Dame Cicely as so essential for quality palliative care, is not lost in the process.

Given these concerns it is appropriate to ask the people receiving hospice or palliative care - the patients - what they consider to be important. It is right to give patients their voice and ensure they are heard as they tell us what is important to them. By seeking to understand their priorities, and to discover if they are being met at this time, this research creates an opportunity to review whether current practice within palliative care is appropriately positioned to best benefit patients and their families.

1.2 Development of Modern Hospice Care

Hospice care has been carried out for centuries, most often delivered by various religious orders. In mediaeval times hospices customarily cared for pilgrims; travellers, the ill, the poor and, almost coincidentally, the dying. (Murray, 2002, Saunders, 2004). The modern hospice movement was established in 1967 with the opening of St Christopher’s Hospice, in Britain. Conceived by Dame Cicely Saunders, herself recognised as the founder of the

modern hospice movement, the hospice offered home care, family support, and bereavement follow up but primarily it offered improved ways of managing pain and symptom control.

Dame Cicely Saunders originally trained as a nurse, then as a social worker, and then completed her medical training specifically to be able to gain recognition and acceptance in her work with the dying, especially in the field of pain relief (du Boulay 1987). After experiencing the death of a close friend, she was strongly influenced by her experiences in both St Luke's, a home for the dying, where she had worked as a volunteer and St Josephs, a home for frail and elderly and those with long term illnesses or terminal disease. Having seen the potential to improve care for the dying she began to develop 'The Scheme' (du Boulay, 1987) which was eventually to become St Christopher's Hospice.

The establishment of St Christopher's was the catalyst for the hospice movement worldwide. It continued to grow and spread through USA, with the opening of the Connecticut Hospice in 1974, founded by Frances Wald; Canada, where Balfour Mount began the Palliative Care Service in 1975; and eventually to other countries, including New Zealand where the first hospice was opened in June 1979. There are now an estimated 10,000 palliative care programs world-wide (Connor, 2009).

1.3 Hospice Care in New Zealand

New Zealand bioethicist McCabe states that "Cicely Saunders, Elisabeth Kubler Ross and Balfour Mount were all influential in the development of the modern hospice movement in New Zealand" (2004, p.2). Calvary Hospital, a teaching hospital run by a Catholic religious nursing order The Little Company of Mary (LCM), had developed a centre for cancer patients in Wellington in the 1970s but increasingly its Mary Potter Ward began to receive terminally ill patients to be cared for there, including by two staff who had worked at St Christopher's Hospice. Eventually, in 1979, the ward was formally opened as a hospice, the first in New Zealand followed later that year by Te Omanga, opened by Marion Cooper in Lower Hutt and St. Joseph's Mercy Hospice in Auckland. The new Mary Potter Hospice, a purpose built facility, was opened at its current site in Wellington in 1990.

In 1986 a number of separate groups with the same interest united together and what is now known as Hospice New Zealand (HNZ) was established. As time progressed further hospices and palliative care units opened around the country and HNZ now comprises 34 hospice/palliative care services around New Zealand, 27 in the North Island and 7 in the South Island. “Today, Hospice New Zealand is actively involved in research and education, workforce development, establishing standards of healthcare, providing information and advice to hospices, stakeholders and to the general public and helping and supporting hospices nationwide” (Hospice New Zealand, 2013, History).

In 2001 the Ministry of Health published the New Zealand Palliative Care Strategy. This was seen as an “opportunity to conclude aspects of the Care of the Dying project that was undertaken by the National Health Committee from 1997” (Ministry of Health, 2001, p.1). Underpinning this document was the World Health Organisation’s 1990 Statement that defined the recognised principles of palliative care. Rewritten for a New Zealand context this strategy contains a vision for palliative care in New Zealand that “All people who are dying and their family/ whānau 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). This document frames the concepts of care which guide the philosophy and daily practice at the Otago Community Hospice where this research was conducted.

1.4 Hospice in Otago

A history of the Otago Community Hospice by Parry in 2003 (unpublished manuscript), portrays the history of palliative care in Otago. Although there was interest in palliative or hospice care as early as 1977 in Dunedin, it wasn’t until 1984 that a small group got together to move this forward, and in 1988 a Palliative Care Unit was set up in Dunedin Public Hospital. Over the next few years it was recognised that, although there were benefits of offering palliative care within the hospital, the patients and their families could be better served in a separate facility. Fundraising began and in March 1990 the Otago Community Hospice was opened, initially offering day care. By August inpatient beds were opened and the facility became a fully-fledged hospice. Originally operating from an adapted large private home, it had eight beds, three of which were in single rooms. As its

reputation grew it also gained increasing community support and, after extensive fundraising, a purpose built facility was opened in December 2001 with 12 beds, each in single rooms with individual facilities. As well as offering inpatient palliative care this building is also the base for an extensive outreach service that provides community coordinators not only in Dunedin but also in North, South and Central Otago, and offers support, knowledge and guidance throughout the region.

1.5 Researcher Interest

I have been nursing for thirty years, a large portion of which has been spent in Oncology and Hospice nursing. This has helped shape my perspective as a nurse. Caring for many people facing a threatened or shortened lifespan helped develop a consciousness of what was important at this crucial time. During the last ten years I have also been through the deaths of four close family members. The widely differing experiences of those occasions also had an impact on my perspective. These four occasions were significant, distinctive in many ways, and gifted me the opportunity to view this experience from the 'other side', that of a dying person's family member rather than a health professional.

My journey into postgraduate study began with a course on palliative care six years ago. I realised very quickly that there was much more to be learned, not only about palliative care, but also about nursing, and about being an 'expert' nurse. The course requirement to complete a personal philosophy of nursing, and to identify and develop a theme based on that philosophy, instigated a great deal of reading, research and thought. The writings of many different authors, from many different perspectives, shaped my own perspectives of nursing and priorities of care for patients. With this analysis I discovered that what was important was making a difference to patients in my care. There was reward in helping them to have a better day, by whatever means possible.

During this time I became more conscious that doing little things for my patients appeared to make a world of difference to them. This included things like warming cold milk so it was enjoyable immediately and straightening a bed that a patient had been in for most of the day, so that the bed, with smooth sheets and freshened pillows, became a restful haven to return to. It meant choosing clothes in a colour they loved, rather than a hospital gown, so they felt, and looked, like themselves; rearranging family photos in their room so they could

see them; taking time to sit down; or simply holding someone's hand. This awareness of the value of little things to my patients inspired a desire to discover just what patients believed made a difference to their day and to their experience as a patient.

With further reading and study I began to wonder what our patients really wanted in palliative care and what was really important to them during their stay in hospice. Then, going a step further, I wanted to understand what really mattered to their families while they were there and what was really important to them as they supported their family member through this time, and as they began to grieve for their own loss. I wondered whether what the families thought was important for the patient was the same as what the patient thought was important. Would it be the little things after all or perhaps it was something else. This was what the start of the journey to discover what is important to patients and their families in palliative care.

1.6 Aims of this Research

The aim of this research is to establish patient and family priorities in palliative care. It seeks to build on current knowledge and establish patient and family perspectives that could lead to enhanced understanding for nurses and allied health professionals working with patients requiring palliative care. The intent is:

1. to review what a hospice does well for patients and their families;
2. to ascertain the actual events, actions or cares that enhance their stay at the hospice and make it a place that meets their individual needs, whether physical (tinana), social (whānau), emotional (hinengaro), or spiritual (wairua) (Durie, 1994);
3. to establish what makes it a place of comfort, safety, peace, solace or support for them and;
4. to define how hospice staff can enhance the patient or family experience.

If hospice care is to be fully holistic it is essential to find out from patients themselves what they consider important. Stomberg (2009), who studied daily life in a Swedish hospice, states that "It is a common attitude that we, in the form of both staff members and relatives, believe that we know what the sick person at the end of life needs and lacks" (p.277). This research creates the opportunity to find out from those that matter most - the

patients – the essentials for good hospice or palliative care. Following a qualitative study of hospice patient's experiences of care, McKinlay (2001) observed that:

Only people who are living with all that it means to be dying – the symptoms of an illness, the threat to mortality, the anticipated grief and losses, the look in their loved ones eyes, the inevitable fatigue and mental clouding – can state what is of value to them (p.27).

Many people say they are pleased to be at the hospice, and that they value hospice care. This research asks the questions why this is so, what do they value about hospice and what is important to them as patients and to their families? It seeks to define the essence of palliative care that means so much to the people receiving it. The intention is to interview a number of participants, both patients and family members, to ensure a variety of responses and in-depth knowledge is gained, as common threads and themes unfold from the interviews. One-to-one interviewing with patients means the researcher can allow them to express their own thoughts, rather than directing the conversation through a series of questions. Their answers may not be able to be extrapolated to all palliative care facilities but they can be used as a guide to prompt questions and reflection on practice in other hospices or health care facilities.

This research will explore, describe and conceptualise the important aspects of care as defined by the dying person and their family. The intent is to learn from the patients and families themselves, and fully understand what it is that makes a difference for them. This information will assist in creating new understanding to support best caring practice in palliative care. The outcomes can be used to inform nursing and allied health professionals, not only within palliative care but within the wider field of health care, or wherever nurses and other health professionals wish to enhance the care they give to those who are nearing the end of their lives.

1.7 Research Approach

To hear the voice of the patients and the voice of family members a qualitative descriptive approach will be used. This is an appropriate methodology that will allow the voices of patients and families to be clearly heard, without over-interpretation or transformation. The data will be collected directly from the participants who have experienced palliative care

and who are willing to share what is valued by them in that situation. The data will be analysed for themes, for ease of understanding and sharing of the knowledge with others.

1.8 Overview of Thesis

This thesis has been divided into six chapters. This first introductory chapter is followed by a literature review analysing what has been previously discovered as important themes in palliative care and seeking evidence of patient voice in palliative care research. The third chapter discusses the methodology on which this research is based, and describes the intended methods and the adaptation of those methods during the research itself. Chapter four reports and analyses the findings from the research, identifying priorities of care from the patient and family perspective and includes results from a further literature search based on what was discovered. This is followed in chapter five by discussion about the findings and what the literature says about those themes discovered from the research. Chapter six describes conclusions drawn from the research and discussion and offers recommendations on how the findings may influence or guide those offering palliative care in a range of settings in the future.

Chapter 2: Searching for the Patient Voice in Palliative Care

2.1 The Literature Search

An initial literature search was carried out prior to the research to ascertain current knowledge of patient and family preferences in palliative care. Literature was sought that defined priorities of care from the perspective of patients who were receiving palliative care, and their families. The focus was on the specific and tangible detail that affected patients, or their family members, at the end of life. In particular their voice was sought – literature that directly reported what patients or their families had said was important to them.

The search was undertaken utilising Proquest, SagePub and Medline Ovid SP, with the terms ‘palliative care’, ‘end of life’, ‘terminal care’, and ‘hospice’ entered into the search engine. With over sixty thousand results a variety of phrases were added, such as ‘patient priorities’, ‘little things’, ‘meaningful acts’, ‘patient choice’, and ‘patient voice’. This caused a profound change in the number of results. When these phrases, expected to be important in palliative care, were added, the results were nil. In particular it was noted that there were no results that linked patient voice with palliative or terminal care. This was a surprising result. Relevant articles on many topics of relevance to palliative care were found but little direct reporting of patient defined priorities. It is hoped that research has been conducted, and literature written, that were not discovered during this search.

A subsequent literature search was carried out during the research process, as themes were identified. Further clarification of the developing themes was sought. The search was extended using the PsycINFO database. Articles were discovered of relevance to the findings emerging from this study which were utilised to expand discussion of the results.

Symptom control must be recognised as a central and vital need for patients in palliative care. Most people are admitted to hospice or palliative care facilities due to troubling symptoms, and symptom control is considered an essential component of palliative care. However there is much research into this aspect of palliative care already and the intent of

this research project was not to further that area of study but to understand other issues that are important to patients and their families. McKinlay (2001), following her research, concluded “The patients recognised implicitly the value of good symptom control, yet they identified other key aspects of care, beginning with the recognition that each person’s identity must be valued” (p.28). It is accepted that symptom control is important and may impact on other themes identified within this research, but is otherwise considered outside the scope of this research project.

Section 2.2 reviews the articles and research from the literature search that are worthy of review because of the insights they provide into either methodology or the place of patients in palliative care. One of these studies is quantitative in nature but other studies found were predominantly qualitative research studies. This may be an indication that research into palliative care is increasingly using qualitative methods, or perhaps that the information sought in this research is more likely to be found in a qualitative than in a quantitative study.

Section 2.3 develops themes from the literature relevant to the patient voice in palliative care. The initial literature search carried out prior to the research established a number of themes of importance in palliative care and included: compassion; touch; presence or ‘being’; expert nurses; quality end of life care; and ‘little things’. These themes are reviewed and discussed along with environment and atmosphere, which were not identified in the initial literature search but were clearly identified during the research project. A further literature search yielded articles discussing both topics. These themes all offered vital clues to what is important to patients and their families receiving palliative care and these will be addressed in this section.

2.2 Overview of Research Seeking Patient Voice

A number of studies were discovered that discussed patient voice or quality end-of-life care but their relevance to this study was limited due to the specific aims or direction of the research being reported. Heyland et al. (2006) used a cross-sectional survey over five tertiary care teaching hospitals to ask seriously ill patients and their families what mattered most in palliative care. Although they asked an initial open-ended question regarding their illness and treatment, the majority of the survey was based on a comprehensive list of 28

elements of care in five domains, and participants were asked to rate each element on a five point scale. The results suggested having confidence in doctors, not being kept alive on life support, and honesty from doctors as being the most important of the elements listed in the survey. Sakalys (2010) conducted a narrative study and discussed “Patient Voices and Perspectives” but this was not palliative care based and, although clinical issues were considered, the focus was on the perspective of patient autonomy. Singer, Martin & Kelner (1999) combined three separate qualitative studies of HIV patients, dialysis patients and residents of a long-term care facility. Their objective was to “identify and describe elements of quality end-of-life care from the patient’s perspective” (p.163). To achieve this they conducted open-ended interviews which focused on the particular themes of advance directives, advance care planning and patient control at end-of-life. Their results reflected the direction of the interviews and provide worthwhile insights on those three themes.

Several studies focused on palliative care in different settings. For example, Nelson et al. (2010) used focus groups in a qualitative study of forty-eight patients and family members who had received palliative care in an intensive care unit, in one of three hospitals in the U.S.A. Their aim was to discover how patients and families define palliative care in an intensive care unit. Communication with compassion was seen as very important as well as patient-focused decision making. Being ‘seen’ as a person was also important and both patients and families placed high value on being able to spend time together and confirmed the benefit of family presence to the patient. Strohbuecker, Eisenmann, Galushko, Montag & Voltz (2011) also used a qualitative study to research the palliative care needs of nursing home residents in Germany. They used semi-structured interviews of nine residents and found participants sought the freedom to make choices, often about little things such as when and if to bathe or shower; they wanted to be ‘heard’ and recognised as a person; they appreciated being connected with family, other residents and the outside world; and they appreciated good symptom control. Both of these studies, though not set in an established palliative care situation, reflect some of the findings in the current research study.

Chapple, Ziebland and McPherson (2006) state that “The patients’ perspective is important when evaluating palliative care” (p.1012). They cite a number of sources to support the belief that while the carers viewpoint is important it is ‘widely accepted’ that the patient’s voice must be heard. They reviewed a number of studies from around the world where

patients with terminal illness were asked about their experience of and insights in palliative care. Interestingly while in each situation patients were asked about their perspectives of palliative care, depending on what the focus of the research was, and how the questions were asked, there was a great disparity of results. The results were not in conflict with each other, they simply offered up quite different responses, sometimes because of the different nature of the settings in which the study took place. Some of these studies looked primarily at community based care. Exley, Field, Jones & Stokes (2005) used a qualitative approach to study palliative care in the community, in particular looking at the adequacy of care for people with terminal illness other than cancer and considering the views of both patients and carers, and the health professional involved. Jarrett, Payne & Wiles (1999) also examined community care in their qualitative study of terminally ill patients and carers and their perceptions of and experiences of community based services. McLoughlin (2002) assessed patient experiences with specialist palliative care nurses in the community using a qualitative approach, and analysed their understanding of the specialist nurse. These studies all looked at patient perceptions and are of great value in assessing palliative care in the community but do not address the focus of this study: the important factors making a difference within a hospice or palliative care unit. Although community care is part of the wider hospice programme it is outside the scope of this study.

A qualitative study was conducted by Bostrom, Sandh, Lundberg & Fridlund (2004) to interview palliative cancer patients and assess their perceptions of pain management and factors affecting it. Likewise, Ng & von Gunten (1998) were primarily concerned with symptom control and conducted a survey in the U.S.A. using a standardized data collection instrument to assess symptomology and attitudes to hospice care. Their focus was patients admitted to an acute hospice/palliative care unit. They found that participants had multiple symptoms needing treatment and also a high rate of satisfaction with the quality of care within the unit. Symptom control continues to be an important issue for patients in palliative care but is excluded from this study, as noted above.

A number of the studies reviewed by Chapple et al. (2006) enquired specifically on the patient's perspective of the palliative care nurse. Cox, Bergen & Norman (1993) used a critical incident technique to explore patients' views of MacMillan community nurses (specialist palliative care nurses) in England, while Richardson (2002) used qualitative semi-

structured interviews to identify and describe palliative patients' perception of the interaction with the community palliative care nurse and how that impacted on their feelings of health and well-being. Luker, Wilson, Pateman & Beaver (2003) did a qualitative exploratory study using an interview guide to identify roles of district nurses as perceived by cancer patients before and after discharge from hospital. Again, these studies are useful and offer meaningful knowledge but they are specific to palliative care nurses and not to the wider palliative care team and situation, as sought in this study.

McKinlay (2001), in a New Zealand qualitative descriptive study reviewed by Chapple et al. (2006), asked patients about their experience of palliative care. She recounted narratives from the participants and identified eleven themes which were compiled and used to develop 'The Circle of Care' (p.25), a model of palliative care that encompasses the members of the interdisciplinary team, including the patient. McKinlay found a central theme of Identity that was surrounded by eight further themes. Five themes generated by the patients were defined as keeping control, chosen isolation, being safe, relinquishment and relaxation, and mortality awareness. Another three were the patient's interpretation of the hospice staff's care and these were defined as being watched, caring qualities, and humour. These eight themes were further encircled by the philosophy of palliative care and an outer circle consisting of the environment.

The above papers discussed patient perspectives and patient voice to some helpful extent but this research seeks to ascertain further specific and tangible details within a palliative care context about what patients and their families need, and what makes a difference to them. Many of the studies were not set in palliative care and though the findings have relevance they were not related to palliative patient priorities.

Although the search did not discover the patient voice that had been sought, there was further development of the themes identified on the initial search and those themes are discussed in greater depth here.

2.3 Key Themes from the Literature Reflective of the Patient Voice

2.3.1 Compassion

Compassion is a theme that is recognised as having particular value in palliative care. It is represented in various guises and is often seen as a moment of caring and connectedness with a patient. In *Caregiver Stress and Staff Support in Illness, Dying, and Bereavement* (2011), Youngson is the author of a chapter on 'Compassion in Healthcare' and describes a situation where a nurse showed particular care in avoiding bumps in the floor. She characterised compassion as being "revealed in the smallest of acts" (p.82). The Nationwide Health & Disability Consumer Advocacy Service (NH&DCAS) of New Zealand compiled a booklet sharing stories of quality care. One of the anonymous contributors spoke of a time of grieving and found that when a doctor cried with her it showed she had the compassion to share her sadness, and this was felt to be heart-warming and unforgettable (NH&DCAS, n.d.).

Jean Watson is recognised for her writing on the caring in nursing with her book *The Philosophy and Science of Caring* (2008), used as a text for nursing students. In this book she describes the Caritas factor and discusses the teaching of it to nursing students. Some of her descriptions include details which are part of what she considers essential care. "Through actions, words, voice, non-verbal presence, thoughts, feelings, and full use of self, the Caritas Nurse connects with the other" (p.82). Caring and compassion can, at times, be seen as interchangeable. While care can be given without compassion, true caring must involve use of self, as Watson suggests, which can only come from a sense of compassion.

In palliative care compassion should be directed to the family as well as to the patient and it may be the family who has the greater need. Pratz (2001), in a narrative account, recounts the time her father was dying and the comfort she received from a nurse who saw her grief and hugged her while she cried. She described this experience as a 'gift' that gave her the strength for everything that followed. Compassion and touch are often associated, and a reflective narrative by Johns (2009) describes touch as compassion, as well as deep listening and giving to a patient in his care.

2.3.2 Touch

From a nurse hugging a grieving family member, to holding the hand of a patient, the use of touch is vital in palliative care. In an article drawn from a research study of exemplary nurses, Perry (1996) identifies eight varieties of touch (defined as procedural, non-physical, talking, trigger, social, diagnostic, comforting, and the final touch) and states that “it became evident that touch was important in the care given by the exceptionally competent nurses” (p.9). She discussed the ‘final touch’ in more detail and in particular as related to caring for those who were dying, saying that many nurses in her study believed that touch is the last sense of a dying person and “because of this belief the exceptional nurses used touch, sometimes exclusively, in communicating with patients during their last days” (p.11).

From a non-health professional perspective, in *The Tibetan Book of Living and Dying* (2002), Sogyal Rinpoche states “A great deal of consolation can be given to the very ill simply by touching their hands, looking into their eyes, gently massaging them or holding them in your arms”(p.180). It is also recognised that even in unconscious patients touch is important and has been recognised by both patients and their families. Perry (1996) cites Watson in the statement “Patients who have no apparent verbal capacity can usually feel a gentle touch and understand its message of caring interest” (p.11). Ira Byock (2004), a noted palliative care author and physician, believes in loving care and his description of personal care gives a fresh perspective to what might be seen as the priorities of washing a patient.

Loving care may occur through routine nursing tasks such as bathing, toileting and grooming – each of which is performed in a manner that intentionally evokes feelings of comfort, pleasure and nurturance. An onlooker, watching a skilful nurse or aide bathe a patient, might think the purpose of the bath was to soothe and bring pleasure to the patient. The fact that the patient becomes clean often seems almost incidental to the process (p.5).

Touch may occur as part of personal grooming or cares for a patient but touch also has meaning when it occurs as something extra. Perry (1996) reported a qualitative study that had used conversation, observation and narrative exchange to evaluate the beliefs and actions of ten nurses identified as exemplary by their colleagues. She defines “silent messages encoded in actions” (p.9) and describes one nurse’s use of secondary touches that

might be considered unnecessary while performing cares. She explains “A squeeze of the hand, a stroke of the arm or a caress of the face said: ‘You are a real person with real feelings. I respect you’” (p.11). This interpretation is supported by a number of stories collected in a booklet produced by the Nationwide Health & Disability Consumer Advocacy Service (NH&DCAS, n.d.). Some of the stories from health consumers offer examples of what they felt had made a difference:

they showed warmth in the way they touched us, in the way they made lots of eye contact, soft smiles, smooth and unhurried voices...they were incredible” (p. 28).

“thanks to those (nurses) who rinsed a face cloth under cold water and put it on my very hot forehead and additionally thanks to the nurse with the cold hands who ‘touched’ my burning forehead” (p. 22).

“especially thanks for that morning when you acknowledged my pain by touching your hand on my leg as you left (p. 22).

There is recognition in the value of touch by Gramling (2004) who conducted a narrative study of ten patients in a critical care unit in U.S.A., the aim being to describe nursing art from the patient’s perspective. She reported that participants in her study could “vividly remember instances of the nurse’s touch, perceived as healing, for many months after the encounter” (p.394). Coggins (2012) wrote a personal account in the New Zealand nursing journal *Kai Tiaki*, in which he recalled caring for a distressed lady in the intensive care unit, whose sister suggested if he really wanted to help he should hold her hand. He went on to say “as if some kind of magic panacea exists in the simple act of holding someone’s hand, a night sat at the side of her bed doing just that, brought her real sleep” (p.30).

Touch means more than just contact, when it is seen as ‘healing’ it becomes therapeutic for patients. Pearcey (2010) studied twenty-five nurses in five hospitals in the United Kingdom, using a grounded theory approach, to evaluate their perspective of the dominant values in clinical nursing. In her article she acknowledged, like Gramling (2001), the value to the carer, and reported a nurse participant saying “I love caring – I love to be able to hold their hand, just touch their arm, their forehead – that sometimes is better than any pill or potion” (p.53). Touching an unconscious patient, letting them know you are there, is something families are encouraged to do also, and benefits both people involved. Saunders, Baines and Dunlop (1995) in their seminal work *Living with Dying; A Guide to Palliative Care*,

suggest that as well as holding a hand, sometimes simply the presence of a loved one is sufficient to bring peace and calmness to an unconscious patient.

2.3.3 Presence or 'Being'

Dame Cecily Saunders, on behalf of patients, asked health professionals to "Watch with me" (Baines, 2011, p.2). Her belief was that in watching we could learn how to understand, how to be silent and to listen, as well as how to "just be there" (p.8). Byock (2004), writing in *Health Progress*, believes that "Simply keeping company with a patient in distress can at times be a powerful intervention" (p.5). Remen (2001) in her book *My Grandfather's Blessings*, also discusses the importance of 'being' and says "Sometimes just being in someone's presence is strong medicine" (p.102). This is likely to be the belief of the care recipient who wrote "Thanks to the nurses who were there when no one else was as I shared my tears" (NH&DCAS, n.d., p. 22).

Presence is valued by patients and their families in many ways. It is not merely being in the room but 'how' the health professional is in the room that matters. Ufema (2007), in her *Insights on Death & Dying* book of collected columns from the journal *Nursing*, states "Kindness isn't what you do or say; rather it's how you are fully present with another. The patient can sense whether or not you want to be with him. It's infinitely rewarding to do so" (p.13). This is also the view of Siegel (1986), a well-known surgeon and author of books on self-healing, who believes that empathy is essential for healing and states that "When a doctor sits down for one minute at the bedside to talk, the patient experiences it as five or ten minutes. If the doctor stands in the doorway, the same visit seems like fifteen seconds" (p.45). Czerwicz (1996) was involved in a qualitative study in Chicago that investigated the satisfaction levels of thirty family members whose loved ones had died at the institution. Her article reporting on that study concluded with advice and direction on caring for dying patients. She advises nurses to sit down with family members, saying "This makes a powerful statement. Not only does it show that you're focusing all your attention on them, but it lets them know that you care enough to set aside some time to simply listen" (p. 36). This compelling message, whether for patients or families, is unspoken but can convey more than any words that the health professional uses.

Presence or 'being' could be seen as use of 'self' in patient care. Dame Cicely Saunders recalled a Hasidic concept that compared listening well to looking on water rather than in a mirror. The inference that can be drawn from this is that one had to be very still to look in water without disturbing it (du Boulay, 1987). The effectiveness of listening, as looking in still water, is determined by how it actually happens. Superficial pretence of presence will be seen, or felt by the recipient. Watson (2008) describes use of authentic presence and fully listening as the greatest gift of healing that one can offer. Genuine use of self and allowing the patient to experience that degree of care could be a part of what differentiates an expert nurse.

2.3.4 Expert Nurses and Quality End of Life Care

While reviewing articles from the literature search, a recurrent theme associating expert nurses and quality end-of-life care was revealed. Several authors examined the qualities of expert nurses in end-of-life care and drew similar conclusions. MacLeod (1994) wrote an article reporting on one aspect of a phenomenological study that involved interviewing ten experienced surgical nurses in two Scottish teaching hospitals about their understanding and experience in nursing and how it contributes to nursing expertise. She found that "When we look at these excellent, experienced nurses' moment-by-moment practices, we see that the 'little things', like making a handle for a chest drainage bottle or placing a bath mat differently, are not so little after all. These everyday, taken-for-granted practices are purposeful, complex, multifaceted and patient centred" (p.365). MacLeod (1994) added "attending to the little things of patient care is one of the hallmarks of nursing experience" (p.365).

Noble-Adams (2006) examined the 'being and becoming' of exemplary nurses in a New Zealand study which involved interviewing ten nurses nominated by colleagues and peers as exemplary. She found that a prerequisite of being an exemplary nurse was a 'love of nursing' and each participant acknowledged they 'loved being a nurse'. Other findings were the importance of making a difference to their patients; being prepared to go the extra mile; walking the talk or practising what they preached; establishing caring relationships with patients and families because they understood that a caring relationship, and being fully present, allowed true healing to occur. While this study was not conducted in palliative care,

a number of the participants worked in palliative care and there is a resonance within their words for nurses giving palliative care in many settings.

In an article reporting her study of exemplary palliative care in a critical care situation, Perry (2005), described an example:

“One nurse often said to her dying patients and their families, “if I could do one thing for you right now, what would it be?” This nurse commented that the answer was frequently surprising. She said, “Often I couldn’t have guessed what would bring them comfort.” Exemplary nurses ask the question and then do what they can to individualize the care to meet the patient’s real desires” (p.18).

This seems a simple question but is perhaps not often asked. What is demonstrated by these nurses is an awareness of detail and how it can benefit their patients. MacLeod (1994) describes the detail of the stories and experiences of some excellent nurses and their character of care, and describes their practice as “purposeful, complex, multifaceted and patient centred.” MacLeod went on to say that “It is argued here and elsewhere that attending to the little things of patient care is one of the hallmarks of nursing expertise” (p.365).

Relatives have understood good nursing care as what they see being done for their loved ones that is valued by them and the patient. In reporting a mixed-methods study exploring fifty relatives’ experiences of the death of a loved one in a Norwegian nursing home Kaarbø (2010) describes factors that were identified by relatives as constituting good nursing care. These included mouth care, shaving, nail care, and changes of clothes or position in bed. They also noticed the behaviour of nursing staff that demonstrated respect and showed genuine interest. It is disappointing to note in Pearcey’s (2010) article that a nurse interviewed in her study described caring as “the little things we are not supposed to do anymore” (p.53). Pearcey noted that the use of the word ‘supposed’ would suggest that these are still done, but wonders whether, while they are valued personally, they may not be by an institution.

Good nursing care has been described by some as the ‘art’ of nursing. Nursing was first described as an art by Florence Nightingale in 1856 (as cited in Gramling, 2004, pg 1) when she referred to it as “one of the Fine Arts: I had almost said the finest of the Fine Arts”. This

compares to Gramling's own interpretation in this century, after interviewing patients in order to ask their perspective on the nursing art. Their response suggested that "The nurse artist was consistently depicted as one who "went out of her way for me," one who "goes the extra step," "went above and beyond" and "remembered to do all the little personal things" (pg.389).

2.3.5 Little Things

As noted in the previous section a component of excellence in nursing was an awareness of, and paying attention to, details and 'little things' in patient care. Kaarbø, (2010); MacLeod, (1994); Noble-Adams, (2006); Pearcey, (2010); and Perry,(1996 & 2005) all reported research which demonstrated excellence in nursing care and also noted the value of 'little things' to both patients and health professionals. The wealth of experience which is a part of being an 'expert' or 'exemplary' nurse assists in developing an understanding of the value of these actions. Perry (1996) studied nurses who had been recognised as exemplary nurses by colleagues and analysed their actions and beliefs. In her findings she recorded various examples of their attention to small details and how they felt that these details, while trivial, were also critical and communicated a message and meaning more adequately than words. Perry (1996) shares a nurse's comment describing warming milk or offering a choice in jam as seeming trivial but being critical. In a later article drawn from the research study, Perry (2005) shares some participant narratives and says "Too often, we underestimate the power of a touch, a kind word, a listening ear, the smallest act of caring, all of which have the potential to make a difference in the quality of life of another" (p.16-17).

Choice was also noted as important in a study by Teno, Casey, Welch & Edgman-Levitan (2001), which used both a literature review of expert opinion and focus groups with forty-two bereaved family members across three cities in the U.S.A. A key theme of the findings from family members was that the patient had some control and freedom of choice at end-of-life. This was defined not only in medical matters but in daily choices such as going outside or when to bathe, and was seen as a vital part of good care.

Arman and Rehnsfeldt (2007) conducted a hermeneutic study seeking clinical indications of good ethical care and investigating ideal nursing care in praxis. They interviewed six nurses and four nursing students using Socratic dialogue, and included data from two former

patients from a previous qualitative research project. Their findings had a particular focus on the value of the 'little extra', describing it as a key concept. They offered a number of scenarios relating episodes of care that encompassed these 'little extras' and analysed the meaning of these episodes. Interviewed patients had claimed that these had a great impact on their lives. Arman and Rehnsfeldt went on to say

“Sitting down to talk with patients, offering to operate on a patient in one’s free time, dressing a patient in violet because she likes the colour, and staying in the room of a dying and unconscious patient, can appear to be minor or insignificant acts of care. However, when seen from the perspective of the ethics of understanding of life, these acts reveal the utmost intention of caring that... contributes to improving patients’ existence. From an ontological/universal perspective this means to ‘become a human being’ by reaching out to one another in interdependence. The patients’ existence is shown to have meaning in a deeper sense to the caregivers themselves” (p.379).

Czerwiec (1996) conducted research with thirty next-of-kin who had a family member die at a Chicago hospital, to assess satisfaction or dissatisfaction with their care. She found that sitting down when talking to patients and families makes a powerful statement; that you are focusing your attention on them and letting them know that you care. She added “Sometimes the things you do that you think are trivial are the most important to them” (p.36).

Palliative care happens in places other than hospice and Carr, Hicks-Moore and Montgomery (2011) conducted their study in a Canadian specialised dementia unit, using a hermeneutic phenomenological approach with open-ended interviews. They studied the meaning of spiritual care as perceived by patients with dementia, their families, and their care providers, including nurses and hospital chaplains. They recruited twenty-nine individuals into their study. While this study was not conducted specifically in a palliative care situation, it should be recognised that any long term care of the elderly facility is involved in palliative care, even if it is not characterised as such. In their conclusions they described little things as simple yet complex and, in sharing some examples, found that they “provided the context for health care providers to address and respond to the physical, emotional, social, and spiritual needs of persons with dementia” (p.405). They found that

the actions were a chance for staff to demonstrate caring and dignity for clients and that the intentional act of 'little things' fostered personhood for the patient.

A study of both acute and long-stay care settings in Ireland was conducted by Casey et al. (2011). They interviewed thirty-three staff across six sites and identified some key factors, in particular, philosophy, culture and organisation of care. Narrative from participants was included and one said "the simple things, so simple that you nearly overlook them, a sip here, a word of encouragement... hold his hand for a few minutes you know if you get the chance... always cleanly dressed and shaved and that they would look well... its important" (p.1829). They found that across all facilities was evidence of sensitivity to individual needs and meticulous attention to aspects of care which was stated as including hand holding, grooming, and talking to the dying person.

Kearney (2006), in a personal account in the *Australian Nursing Journal*, discusses the benefits of remembering the small things and reports that these can affect the final health outcome. She concludes by saying "There is a saying 'don't sweat the small stuff', but in our profession, I think the small stuff is vital. So, for a healthier patient, make sure you do sweat it" (p. 48). A personal account from Cater (2003), now a registered nurse, explains the significance of a 'little thing' during a personal experience as a child in hospital. These personal accounts offer the perspective of a patient that is now viewed through the lens of a nurse. They support the idea that what can be thought of as 'small stuff' can have an enormous impact on patients and on their families but is not always recognised by a health professional.

During a phenomenological study in two hospices in New Zealand, with twelve terminally ill people coupled with a family member, Janssen and MacLeod (2010) sought to discover their perception of medical care and what care means. They share the thoughts and words of some patients who describe important factors as "Little personal things – always just called me B, shook my hand and made me welcome and really cared" and "maybe a touch on the shoulder ...not a feeling of intimacy but of friendship...it makes a big difference" or "the little things – a glass of water, arranging the pillows on the bed for comfort" (p.436-437). Janssen and MacLeod went on to say that patients were not expecting a lot but that the simplest acts differentiated between feeling cared for or not.

Barnard, Hollingum & Hartfiel (2006) interviewed fifteen nurses, in a phenomenological study in Australia, to understand the experience of palliative care nursing and they found that “The simple things in life had significance and meaning while materialistic concerns had less importance” (p.10). This message is repeated by Perry (2005) who stated “It was often the small, seemingly insignificant nursing actions and acts of human kindness that made the greatest difference to the patients and their families when they were close to death” (p.16). Perry also described a tiny gesture as having immense power when delivered with compassion and sincerity. Spichiger (2008) conducted a qualitative study in Switzerland with ten patients and close family members to explore their experiences of end-of-life care. She describes many details of their reported experiences, including little gestures such as having a glass of wine, photographs on the wall, and shared meals, which had affected their lives and enhanced their experience at a crucial time.

The research and articles referred to in this review have been drawn from a diversity of countries including Australia (Barnard et al., 2006; Kearney, 2006); Canada (Carr et al., 2011); England (Pearcey, 2010); Ireland (Casey et al., 2011); New Zealand (Janssen & MacLeod, 2010; MacLeod, 1994); Norway (Kaarbø, 2010); Sweden (Arman & Rehnsfeldt, 2007); Switzerland (Spichiger, 2008); and the USA (Czerwiec, 1996). These articles from around the globe have all identified and reported details of care, often described as ‘little things’, which had affected patients and their families. Many of these articles included compelling, direct quotes from people who noted the impact these acts of care had had for them which suggests that these ‘little things’ have a world-wide importance. Ufema (2007) validates this, saying “The most important thing to remember is that the little things really mean the most to everyone involved” (p.210).

Results from this literature review demonstrate that it is often the small actions that have the biggest impact on an ill or dying person. Arman and Rehnsfeldt (2007) describe how the ‘little extra’ can have a great impact and can preserve dignity, create feelings of value, compassion and mercy, and offer hope. They also report a patient’s description of these actions as a feeling of “being seen” (p.381). This is also defined as individualising care and it would be expected that this is recognised in most palliative care facilities, especially St Christopher’s where “concern for the individual wishes of each patient is the key to the very special care given by the nurses” (du Boulay, 1987, p.178). This stems from the founder of St

Christopher's and modern hospice care, Cicely Saunders, whose passion for detail du Boulay (1987) reports, "finds its most creative outlet on the wards, for hospice nursing is above all attention to detail" (p.177).

2.3.6 Environment and Atmosphere

Florence Nightingale was the first nursing leader to identify the importance of the environment on the health of patients, albeit without using the word 'environment'. She spoke of the need for proper ventilation, identified light as a particular need, especially direct sunlight, and cleanliness was also considered a critical component (this was prior to the development and understanding of 'germ theory'). She also included the concepts of quiet and diet in her theory (Pfetscher, 2010). Nightingale (1969) spoke of the need for a healthy environment, free of dirt and odours and stated "What nursing has to do is put the patient in the best condition for nature to act upon him" (p.133).

The environmental field is described as integral with the human field by Rogers, in her 1994 nursing model (as cited in Gunther, 2010). This suggests that people cannot be separated from their environment but are affected by the elements of it. Watson (2008), a recognised nursing theorist, defines one of her ten carative factors as "providing for a supportive, protective, and/or corrective mental, social, spiritual environment" (p.31). She agrees with Nightingale on the importance of light, ventilation and cleanliness and adds the importance of aesthetics, saying "A personalized, pleasant, aesthetic environment elevates one's experience. There is often need for order, beauty, and symmetry as a means of connecting with the human soul; such order and equilibrium can help bring closure and completion to an experience" (p.136). Perhaps patients and families do not think about environment in these terms but it is certain that they notice the difference between the hospice environment and that of a large hospital.

McKinlay (2001) in the 'Circle of Care' study located environment as encompassing all other themes of palliative care as she describes the environment as also comprising aesthetic and spiritual dimensions. Her patient narratives included words such as peace, serenity, tranquillity, compassion, happy environment and relaxation.

The environment and atmosphere was seen in a very positive light with comments such as 'laid-back', 'living life', and 'very happy' by Broom and Cavenagh (2011) who used

qualitative interviews of twenty patients to explore their experiences of living and dying in an Australian hospice. Participants expressed that the hospice could be positive and happy and enjoyment of the 'normal' things that went on there. They also remarked on the difficulty some people had in coming to the hospice because of a sense of trepidation in transitioning to hospice and what it meant. It was noted there was relief for participants once the reality of being in the hospice was recognised.

Stomberg (2009) studied terminally ill people in a Swedish hospice, using open interviews, and reported results that provided important insights. She categorised her results as 'internal essentials' and 'external essentials' which offered a worthwhile perspective. Definitions of some of the 'external essentials' included the 'home-like' environment; the attitudes of staff members who listened with empathy and were supportive and calm; and the fact that the care was adapted to the individual situation rather than to general routines. This was unfortunately a brief article and contact with the author established that additional information was available only in Swedish.

A qualitative descriptive study of ten patients in a Canadian palliative care unit by Gourdji, McVey and Purden (2009) asked what they believed affected their quality of life in their palliative care experience. They found three particular themes of importance including "Doing things that I usually do", "Being helpful to other people", and "Living in a caring environment" (p.43). The 'caring environment' included relationships, quality of palliative care and the physical environment. Their participants described activities such as being able to do their usual daily activities or being able to do something to help others as being very important to them. They also commented on the warmth and friendliness of the staff, not only to the patients, but to their family members as well, and this was much appreciated.

Rasmussen and Edvardsson (2007) present a conceptual framework describing the influence of environment in palliative care. They found that despite environment being seen as a central feature of palliative care they could not find any studies that had placed it as a focus of research. They believe that "nursing care and the psychosocial and physical environment are inseparable entities, interacting in such a way that it is the 'atmosphere' of a place, rather than an individual nurse, that either supports or hinders the experience of well-being or at-homeness" (p.1200). They also describe components of physical aspects of a setting as

achieving “symbolic meanings concerned with supporting a continuation of self” (p.123) for a patient. The descriptions of the participants have been represented into three concepts of atmosphere; hospitality, safety and ‘everydayness’.

2.4 Conclusions

In systematically reviewing a wide range of literature, very few references directly reported ‘the patient’s voice’. The literature does reveal important issues in palliative care but the review failed to find research that specifically focused on reporting patient and family answers to the question “What do you think is important?” in the field of palliative care. Certainly there are valuable narratives from patients, and from carers that have been recorded in the research articles. However when health professionals who are researchers state their conclusions, there is a risk of their perspective overwhelming the authority of the authentic patient or family voice. It is the patient voice that is key; it is intended to retain prominence of the patient and family voice in this research text. I concur with McKinlay (2001), when she suggests it is only those who are living with dying who can actually declare what is of importance to them. If we are not to be seen as paternalistic and think of ourselves as all-knowing then the patient should be asked, and must be heard. Randall and Downie (2006) suggest “The patient’s actual description of the situation, or less structured interviews, might best serve to bring to light patients’ concerns or point to the possible solutions” (p.47).

There is a wealth of literature in journals, as well as books with valuable insight and knowledge by eminent palliative care authors such as Byock (1997), Kuhl (2005), and Saunders, Baines and Dunlop (1995) and Doyle, Hanks, Cherry and Calman (Eds.) in the *Oxford Textbook of Palliative Medicine* (2004). These offer guidance and knowledge to patients, families and health professionals alike on many important topics in palliative care. However the intent of this research is to find out the practicalities, or the ‘essence’ of what makes a difference each day. To define what the specific and tangible details are that make someone say “It’s so wonderful here”. Concepts described in the literature such as truth, communication or touch are recognised as being so important in health environments as to be prominent in institutional policy and key in quality audits. It would be difficult to believe

practice in hospitals or rest homes might occur without this appreciation. This research aims to find out what makes a difference then, when people come to the hospice.

Compassion has been strongly identified as important by Watson (2008) and Youngson (2011). It can be recognised as important in many forms in palliative care writing, especially in narratives from patients and families, but no research articles were found during this literature search to suggest that it has been a specific topic of research. The subject of compassion in palliative care warrants further examination.

Despite much valued writing and well-researched studies there remains a gap in the literature for a qualitative research approach to study patient and family priorities in palliative care. While many aspects of palliative care are recognised and inform this research, this project will seek to find the 'essence' of palliative care, through identifying the details that make a difference to patients and families from their own perspectives as stated in their own voice. The following chapter will present the methodological design of the research project.

Chapter 3: Methodology and Methods

3.1 Methodological Aims

In planning this research credence was given to Dame Cicely Saunders herself “whose only methodology was ‘listening to people’” (Oliviere, 2005, p. 203). Simple, yet strong and effective, this was an ideal foundation on which to construct a valid palliative care research model seeking to hear patients’ and the families’ voice. Dame Cicely began research in palliative care before St Christopher’s Hospice was established, while working with the Irish Sisters of Charity in East London (Saunders, 2006), where she began making tape recordings of many patients. These recordings were the basis of her extensive study “The Nature and Management of Terminal Pain”. This was an on-going study during her career which formed the basis of her many presentations and publications. These are collated in an extensive bibliography by Professor David Clarke on the website of Cicely Saunders International, (Clark, n.d.). Once St Christopher’s Hospice was founded she was determined that it would have a research team to establish scientific foundations for their teaching (du Boulay, 1987).

While much of the early research was based on pain control and other physical symptoms, Doyle (2007), in an article discussing the changes and growth in Palliative Medicine, reports that research groups today are increasingly publishing papers based on a variety of topics including psychosocial, spiritual, and relative’s needs. It is likely that research on these topics will frequently utilise qualitative methods to achieve answers relevant to the aim of their enquiry.

Like Dame Cicely, this research aims to listen to people and then to record and report their responses. Only those who have been recipients of palliative care can genuinely answer the question of what is important to a patient or their family in palliative care. Only if their own voice is heard can we be sure that it is accurately conveyed to a wider audience. This intent meant that qualitative research was likely to be the most appropriate approach for achieving the desired end results.

3.2 Qualitative Research

“Not everything that can be counted counts, and not everything that counts can be counted”

Albert Einstein (as cited in Patton, 2002, p.12).

3.2.1 The Scope of Qualitative Research

Qualitative research is a collection of methods that have a broad approach to data collection and analysis, defined by Denzin and Lincoln as “a situated activity that locates the observer in the world. It consists of a set of interpretive, material practices that make the world visible” (2000, p.3). Payne outlines two major types of qualitative research as experiential (people’s understanding of their world) and discursive (how language creates the world). She suggests the experiential is recognised in palliative care from methods such as phenomenology and thematic analysis, both of which are elements of this research project. Patton (2002) states that qualitative methods allow for depth and detail in the study and that not being “constrained by predetermined categories of analysis contributes to the depth, openness, and detail of qualitative inquiry” (p.14). Also relevant to this research is Sandelowski (1997) who states “the stories collected in most qualitative research encounters are renderings of the particular and concrete, but also of the universal and general. Lives are lived and told in relation to other lives and in a historical and cultural context” (p.127-128). The stories collected during this research will be related to other lives lived in the palliative care context so that the knowledge gained can be used to enhance their experience of end of life care.

Qualitative research is an appropriate methodology for developing an in-depth understanding of human experience. Although quantitative research is used in palliative care the information sought here is better gained from using a qualitative approach. Payne (2007) states that “qualitative methods are among the most useful and frequently used methods in palliative care research” (p.139). Lee & Kristjanson (2003) also state that qualitative methods can be the most appropriate to use in palliative care research because they “allow an in-depth investigation of unique care experiences and can be designed to suit the available energy and resources of the subjects” (pg. 15). This research is designed to obtain rich and thick description in order to illuminate the priorities and definitions of the participants involved. As the people involved, or a loved one, have serious personal health issues, qualitative research allows for unstructured interviews that are able to take account

of their energy and resources so that the most can be gained with the least negative impact on the participants.

What is sought are the rich insights that Lee and Kristjanson (2003) suggest might be hidden within palliative practice. Those who are receiving palliative care are well-placed to make known those insights and to share their importance so that others can better appreciate the priorities according to patients and families themselves. Clark (1997, 2001) believes that qualitative research has already made a significant contribution to palliative care studies and that there are many examples now being reported in specialist palliative care literature. He also suggests that qualitative research has the potential for greater development in palliative care. Chapter 2 reported on palliative care research and reviewed a number of key studies using qualitative methods, (for example, Barnard et al., 2006; Broom & Cavenagh, 2011; Gourdjji, McVey & Purden, 2009; Janssen & McLeod, 2010; McKinlay, 2001; Nelson et al., 2010; Spichiger, 2008; Teno et al., 2001).

As it is intended that the voice of the participant be heard a qualitative methodology was sought that allowed the responses to be heard with clarity and without the distortion of over-interpretation. Qualitative description emerged as an appropriate methodology to use.

3.2.2 Qualitative Description

Qualitative description, as explained by Sandelowski (2000) is a perfect fit for the planned research. She states “Qualitative description is especially amenable to obtaining straight and largely unadorned (i.e., minimally theorized or otherwise transformed or spun) answers to questions of special relevance to practitioners and policy makers” (p.337). In wishing to accurately convey patient and family voice it was important that the voice not be overly transformed or distorted by well-intentioned interpretation. Sandelowski (2000) defines the description as entailing the “presentation of the facts of the case in everyday language” (p.336), so the voices will not be ‘spun’ or re-presented as interpretive data but simply allowed to be heard in their own everyday language.

Neergaard, Olesen, Andersen and Sondergaard (2009) believe that qualitative description traditionally fits qualitative research as “an empirical method of investigation aiming to describe the informant’s perception and experience of the world and its phenomena” (p.53). Qualitative description allows the researcher to describe the data as it is recorded

and transcribed and therefore Neergaard et al. (2009) suggest that the final outcome is a description of those experiences in the participants' own language which fits the intent of this research to report the voice of the participant. They also proposed a useful guide for planning qualitative descriptive research in the form of a table based on Sandelowski's work.

Table 1: Qualitative Description design issues as proposed by Sandelowski

Design issues	Design specifics
Philosophy	Pragmatic approach Overtones of other qualitative approaches (phenomenology, grounded theory, ethnography or a narrative study)
Sample	Purposeful sampling
Data collection	Minimally-to-moderately structured open-ended interviews with individuals or focus groups Researchers are interested in the Who, What, Where and Why of the experience Review of documents or other pertinent materials
Analysis	Qualitative content analysis using modifiable coding systems that correspond to the data collected Stay close to the data – low level interpretation Goal of the analysis strategy is to understand the latent variable (useful for concept clarification and instrument development)
Outcomes	Straight description of the data organized in a way that "fits" the data (chronologically by topic, by relevance etc.)

(adapted from Neergaard et al., 2009, p.54)

These design issues are discussed in this chapter.

3.2.3 Philosophical Orientation

Although there is a pragmatic approach underlying this research based on the criteria in the previous section, there are also overtones of phenomenology and of praxis based research. Pragmatism is seen in the straight forward structure and analysis of qualitative description. Although not to be mistaken for 'easy' the simple clear lines allow for direct relation of the data without over-complication by "synthesizing, theorizing and recontextualizing rather than simply sorting and coding" (Neergaard et al., 2009, p.53). "In qualitative descriptive studies, language is a vehicle of communication, not itself an interpretive structure that must be read" (Sandelowski, 2000, p.336). Sandelowski also suggest that this low-inference interpretation makes a consensus between researchers more likely, helping to ensure validity of results.

Nuances of phenomenology and praxis based research will be used as the researcher endeavours to categorise or clarify the conversation or interview content that is acquired from the participants. But the text that conveys the essence will remain undistorted and true to each participant.

Phenomenological research does not seek solutions to problems but, as van Manen (1990) proposes, meaning and significance, and interpreting these to a degree of depth and richness. A phenomenological approach fits this research because it aims to understand the individual lived experience and its significance to individuals. Grace and Ajjawi (2010) state “An underlying premise of phenomenology is that experiences and their significance to individuals are valid sources of knowledge” (p.197). This is expanded by Marshall and Rossman (2011) who describe participant interviews as being unique expressions that are analysed and when compared can help to ascertain the essence. It is this ‘essence’ ascertained from the participants who are the ‘valid source of knowledge’ that is sought to be understood and shared in this research project. McWilliam (2010) states that phenomenology could potentially “enhance professional practice” and “inform programmes, services and policies in ways that promote positive change” (p. 230). Conceivably the results of this research could be used to promote positive change in palliative care or in areas wishing to establish palliative care.

While Marshall and Rossman (2011) suggest that a phenomenological approach “typically involves several long, in-depth interviews” (p.19) this study will comprise of only one interview for each participant. The reason for this is to minimise the impact on a seriously ill person by minimising demands on their time.

Mayo (2006) states that praxis-based research is carried out by a researcher concerned with the political and social consequences of their work. It would be beneficial to understand the ‘political and social consequences’ of the work done at hospice. Sharing that understanding can then effect improved consequences for others in hospice care. Mattson & Kemmis (2007) suggest praxis-related research demonstrates relevance to the situation as it is lived and experienced by participants in the situation” (p.192). This research aims to discover what the participants have ‘lived and experienced’ within palliative care.

The underlying premise for this research will be the pragmatic approach of qualitative description but, undoubtedly, there is benefit in acknowledging the potential enhancement of an understanding of phenomenological and praxis-based approaches and allowing for overtones of those within the research process. What must remain evident throughout is the strong, well-defined voice of the patient and of the family.

3.2.4 Rigour and Credibility

The sampling strategy was clearly described and, as suggested by Milne and Oberle (2005), was designed to be purposeful and selected those participants who held in-depth knowledge relevant to the research. The data collection was participant-driven with open questions designed to allow the participant to define factors of importance to them. Milne and Oberle (2005) defined authenticity as requiring that "(1) participants had the freedom to speak, (2) participants' voices were heard, and (3) participants' perceptions were accurately represented" (p.415). Raw data in the form of direct quotes from participants is presented to ensure accurate portrayal of participant voice and perceptions. This study emphasised participants' priorities and meets these definitions of authenticity.

Credibility is demonstrated in that the purposeful selection defines the participants as being consumers of palliative care in a hospice and therefore uniquely qualified to comment on the priorities of care from their perspective.

Transferability relies on the understanding that each individual receiving palliative care has their own needs and priorities and these findings should not be generalised as specific solutions, merely guidelines to a starting point. The findings of this research may be used in other areas offering palliative or end-of-life care as a guideline to points that these participants have offered as being important to them. Sandelowski (1997) argues that while frequently cited, it is false to say results from qualitative descriptive studies are not generalisable. The results from this study are relevant and worth consideration wherever people are receiving end-of-life care, providing their care remains individualised and patient-centred.

It was not feasible to review the transcripts with the participants which may have helped ensure trustworthiness. However, peer review occurred during the research progression in discussion with the research supervisor, an extremely experienced palliative care nurse.

3.3 Research Setting

Otago Community Hospice is situated in Dunedin, a university town in Southern New Zealand, with a population of approximately 125,000. The hospice supports the wider Otago region which covers approximately 32,000 square kilometres and has a population of over 210,000. As well as the in-patient unit the hospice has community co-ordinators and supplies an out-reach service to the greater Otago area.

The hospice is a very pleasant purpose built facility that has twelve beds, each with its own room and bathroom facilities. It has been positioned so that all patient rooms are not only angled and off set for a degree of privacy, but also face into gardens, beyond which are tree clad hills and a stream. They are in a wing away from the street for increased peace and quiet while the administration is housed in the front wing with a welcoming foyer centre front.

There are three lounges for family use, two of which have fold away beds for use by extended families wishing to stay near a loved one. An extra bed can also be placed in the patient's room. There is also an outdoor play area so that visiting children have somewhere to play away from patient rooms if they wish.

As well as medical and nursing staff the hospice has a social worker, counsellors, community workers, and a chaplain on staff, and is able to call in physiotherapists, occupational therapists, a dietician, podiatrist and massage therapist when required.

3.4 Research Objectives

Within the context of the broader aim of this research, to reveal the voices of patients and families in palliative care, the specific research objectives are set out below: These objectives are:

- To establish the factors that are important to patients in palliative care;
- To indicate how needs are met, in appropriate ways, as determined by the patient;
- To establish family perspectives of patient and family needs in order to obtain a full representation of what is required to holistically support people in palliative care.

By establishing these factors future patients can benefit from enhanced knowledge, care and facilities in palliative care. As this study looked at the perspective of both patients and their families, the research was designed to be conducted in two parts.

3.5 Part One: Interviews with Patients

3.5.1 Overview

This part was conducted as individual, in-depth, face-to-face interviews with patients who had been inpatients at the Otago Community Hospice for more than seven days. It took place at their home, or place of their choice, after discharge from the hospice. Interviews are often a good technique for gaining information from palliative care patients. This is supported by Payne (2007) who suggested that, for a number of reasons they are an appropriate choice because they build on experience of previous interviews, people often enjoy the opportunity to chat with attentive listeners and while it requires the ability to talk and understand questions it may be less demanding than writing to complete a questionnaire. A one-to-one interview may be less stressful and tiring than a group discussion and can easily be paused or even stopped if desired. Interviews were timed to best suit the participant's needs, e.g. fluctuating energy levels at particular times of the day, avoiding the time of expected visitors.

Each participant was interviewed only once. Due to the conceivably fragile state of health of the participants, conducting repeated interviews may cause unnecessary stress and was likely to be impractical.

3.5.2 Selection and Sampling

Selection was by 'purposeful' sampling, rather than other methods. Kelly (2010) indicates that "Judgment or purposeful sampling is used to select respondents that are most likely to yield appropriate and useful information. The researcher may use a set of eligibility criteria to define the research population" (p.317). The aim of the selection was to sample people with specific knowledge valuable to this research. Tham (2005) states judgement sampling "occurs when the researcher selects people who have the required status or experience or are endowed with special knowledge to provide the researcher with the vital information" (p.182). These participants all have the experience and knowledge of being an inpatient or family at hospice, and held the vital information sought.

The intention in Part 1 was to interview a minimum of five patients. This number allowed for variation in views but remained a small enough size to enable manageability for the purpose of a Master's thesis. Crossley (2007) suggests that because qualitative research outcomes are contextual a small number of participants are an appropriate sample size to allow for in-depth interviewing and 'rich' or 'thick' description. This is supported by Bogdan and Biklan (1998) who say "most often the researcher works at getting the subjects to freely express their thoughts around particular topics. Because of the detail sought, most studies have small samples" (p.3). Kelly (2010) states "sample size in qualitative interview research does not strive for statistical adequacy but rather ties adequacy to the interview technique, the quality of the information collected, the population from which the samples are drawn and the intended uses of data" (p.317). The aim of qualitative research is to interpret subjective meaning rather than reach probabilistic generalisations. As Bowling states (2002) "The data obtained from qualitative interviews are used to increase our insight into social phenomena rather than assume representativeness" (p.380). As we improve our insight into the needs of patients in hospice care, we can improve the care we offer. The information gained can also be offered to those offering palliative care in other settings, where they can evaluate its appropriateness for their situation.

Each interview was reviewed and assessed. The results from that interview were then used to inform and contribute to further interviews. During recruitment six patients and families opted to be involved so all six were included in the research project.

3.5.3 Eligibility Criteria

The first criterion was that the participant had been an in-patient for more than seven days in total. The seven day requirement was to ensure that participants were not overwhelmed on initial admission to hospice, to allow them time to become familiar with their surroundings and to begin to deal with any symptoms or problems that may have initiated their admission. People who had been an inpatient for less time were excluded also because more urgent issues or symptoms may have needed to be resolved without additional interviews or information being requested, and they would not have been inpatients long enough to form opinions on the topic in question.

A second criterion was that participants were well enough to be interviewed. It would be unethical to ask to interview patients who were affected by unresolved symptoms, unwell or distressed so only those patients whose nurses felt were well enough to participate were offered the letter of invitation.

A third criterion was that the participant was, at the time of the recruitment, intending to return home. Being in their own home, or place of their choice, would have helped alleviate ethical issues of power or coercion and enables participants to feel more able to be honest in their comments. Interviewing post discharge was thought to have ensured greater clarity of recall of what affected them, rather than risk distortion by a recent occurrence while still an inpatient. Kelly (2010) suggests that interviewing people in their home separates them from the power and meaning of the clinic (or hospice) setting, where certain aspects might have been 'cued' by the surroundings.

The fourth criterion was that the participant could not have been nursed by the researcher. Again, this was to avoid or at least reduce issues of power or coercion. It also helped in diminishing the participant's possible feelings of obligation to say what they thought the researcher wanted to hear. This helped ensure that results would not be influenced by previous nurse–patient relationship between the researcher and the participant.

Participants needed to have indicated willingness, after reading the information sheet, to be involved. This was discussed further at the time of the interview to ensure that the participant still wished to be involved in the research. The option of withdrawing, without any negative impact, was reiterated at the time of the interview.

Another criterion was that the participants needed to speak English. This was to ensure full comprehension for both participant and interviewer. The number of non-English speaking patients at the Otago Community Hospice is typically very small. However in the research studies reviewed as part of the literature review, limiting interviews to English speaking participants was common. There are likely to be knowledge gaps that need to be addressed and this would be worth considering in future investigations, but it is outside the domain of this particular research.

3.5.4 Recruitment

Nurses in the inpatient unit of the hospice were able to have a discussion about the research, led by the researcher and prior to its commencement, and were aware of the criteria. This was supported by an information board in the clinical office which detailed information about the research and a list of the eligibility criteria. It also contained contact information for the researcher in case of any queries. Patients deemed well enough and who fitted the criteria were offered the letter of invitation (Appendix 1) by a nurse along with a brief explanation of the research. Those that expressed an interest were then either visited by the researcher or telephoned at home after discharge to discuss the research and, if they wished, to arrange the interview. At this time the participant was given a participant information sheet (Appendix 2) which further clarified the details of being involved in the research. The participant was given the opportunity to discuss the project and ask any questions, before signing the consent form (Appendix 3). It was made clear that there was no compulsion to participate and that they could choose to not participate or to withdraw without problem at any time.

3.5.5 Data Collection

In-depth interviews were conducted with open-ended questions and statements to act as a catalyst to encourage and enable the participants to talk freely. These questions were intended as a prompt only and to offer gentle guidance, the intent being to hear what the participant had to say. Randall and Downie (2006) suggest “The patient’s actual description of the situation, or less structured interviews, might best serve to bring to light patients’ concerns or point to the possible solutions” (p.47). The intent was that these interviews would seek the patient’s own descriptions in their own words.

Data collection involved interviewing each patient in their own home. The interviews lasted between 30 minutes and 2 hours, but most commonly were 30-45 minutes in length. Three patients had a family member present at the interview, and while the questions were directed to the patient, at various points the family member joined in.

Examples of the open-ended questions included: Can you tell me about your experience in hospice? How would you finish this sentence – The important thing is...? If they required gentle prompting the questions included: Can you tell me what made a difference to you during your stay at the hospice? Was there anything in particular that particularly helped

you during your time at hospice? As participants responded to the questions further 'probes' (Patton, 1990; Rubin & Rubin, 2005) were used to elaborate and deepen the responses enabling an increased richness in the data obtained. The questions remained open ended and included "If someone asked you what the most important thing in hospice or palliative care is, how would you answer?" There were many unexpected responses, often recurrent in differing interviews, which have given a richer depth to the data.

One aspect that developed during the interviews was the use of role-playing. Patton (1990) states that this can sometimes be helpful to establish a context if a question is a little difficult to answer. It allows the person being interviewed to see themselves as the 'expert' who has something to share with someone less knowledgeable. In this instance the participants were each asked the hypothetical question "If someone was to come to you, knowing that you have experienced hospice care, and ask you what was important in palliative care and what they could do to improve the palliative care they offer in their facility (such as a rest home or hospital), what would you tell them?" This allowed the participants to expand their answers and gave them an alternative perspective to frame their thoughts. Interestingly some participants felt they couldn't possibly offer any advice to someone in that situation but, despite this, the question did seem to help expand their thinking.

During interviews 'hospice' and 'palliative care' were both used interchangeably. This was deliberate in order to avoid confusion caused by different understandings of the terms. Despite having different meanings in the broader context, if a person was more familiar with one than the other, it was made clear that both had similar meaning for the purpose of this research.

During discussion prior to the interview it was explained that the intent of the research was to allow the voice of patients and families to be heard, and that this meant that extensive excerpts from the interviews would be published in the thesis and in other publications. As a name would be attributed to each of these excerpts, each participant was asked if they wished a pseudonym to be used and they were given the opportunity to choose a name they would be known by. This was guided by Sheldon and Sargeant (2007) who said "It is becoming more common to ask participants to choose a false name for themselves, and

some may wish to retain their own name” (p.176). All of the patient participants were very clear that they wished their own name to be attributed to their words. Perhaps this is part of ‘being heard’ or maybe a way of leaving their mark, a legacy to be left behind.

The interviews were audio recorded (with permission) and transcribed by the researcher.

3.6 Part Two: Interviews with Families

3.6.1 Overview

The second part of the research intended to involve group interviews with the individual participant’s family or friends, the aim being to discover the family’s experiences and their perspective of what was important to their family member or to themselves. How did they see the patient’s experience? What was their own experience? This is supported by Kitzinger (2007) who states that group processes can help people to explore and clarify their views in ways that would be less easily accessible in a one-to-one interview. Group discussion is particularly appropriate when the interviewer has a series of open-ended questions and wishes to encourage research participants to explore the issues of importance to them, using their own words, generating their own questions and pursuing their own priorities.

Halcolm (as cited in Patton, 1990) advises “Always be suspicious of data collection that goes according to plan” (p.143). While Part One of this research was relatively straight forward and mostly followed the original intent, Part Two developed somewhat differently. Many patients were keen to be involved themselves but there seemed to be some reluctance from the patients to allow the researcher to ‘bother’ the family. The first patient interviewed was from out of town and suggested that a grandson who had visited a lot was the most appropriate person to be involved, and that as most of her family lived near her, they had not been in to visit and would not be ‘much help’. One patient, an older person with no family, did not feel that any of his few visitors were appropriate for the researcher to speak to and asked just to be interviewed himself. Three patients who chose to be involved had a family member present at some point during their interview. It developed during the interview that the family member became part of the interview. When it was suggested that perhaps a group interview could be arranged at a later date, it was invariably

thought more convenient for it to happen at the same time as the patient's interview. Despite wider family groups existing, the patients each chose just one person, most often their next of kin, to participate in the research. A sixth patient was unable to be interviewed, due to declining health, but one family member chose to continue involvement with the research.

Patients' wishes were respected in these decisions and no further encouragement was given for them to enrol more family members, or to interview the family members separately from the patient. Ensuring that this research remained patient-centred, it was appropriate to respond to the patient and family preferences and adjust the intended methods to suit the participants.

3.6.2 Selection and Sampling

Like Part 1 this was also to be purposeful sampling. The patient participants identified the family member who they wished to involve. Family and friends can have vital information and knowledge valuable to this research both from their own perspective as to the needs of family and friends of someone receiving palliative care, but also their perspective of what made a difference to the patient. These participants were each given their own copy of the participant information letter and each also signed a consent form.

3.6.3 Eligibility Criteria

The patient indicated those they wish to be involved so their connection was identified at that time. It was important that these participants also did not feel overwhelmed by their own distress or suffering. These participants needed to indicate they were willing to be involved and the choice to withdraw at any time without negative impact was reiterated. Again it was important that these participants were English speaking for clarity of information.

3.6.4 Recruitment

Part 2 was expected to involve 5 to 28 relatives or friends of those patients who participated in Part 1. The number and participants were defined by the patient participant, who decided which of their family or friends they wished to meet with the researcher. It eventuated that five family members took part in the research. They were also given a copy of the information letter (Appendix 2) clarifying the details of being involved in the research, and

were given the opportunity to discuss the project and ask any questions before signing the consent form (Appendix 3). It was made clear that each of these potential participants could also freely choose to be involved or not, and that this would not have impacted in any way on any other participant or on the patients care at the hospice.

3.6.5 Data Collection

The interviews proceeded as described in section.5.5 above but family members were also asked questions such as “Can you also tell me about your family members experience in hospice?” and “Was there anything in particular that particularly helped you or your family member during their time at hospice?” The aim was to discover whether they identified particular needs as family members and whether they could see something that would benefit a patient that patients had not identified for themselves.

During initial discussion at the time of the interview the use of a pseudonym was discussed, as it was with patient participants. One participant asked for a pseudonym to be used. Participants were not told whether other participants had chosen to use a pseudonym or not so they had freedom of choice and most chose to use their own name.

3.7 Analysis

3.7.1 Transcription

The audio-recordings were transcribed by the researcher using a naturalistic approach that captures pauses, hesitations and cultural use of language, including laughter or idiom. Maintaining individual voice is a vital part of credibility and ensured that the voice of the participant is heard without it being interpreted or distorted by the researcher. By reporting the actual words of the individual participants it remains the perspective of the patient or of the carer and not the perspective of the health professional.

Self-transcription allowed the researcher to be immersed in in the data which enriched comprehension and understanding. It assisted in hearing the ‘voice’ of the participant and helped to capture emphasis, inflections and tone so that on repeated reading and analysis of the transcripts the voice of the speaker was heard through the written word.

3.7.2 Data Analysis

Thematic analysis was used to identify patterns of similarity in the transcription texts, in order to group and summarise common phenomena across the participants. Common themes identified were then further developed and the data was re-examined for additional themes. Part of the analysis was examining if the themes of importance for patients and for families were similar or whether they had different priorities. Payne (2007) describes how thematic analysis can be used to look at both manifest content and latent content which could be useful, especially when interviewing the families who may be from a variety of backgrounds and may use different terminology to describe similar circumstances or events. Payne also suggests that thematic analysis might be appropriate if the “aims of analysis are descriptive accounts which summarize phenomena across individuals” (p.155). This fits well with the intent of this research. These descriptive accounts could be then grouped and presented as part of the results of this research. Personal accounts often have a greater impact on those reading them than a summarised analysis, whether quantitative or qualitative.

Using thematic analysis the transcripts were searched for common phenomena and identifiable themes that recurred through the transcripts. These were then grouped into four major headings, each with a number of sub-themes that composed and defined the responses of the participants. While these themes had some similarities with those identified from the review of the literature, they clearly represent the words and thoughts of the participants. Payne (2007) explains that in thematic analysis themes are sought after data collection, not established prior to collection. Rather than trying to make the results fit the previously discovered themes or headings, the participants’ voices are allowed to speak for themselves and are grouped only by their own content.

3.7.3 Bias

The researcher is a registered nurse at the facility (hospice) where the participants had received palliative care. The researcher was not involved in the care of any of the participants or their families prior to the research taking place. Most of the observations made during the interviews were placed in the third party however there was, on occasion, a comment that alluded to the researcher being positioned within the ranks of the staff by referring to the global/plural ‘you’. Efforts were made to ensure that the participant

remained aware that it was important that they described what was important to them and that honesty was vital to ensure benefits for future patients and families. As part of this, each was also asked what they would like to see done differently or anything they did not like in their experience at the hospice. These results are also included in Chapter five.

3.8 Ethical Considerations

3.8.1 Ethical Challenges

There are many ethical challenges facing research in palliative care. It may be assumed that patients and/or their families are unlikely to wish to be involved in research at such a difficult time. Patients may be troubled by multiple symptoms while family members may be distracted and exhausted by both the physical and emotional efforts involved in caring for a dying relative. However Lee and Kristjanson (2003) argue that research in palliative care gives a better understanding of terminally ill patients' experiences and they go on to say "Without research there is a risk that we try nothing new and fail to scrutinize how we care for dying people" (p. 15).

As a researcher it is important to maintain awareness that those involved in the research are sharing their valuable time with the researcher, time that may alternatively have been spent with family. However there is support for the view that although patients in a hospice may be ill and aware of a shortened lifespan, this does not preclude them from involvement in a research project. Lee and Kristjanson (2003) state "The suggestion that palliative care patients should not be involved in research denies these individuals an active role in living and prevents them from contributing to knowledge about how to improve care for others" (p.14). Addington-Hall (2007) agrees, suggesting that despite no palpable benefit there may be a benefit from being altruistic and being able to give something back. Wilkie (2001) acknowledges that much of palliative care research will not benefit participants, as may be the case in other research, but goes on to say

Patients may very much wish to participate in a project even though their participation may cause them inconvenience, even discomfort, and may also be time-consuming. Patients may wish to help and to 'give'. In addition they may gain

from the knowledge that their participation in the research may benefit future patients (p.70).

It was vital that inconvenience or discomfort be avoided as much as possible. By keeping to a single interview, without repeated visits, the intention of this research project was to consume as little of the participants time and energy as possible, while still gaining valuable insight and knowledge.

3.8.2 Principles of Ethical Conduct

Tolich and Davidson (1999) describe a core of five principles of ethical conduct which are an excellent guide for a research study. These are expanded by Mutch (2005) who offers twelve ethical concepts that underpin good research and many of these were very simply resolved within the planned project. The particular ethical concepts that needed to be addressed included:

Informed consent: An initial information letter detailed the project and all necessary information, based on these twelve concepts. The letter was followed by a visit with the chance to explain further or answer any questions. The researcher was also be guided by Sheldon and Sargeant (2007) who say “Consent has to be developmental and based on trust” (p.166).

Voluntary participation and the right to withdraw: There was no pressure when the letters were offered to patients by a neutral party and it was be entirely up to them to express a wish to find out more. Anybody who wished to be involved was told they had the right to withdraw at any time. This was included on the consent form and it was reiterated in each conversation that they could withdraw at any time without any impact on their care at the hospice.

Coercion: This particular concept needed to be carefully observed. Patients may have felt obliged to participate because a nurse at the hospice was involved in the research. It was made clear that not being involved would not affect their care in any way. This was aided by the information letters being given out by other staff, not the researcher/nurse, so that they did not feel obliged by the researcher’s presence to agree to be involved. Sheldon and Sargeant (2007) say “Where you undertake research in your own setting, power dynamics and expectations are already established, which may influence colleagues’ or patients’

decision to participate or not” (p.175). Lee and Kristjanson recommend that there is distance between researchers and participants thus ensuring that the participants are not dependent on the researcher for care. In this research the nurse researcher was not involved with the care of any patient prior to their participation in the research.

Confidentiality, privacy and anonymity: All participants were offered individual interviews to maintain confidentiality and privacy. The researcher was guided by Kitzinger (2007) who states “The presence of other research participants can compromise the usual confidentiality of a research setting, so special care should be taken, especially when working with ‘captive’ populations” (such as patients in a hospice) (p.23). The direct data from the interviews was only seen by the researcher and the thesis supervisor, and was kept in a locked cabinet. To ensure anonymity in reporting the research all participants were offered their choice of a pseudonym or they could use their own name if they wish.

Power: Besides the matter of coercion to be involved or not, there is the issue of power relations when responding to questions. Participants may feel obliged to say what they think the researcher wants to hear; fear that what they say may influence their or their relatives care; pressure to respond only positively. Discussion reinforced that they were welcome to say what they believed, that the research only has value if participants were honest with their answers.

Minimisation of Harm: A risk to participants is that they may have, during conversation, uncovered areas that were distressing or emotionally painful. If this occurred, and the participant wished, arrangements were in place for them to see a counsellor. Many of the participants may already have had involvement with the counselling service at the Otago Community Hospice and could have revisited them if the interview caused any distress and was not immediately relieved. If they did not already have a therapeutic relationship with a counsellor then a list of counsellors was available. Fortunately no episodes of distress occurred at the time of the interviews or were reported afterwards.

Underlying all ethical considerations for this research was the Declaration of Helsinki which asserts ethical principles for all medical research involving human participants.

3.8.3 Ethical Approval

Ethical approval was sought from the Lower South Regional Ethics Committee and was granted on 7 July 2011 (Appendix 4). As part of this application a Locality Assessment was completed by the Otago Community Hospice and they gave their approval and support for this research.

This research was implemented and the research interviews took place between June and October 2012. The analysis has been in progress since the first interview and the results are considered in the following chapter.

Chapter 4: Hearing the Voices

4.1 Introduction

This research seeks the patient and family voice and it is their voice that will be heard on the following pages. Using their own words, the participants describe what is important and that is what is heard. They spoke about what made a difference to them during a challenging time in their lives and they shared what they believed to be important aspects of palliative care.

Undertaking a thematic analysis of the transcribed interviews, four major themes were identified, each with sub themes. The environment was noted as being important by many participants and this included both the physical surroundings and the atmosphere at the hospice. The 'little things' were noted as being of value within the major themes. The section entitled Philosophy discusses participant's perceptions around having freedom of choice, time with staff and the connections made with other people during their stay in the hospice. Hospice is not just a place to die was also acknowledged. The holistic care offered by hospice was appreciated by participants with references to how families were acknowledged and cared for and with recognition of improved sense of well-being by patients. The most prevalent theme was that of 'The People', a compelling feature identified by every participant in the research.

4.2 The People

A strong theme amongst those interviewed indicated that the people who staffed the hospice were a very important factor in palliative care. Every participant made comment on the hospice staff, both paid and voluntary, and suggested they were an important element of their hospice experience. For some this was apparent from their first arrival at the hospice.

4.2.1 First Impressions

Almost all of the patients interviewed commented on how the hospice felt to them as they entered. No questions were put to participants regarding first impressions yet most offered unsolicited comment on this during the interview. Perhaps this reflects how the hospice

may still be seen in the community, as a forbidding or grim place to enter. There is still a perception that most people in a hospice die, that it is a place of death not of living (Broom & Cavenagh, 2011; Connor, 2009; Murray, 2002; Rasmussen & Edvardsson, 2007; Thomas, Morris & Clark, 2004). Conceivably, the contrast with the expectation of a grim and forbidding place made it more noticeable and therefore worthy of comment. A warm welcome was noted in a number of studies and Thomas et al., (2004), in their qualitative research study, also describe negative pre-conceptions of patients who expected a grim place and were surprised at the welcoming and cheerful ambience of a United Kingdom hospice. Rasmussen and Edvardsson (2007) reported a hospice patient as saying “It feels good here the moment you walk in the door” (p.119). They found that ‘welcoming’ was an important factor in the atmosphere and another participant said that on her arrival the welcome made her feel as if she were coming home. In this research both patients and family members spoke of the welcome they received and have shared what it meant to them:

Even when I first walked in it I knew I was going to be okay... I just think the atmosphere when I walked in... everybody was so friendly. (Frances, patient)

Paul had a similar first impression:

Well it's the welcoming nature of the staff for starters... they make you feel, when you do arrive, that you're actually a person rather than a number... rather than a patient number... and they take the time to introduce themselves and to make sure that the right people are talking to you... that's the first thing that stood out when I went there... for the first time... once they get to know you, they don't forget you. (Paul, patient)

This has been an important factor for Paul and helped him to feel like a person, rather than a hospital number which he commented had been his experience elsewhere.

While Sue had had contact with the community team she had not met any of the other staff within the hospice and was nervous prior to arriving for the first time. She was pleasantly surprised by what she found. Sue's first impression was a mixture of place and people:

The things that struck me the most, when I first came to a room was the spaciousness of the place, the warmth, the feeling of a place I'd never been before... the greeting when I arrived, they didn't know me at all, as though I was a long lost friend. Some I knew, some I'd met ... just that feeling of welcome. (Sue, patient)

When asked whether that initial impression of warmth was physical or atmospheric, Sue was clear that it was both and described the hospice as:

A warm, cosy, friendly place to be. (Sue, patient)

This warmth was also a factor for a family member:

I think it's just the warmth... you walk through the door and somebody greets you the minute you walk through the door and that... you actually feel as if you're in a home...everyone at the desk seemed to say hello and it didn't matter what time we came though... it was just absolutely phenomenal. (Sally, daughter)

Ron was very clear throughout his interview that his comments included all the staff, not just the doctors or nurses:

I just got the impression, almost immediately... that the people in there, every one of them, care. (Ron, patient)

First impressions can do a lot to dispel fear and worry and it clearly helped each of the participants who commented on it. The warm welcome they spoke of receiving helped put them at ease, despite the strangeness of an unfamiliar place with possibly unpleasant connotations.

This is something that can simply be replicated in other facilities by staff who are genuinely welcoming when they meet or greet someone, especially being aware of those who are arriving for the first time. A welcoming culture can pervade an entire establishment, helping to create an atmosphere of warmth and safety.

From initial impressions to throughout their stay at the hospice, caring was a common theme discussed by both patients and their families.

4.2.2 Caring

Mount (1993) states that palliative care means caring for the whole person – body, mind and spirit - as problems in each of these domains influences all other domains. Rousseau and Kukulka (2003) define the dimensions of nurse's caring as containing a number of components and suggest that nurses provide not only physical care but also spiritual and psychosocial care. While the participants in this research did not define the dimensions of care, their descriptions of caring that affected them also covered a number of aspects; being

talked with, friendliness of all staff, the feeling that nothing was a problem, and being treated with respect.

Johns (2009) said "I know that paying attention to the little things, such as giving a foot massage, we communicate our concern and make such a difference to the patient's caring experience" (p.135). Perhaps this is why it is significant to the participants who spoke of the caring they experienced. This caring showed in the details for some while others suggested it created a feeling of safety. The caring attitude of staff suggested to participants that they could be trusted to look after the best interests of patients.

A vital point was that participants made it clear that the caring they felt was evident in all the people they met, and not just professional staff. The caring was seen as being a part of the manner of the entire hospice team:

There was people that actually cared about you... the staff really cared... it was the caring, cos it come through everybody... even the cleaning ladies, they were nice and friendly...the people that brought the meals, morning and afternoon tea. (Frances, patient)

That's the difference in the hospice... people care... everybody, you know... the cleaning lady... quite happy to talk to you. (Ron, patient)

For some the caring made them feel safe and had a purpose:

A caring environment... and its comfortable, non-threatening, nice place to be... all the care is designed to get you feeling the best you possibly can. (Paul, patient)

It's just the personal attention I think. (Colin, husband)

Nothing seems to be a problem at the hospice...if you want something, it's there. (Felicity, patient)

The care that Felicity got, that was exceptional... and it took the pressure off me. (Gordon, husband)

For one family member especially, seeing the way in which her father was cared for demonstrated respect:

It's the respect they're given there... they're made to feel as if they are the only person there... he didn't lose his dignity. (Sally, daughter)

Loss of dignity is a fear of many people receiving healthcare. There is a widespread expression 'leave your dignity at the door' when you enter a hospital. It can be hard for family members to see a loved one looking diminished and loss of dignity can make them seem less like the person they have always been. These narratives demonstrate that a caring attitude can make all the difference. Treating people with care and respect allows them to retain their 'personhood' and their dignity. Feeling that nothing was a problem also indicated that the person was not a problem either, which always seems a possibility when you have become dependent on others for care. So caring becomes more than an aspect of warmth and safety, important though they are; it becomes a way of ensuring a person maintains their sense of self.

For family members, knowing that their loved one was being 'cared' for eased their own burden. They could trust that their loved one was safe and could relax a little from carrying the concern on their own. It 'took the pressure off' and allowed them a breathing space, while someone else shared the care.

Cicely Saunder's concept (Saunders, 2006), to help someone 'live until you die" (p.273) is demonstrated in Paul's comment that the care helped you feel the best you can. By feeling the best you can, you have a greater opportunity to 'live until you die', rather than just sit around waiting for death to come.

So caring has many components and many benefits, not all of which are obvious at first. But a caring attitude makes all the difference to patients receiving the care, they feel safe and cared for; to family members who are able to trust the team caring for their loved one when they see how the care is given, with love and attention; to patients who see their family member being cared for also, which helps to ease their worries and concerns about family.

All of the participants quoted believe that the caring was a key ingredient but noted that this caring was not limited to the nurses or doctors. It was clearly identified that the caring came from all the people that form the hospice team; professional, non-professional and volunteers.

4.2.3 The People

'The People' was the one theme that was identified by every participant in this research. It was also interwoven with most other themes that developed. While not specifically

identified in the first literature search, secondary analysis of the articles after the interviews took place showed that the people who staff a palliative care setting have a great impact on the people who are receiving palliative care.

Spichiger (2008) reported from her qualitative study that “A friendly and pleasant voice, a smile, or a cheerful face were rays of hope for people who found themselves vulnerable in an alien hospital world” (p.224), but she also noted that “to be experienced positively, attitudes had to be rooted in empathy, consideration and respect”, (p.225). Patients and families are able to perceive the difference between those who are ‘putting on’ a friendly face and those who are sincere in their approach and they appreciate those that are genuine. This supports the idea that it is the people in a facility who make a difference to those entering or living within it. Frances perhaps summed this up when asked how she now felt about returning to the hospice, given her previous reluctance to be admitted. She replied that it would be “*Coming back to family*”.

McKinlay (2001) similarly found ‘people’ were important in her qualitative study of hospice patients, that the manner of the staff created a therapeutic effect for patients and cited a patient who said “I think it’s the people that work in a hospice that make it” (p.22). Although participants in her study were not specifically asked about those giving care, they too spoke of how they valued the people that cared for them.

Compassion is seen in a number of the statements from participants. While it has not been defined as such by the participants, it is revealed in some of the descriptions. True caring which comes from a sense of compassion, as described by Watson (2008), is revealed in the descriptions of the ‘warm feeling’ and the ‘pop in to see how you are going’ as well as the thought that the staff made a patient feel ‘great’

A number of participants discussed the warm impressions that staff made:

The staff was marvellous... they made sure that you were relaxed and happy and that, you know? When they show you to your room, and they come in and talk to you, different ones come in. It was amazing actually. (Frances, patient)

The staff I’ve spoken to, in passing, always really good. (Jono, grandson)

The [warm] feeling that came from the people. (Sue, patient)

Everybody just went out of their way so... we just couldn't fault it... it was magic... the attention from the people in the hospice I think. It's the people that make these things, don't they? ... It's just the personal attention I think. (Colin, husband)

Well it's all about people isn't it? ... You want caring staff. (Sue, wife)

[Nurses] just made it... made him feel great. (Sally, Daughter)

Paul liked the connection with some of the staff, and how they would drop in for a chat on a regular basis:

Just to pop in and see how you're going and having a chat with you (...) Nursing staff and doctors (...) got a good manner with people ... generally most of the doctors have... there are some good nurses there. (Paul, patient)

Several participants commented on the abilities and professionalism of the staff:

Such specialist nurses on that palliative side of it anyway ... it was really that they knew what they were doing... it was the calibre of the people there... and just the way they went about things. (Gordon, husband)

The professionalism... I found that the human contact was the best ... the best feeling I had in there... I found that I... so many people to talk to... that are quite happy to listen to me as well, you know... that was, I found... one of the key things. (Ron, patient)

This 'specialist' or 'professionalism' is recognised as a component of expert or quality end-of-life care. Gramling (2004), Kaarbø (2010), MacLeod (1994) and Perry (1996) all described aspects of quality end-of-life care and the participants' voices above add to that description. Perhaps most telling is Gordon's phrase 'just the way they went about things'.

The fact that the hospice is a 'team', with many components to it, was not lost on patients and family members. Ron, like other participants, had noticed that it was not just the doctors or nurses who were friendly and approachable:

You think of administrators, well they'll be in the office stand... well they'll be there... as administrators... but that's not so... they are also part of the hospice and they'll talk to you, just like anybody else... and just as friendly too. (Ron, patient)

Paul appreciated that the team worked together and had a common focus:

All the people there are working for the same reason... and they're working together and consult each other on what's going on with the patient. (Paul, patient)

Felicity had been impressed by the fact that all the staff, both professional and volunteers were a part of the team and wanted to help:

Even your volunteers are there... to help... I mean, if a nurse was busy, a volunteer would poke their nose in and say, well I can go and find a nurse... so it's the whole system, the hierarchy, the whole system (...) well there's a lot of volunteers there that do go in and make a difference in the hospice, they go and they clean the bathroom and they lux the floors and they do all the sort of stuff ... and do it with a smile and a chat and everything else... it's not just the hierarchy, the doctors and the nurses... but the actual volunteers... are what's making it as well. (Felicity, patient)

Felicity also appreciated that people seemed to have time for patients and families and spoke at length not only about how that felt, but also about what that meant to her:

I enjoyed meeting the doctors at the hospice ... I found them really nice ... they weren't in a rush (...) if you wanted to just sit and have a quiet chat ... they just sat and had a quiet chat ... they didn't want to get to the next patient or... which is quite nice... for patients, because... you can sit there and have a chat and think, 'now I think they've actually taken on board what I had to say' ... they've listened to me ... they're going to help with whatever problem you might have had (...) that's a big plus (...) if they spend twenty minutes with you, they spend twenty minutes with you... not necessarily talking about... your medical condition ... might be talking about all sorts of things (...) it's not a rush... which is nice (...) you never got an impression that they didn't want to sit there and talk to you,... they weren't sort of looking at their watch, they weren't looking at the door... they were sitting there, just talking to you... which is nice... the same with you nurses (...) if you wanted to talk... you didn't get rushed away or anything else... nobody seems to want to rush you ... you can do it at your own pace. (Felicity, patient)

For Felicity the fact that people were approachable and allowed her to feel they had plenty of time, in this instance especially the health professionals, was an important factor in feeling well supported.

Issues such as symptom control are obviously a vital component of palliative care. This has been acknowledged by the participants, and is referred to in comments about 'specialist' and 'professional' staff. It is clear that having control of symptoms is important but this is already widely acknowledged, expected, and generally seen as an aspect of palliative care

that hospices are known for doing well, whereas the other factors being identified in this research are not as well known or recognised.

Amongst the voices here is the suggestion of Presence or 'Being' that was identified as important in the initial literature search. Byock (2004), Saunders (2006; 2005; 2004), Siegel (1986), and Ufema (2007) have, among many others, recognised the value of the use of self. This has often been recognised in writing about nurses but, in the participant voices above, it appears to be found in people throughout the organisation. Perhaps this, which Watson (2008) described as the 'greatest gift of healing', is a part of the reason that hospice care is highly valued by those who have experienced it.

4.3 Environment

The atmosphere and surroundings were other factors that made a positive impression on participants. Stomberg (2009), in her study of patients in a Swedish hospice, found they "appreciated the tolerant and home-like environment" (p.279). This study supports that, in that nearly all participants discussed the impact that the environment had had on either themselves or their family.

4.3.1 Physical Surroundings

The physical surroundings were an important factor for many of the participants interviewed and this showed not only in appreciation of the surroundings themselves, but in how they made people feel. Rasmussen and Edvardsson (2007) described the physical aspects, including such things as an accessible porch and flowers in the room, as having symbolic meanings that helped in supporting a continuation of self for a patient. Gourdji et al. (2009) found the physical environment provided their participants with a sense of security and confidence and noted previous studies with similar results. In this study different aspects of the surroundings were significant for different people. For some it was the gardens, which included a stream; being able to view them from their rooms, or walk in them when they wished to. Many mentioned aspects of the aesthetics; the colours used, the fresh flowers, the paintings on the walls, the hand-made rugs and quilts; these were all noticed and felt to be a part of what made the hospice what it was.

The layout was thought to be important; having individual bathrooms in easy reach; individual televisions so you could choose if, or what, you wanted to watch and that it could

be watched without disturbing others; the family areas and lounges that created spaces for gathering, either with your own family or to meet others; a kitchen with supplies for snacks as well as a hot drink as well as room for families to prepare a meal:

The room I was in was ideal. Yeah, cos the bathroom wasn't far, just a hop, step and jump out of bed, which is cool. I didn't have to walk too far at night. And the other thing too, when... I had odd nights where I didn't sleep or woke up... and to be able to wander down and make myself a cup of coffee, and come back to bed and have it... and being able to... when I felt... some nights I get very unsettled, I do at home too, and to be able to put your TV on, yeah, without disturbing anyone else. (Frances, patient)

It's much nicer to be in the hospice... to have the access to the family rooms... having your own bathroom's nice too. (Sue, wife)

It was well set out... with all the lounges and stuff, the kitchen and the big lounge that you can go and sit in... eat in and meet other people so... I found it was fine the way it was... quite like the way the rooms are off set so that your doors aren't... someone's been very clever, cos the doors aren't all facing out all the time... gives you that little bit of extra privacy. (Felicity, patient)

The Spa room was identified as useful both for relaxation and an aid to sleep:

And she's not one for spa bath (...) but she really enjoyed that and that sort of... wore her out... tired her out and so she slept better after having the spa. (Gordon, husband)

Some people commented on the aesthetics and considered that this too had an impact on how the hospice felt. One participant liked the home-like feeling but believed it was important not to be too home-like:

A good environment, isn't it? ... I mean the rooms are beautiful... couldn't need for anything more really... we were just over the moon with the treatment. (Colin, husband)

Things need to be aesthetically pleasing... like you need nice colours and... that type of stuff... you don't want austere colours or things like that, you just want it to be sort of like home, that feel... but without it being home... cos people... if it was too much like home, people wouldn't trust it, I don't think... you still want to have that idea that it's a hospice that you're still going to be looked after... you've still got that little hospital part there, I

think... for some people... that's what they would require... just to know that it's slightly hospitalised... but yeah, I think, just as long as its aesthetically pleasing... that you can just relax and chill out. (Felicity, patient)

The garden areas were much appreciated, both for walking in and enjoying the view from their bedroom windows:

Looking outside at the garden all the time, there's always something to look at out there. (Felicity, patient)

And the outside, the environment it's in... is lovely... you can go out, go for a walk... things like that. (Sue, wife)

The stream down there, so I went and had a look... I had a look at the gardens; I thought what a wonderful idea. (Frances, patient)

Participants in this study appreciated the physical surroundings and spoke of their enjoyment of the different aspects. Having warm, bright, 'beautiful' surroundings appeared to bring comfort and enhanced the impression of the hospice being helpful and this is similar to the conclusions of both Gourджи et al. (2009), and Rasmussen and Edvardsson (2007) who found that the physical surroundings symbolised the care patients could expect to receive. An untidy and unclean environment conveys the idea that patient care will be the same while clean and bright surroundings provide a confidence that their needs will be met.

Participants demonstrated concern for others in appreciating the ability to watch television or listen to music without disturbing other patients. Gourджи et al. (2009) similarly recognised concern for others among their participants and found caring or doing something for others a key factor in quality of life for palliative patients. Participants in this study spoke of enjoying watching television for distraction during the night and felt this wouldn't have been possible if they had been sharing rooms or had to go to a central lounge to do so.

The physical surroundings were a significant factor in creating a positive or cheerful atmosphere which was also a common theme raised by those interviewed.

4.3.2 Atmosphere

Rasmussen and Edvardsson (2007), following their palliative care research, state “the atmosphere is created in the meeting between the person’s needs/expectations and the environment” (p.119). There may also be a space between needs and expectations. Many people expressed an expectation that the hospice would be a sad, grim or depressing place to enter and, subsequently, have expressed a surprised pleasure at what they actually found. Broom and Cavenagh (2011) found participants in their study were surprised that that the hospice could be a positive place and that they too could be positive and happy.

Nearly every person interviewed during this research discussed the atmosphere at the hospice and defined it as something that was important in palliative care. Similarly, McKinlay (2001) observed how the atmosphere and environment impacted on those in hospice and patients acknowledged that, despite many deaths, the hospice was not a sad place but a happy place, and displayed evident compassion.

Some participants in this study commented on the laughter they heard at the hospice and how much they enjoyed it. Laughter is often said to be the best medicine and perhaps nowhere more so than in a hospice. Gourdji et al. (2009) reported from their qualitative study that a sense of humour was therapeutic for many participants and contributed to their quality of life. McKinlay (2001) and Broom and Cavenagh (2011) also noted the value of laughter and joking with staff.

For some people comparison with hospitals or rest homes helped to clarify the difference from what had been expected of a hospice:

The whole atmosphere was different (from a hospital ... everybody was so friendly.

(Frances, patient)

It’s not that dreary, decaying type environment... it’s not an uncomfortable place to come to. (Jono, grandson)

It’s not a heavy hospital strained... that you have to be at a certain place at a certain time... in a hospice the feeling is less to that of a timetable... there’s just that feeling of relaxation. (Sue, patient)

It’s just nice and peaceful and you don’t have that sterile hospital feel about it.

(Felicity, patient)

It gives you that little bit of extra privacy that sometimes you actually need, that you don't really get in a public hospital, unfortunately. (Felicity, patient)

A lot less noisy than a hospital... so you're getting your rest. (Gordon, husband)

For other participants, both patients and family members, there was an evident feeling of friendliness that was identified as being important:

Oh just the warm and friendly atmosphere I suppose, yeah... and good environment isn't it? (Colin, husband)

Just the friendliness and... the informality of it... I think that makes a difference too... it's not stuffy and formal. (Paul, patient)

It's a caring environment... and it's comfortable, non-threatening, nice place to be. (Paul, Patient)

It's just an environment which is friendly and warm. (Felicity, patient)

The feeling that came from the people... and from the actual building itself... a warm, cosy, friendly place to be. (Sue, patient)

If you can convey that friendly atmosphere... and it was there for me all the time. (Ron, patient)

Felicity particularly valued peace and privacy, the ability to choose to not have visitors, and believed there are benefits to be had from this:

At hospice things are a lot more mellow... it's a lot quieter and calmer and things like that. (Felicity, patient)

At the hospice, it's just quiet... if you don't want to see anybody, well you don't see anybody... you can, like, shut the door, you can tell the nurses, shut the door... I don't want to see anybody... and you know that no-one's going to come in. (Felicity, patient)

Just the relaxed atmosphere and everything else, they might just actually open up and say well this has been worrying me at home ... and I haven't seen anybody about it and I'm

too scared to see anybody about it but... that quiet relaxed... thing... they're probably more likely to say... well... it has worried me... what am I going to do? (Felicity, patient)

Two participants especially in this study enjoyed laughter and thought it was important:

I'd have the music... a lot more laughter from the people around, surrounding the person... always say laughter's the best medicine and it surely does... if you hear laughter in the background... [Interviewer: And did you experience that while you were at hospice?] *Oh... I thought wow! ... and it was good laughter... hearty laughter, not strained.* (Sue, patient)

You'd hear [staff] laughing and joking and Dad would say 'Oh that must have been a good story'... and it was just the happy atmosphere. (Sally, daughter)

The joy of laughter is universal and in her Swedish study Stomberg (2009) reported "The possibility of being able to joke with the staff members was described as positive" (p.279). This may surprise those who have not spent time in hospice surroundings, but was certainly appreciated by the participants in this study.

The difference between hospitals or rest homes and the hospice was noted by a number of participants. This was about time and fitting into schedules, quiet and peacefulness, privacy and friendliness. Some of these would be difficult to replicate in a bigger institution but friendliness does not need to take time, peace and quiet can be partially met with careful planning of the environment, and privacy should always be acknowledged as a vital factor in any healthcare facility.

The friendliness of staff, all staff, at the hospice was a noted factor. This could be hard to define but was shown in the way people connected with the patients and the families. Patients found the environment supportive and caring and it is reassuring, given the higher acuity of patients and increasing pressure on the service, that this is still being met. A favourable working environment also impacts on staff which, in turn, impacts on patients. So this is more important than simply pleasant surroundings to look at.

Some of these aspects of atmosphere and surroundings could easily be written off as little things that were not very important but in fact a number of people interviewed indicated the little things were very important.

4.3.3 Little Things

Results from the literature search indicated that 'the little things' could be seen as very important, especially in palliative care. Murray (2002) states "apparently trivial matters enhance the quality of care" (p.68), while Broom and Cavenagh (2011) found that the "'normal' things that went on, including chats, cups of tea, an afternoon bar service and laughter" (p.104) helped create the positive environment appreciated by patients.

The Otago Community Hospice, like many facilities, recognises the importance of patients having access to animals. Nightingale (1969) believed that small animals can be excellent companions for those that are unwell, especially for those unwell for an extended period. The hospice has a resident cat, visits from an accredited dog visiting service, and also encourages patients to have their own pets come to visit them. This has often brought a great deal of comfort to patients and can ease worry about how a beloved pet is coping without them.

Personal touches such as putting up personal photos on the wall; flowers in the rooms and on meal trays; the offer of a drink before dinner; these were mentioned by many of the participants. For Sue and Colin, the fact that someone took the time to put one of Sue's own paintings of her dog on the wall where she could see it, was greatly appreciated. These 'little things' were acknowledged as making a difference to people and impacted on how they felt; they created a sense of the individual and of 'person-hood' for some patients.

Although the respondents in this research have defined a number of important features, they have also noted a number of 'little things' which were significant to them. Some of these related to the facilities on offer:

The tea and coffee making facilities... being able to use the fridge. (Paul, patient)

The kitchen area [where people can prepare their own food]. (Sue, wife)

Your chairs were lazyboys... your beds were... granted they're hospital beds but they were still comfortable... you had nice pictures on the walls, things like that... things that just made it... just relaxing. (Felicity, patient)

Having animals visit was much appreciated:

And that lady that come round with the dog one day... I thought what a wonderful idea... the other thing that impressed me to see the cat wandering around the place, cos that's good for people that are sick. (Frances, patient)

There's a cat in there (...) and someone said there's a dog that can visit or you're allowed to have a pet (Sue, wife)

For some, these little things created a sense of personalisation, defying the institutional feel of being 'just a number':

A crocheted bedspread as well... that someone had made... and the paintings' on the walls... The little bunch of flowers every meal time... on your tray... and then they come round and regularly change them in your vase (...) Morning and afternoon teas on a trolley... there was always something to nibble with them... whether it was a cracker and tomato or whatever... they'd taken the time to do that... personal touches... make you feel like a person... not just a national health number. (Paul, patient)

Coming around with the whiskey run ... little touches like that very important ... made it more personalised. (Gordon, husband)

The fact that [staff member] went and got him Kentucky Fried Chicken mashed potato one night, with gravy... I couldn't get over that... it was just those little personal touches, you know... even the cook coming into his room and asking him what he fancied and suggesting things... that, to me, was impressive... it was just those little things. (Sally, daughter)

Two patients mentioned the value of having their own television, the freedom to watch what they wanted as well as not having to worry about disturbing others:

To be able to put your TV on... without disturbing anyone else... I thought when I went in... I would have to go into a lounge and sit and watch telly and you have to watch what whoever had the remote, they decided... but I found out I could keep up with all my programmes. (Frances, patient)

You've got nice rooms, you've got TV's in every room and you can listen to music, watch DVDs, you can... do your own thing. (Felicity, patient)

Things like being able to play your own DVDs... have an area where you can do your own... every room having their own DVDs, their privacy... but having the rooms too, where you can go to with your family, like the lounge. (Felicity, patient)

An interpretive study by Arman (2007) suggested that the willingness to do 'the little extra' was a sign of 'good care' and found that "what we label as 'little things' in care have the power to preserve dignity, as patients feel they are valued" (p.87). Aspects of the 'little things' include physical items such as flowers on meal trays, crocheted blankets, access to a personal TV; others related to gestures from staff such as going to get a favourite food from the shop. All the physical things did, at some stage, rely on people being prepared to go the extra step, such as making the blankets and cutting the flowers. These are all things that can be replicated easily. They just take a little time and forethought to make happen. But in realising the importance to patients and their families, they are easy to justify and make happen.

Perry (2005) sums up the value of the little things in wondering about a world "where bigger has often come to symbolize better, where we seem to value grandeur, opulence, speed and technology, we may have lost sight of the immense power of a tiny gesture rendered with sincerity and a compassionate heart" (p.16).

4.4 Philosophy

A number of philosophical aspects of care were identified by participants as having a vital impact on their hospice experience. Having the ability to make choices about their lives was appreciated by both patients and family members, while patients in particular noted that the health professionals had time for them, something they had felt denied elsewhere. This was supported by the accessibility to staff at any time, including from outside the hospice, enhancing communication opportunities. The realisation of the prospect for better-quality living at hospice was an added enhancement for those who expected only a place for dying.

4.4.1 Freedom of Choice

Choice is something often perceived as lacking for people receiving palliative care. People may feel they have no control over their own lives. They have perhaps lost the choice of treatment options; they may have decreased choice in how they live their lives, restricted by

health issues. It is vital that wherever possible patients are able to make choices for themselves. Viktor Frankl (2006) describes the last of the human freedoms as the ability “to choose one’s attitude in any given set of circumstances, to choose one’s own way” (p.66). It is easy to understand then the importance that a patient might place on the ability to make choices about when, or if, to bathe; when or what to eat; how to spend their time.

Having the ability to make choices, even mundane choices such as when to bathe, was seen by Teno et al. (2001) and Strohbuecker et al. (2011) as giving back some control to people who no longer have much control in their lives, and could be a factor in improving quality of life. Being able to make choices each day created a welcome sense of freedom for some patients. Whether it was to do with their meals or just simply going for a walk, it gained significance simply because it was a personal choice when, for many people, choices had become limited:

Yeah if you wanted to go for a wee wander around the grounds, nobody stopped you... so you had that freedom as well. (Frances, patient)

Instead of just a chef paper that comes around on the tray... to have the chef come round... that was good. (Paul, patient)

You want people to have some kind of... choice in what they want... I guess... in what’s right for them... so that they feel like they’ve got some kind of control over things like asking what they want for a meal... you know if that’s feasible... giving them choices. (Sue, wife)

If you’re not quite ready to have your evening meal because you’re just feeling a bit yuck, well... that doesn’t matter. (Felicity, patient)

If you don’t want to do it you don’t have to do it... at the hospice which is quite good... you can do it when you’re ready... and not tied to it... if you want to go to sleep, go to sleep... which is easier in the hospice than in the hospital. (Felicity, patient)

It is easy to consider some of these as trivial but to the patients they were important enough to remember and comment on, so they were important to them. In a large hospital or institutional setting many of these choices are not available, but to patients who have lost many choices in their life due to deteriorating health and the restrictions imposed by

that, gaining the freedom to choose something as innocuous as when to go to sleep, or having a meal later than planned has much greater meaning. Allowing people the freedom to make choices whenever possible is a key factor that can be instituted in many situations with a little forethought and by implementing person-centred care, therefore putting the person first rather than the rules of the facility.

4.4.2 Time

Some participants felt that they had more time with health professionals at the hospice, or more importantly, that the health professionals had more time for them. Stomberg (2009) similarly noted in her study that an important component for her participants was that the staff had time for them.

Mount (as cited in Hamilton, 1995) states that “you make a difference when you take the time to sit down and listen, when you stay there in the face of unanswerable questions” (p.335). This was found in a randomized controlled study of 120 patients in a surgical ward. The study by Swayden et al. (2012) demonstrated that hospital patient perceptions of the length of time the doctor spent with them, and the quality of the interaction, was more positive when the doctor sat rather than stood during the visit.

For the participants in this study it was perceived that the staff had time to listen and also to understand them. They felt free and safe to open up and some identified this related to not feeling pressured that the staff had to move on to the next patient. This was an important factor, for some patients especially:

You still get that care in a hospice but the feeling is less to that of a timetable... although you must be, you have to do certain things by a certain time, but there's just that feeling of relaxation I guess (...) Something that was worrying me... I was able to tell someone about it... which you don't normally... do with someone you don't know very well. (Sue, patient)

Hospital's totally different... yes... they just... they haven't the time... in the hospitals. (Ron, patient)

Felicity 's voice was heard earlier in this chapter(section 4.2), describing the value of feeling that staff had time to be present with her, listening without giving the impression of needing to be elsewhere. She went on to say just why that was important:

And the other thing too, is doing that, you might pick up a little niggle that's been niggling away with a patient that probably has bought it into hospice with them and (...) and I think because nothing's rushed like that... people probably open up a little bit more... to the doctors... and there might be the odd niggle that's worrying them before they go home and things like that... I think quite possibly that situation does help... help people just get that one little thing... just to get it off their chest... then it can get fixed and they're a lot happier in themselves... which, if you're happier in yourself you actually feel better and heal better and live life a little bit differently and life isn't quite so tough.

(Felicity, patient)

Two participants said that they were able to open up about a small problem that had been worrying them, because they felt safe and they felt heard. Something that has been a small problem can easily grow into a big problem if it is not dealt with so it is of real value to create the sense of time and being heard for patients. A simple change such as sitting when with a patient has been shown by Swayden et al. (2012) to require no more actual time than standing at the end of the bed. This simple change by health professionals would enhance the patient's perceptions of time and understanding and greatly increase the communication between them.

4.4.3 Connections

Connections and communication were identified as important factors for both patients and for family members. Two different aspects were particularly noted. One was the ability to make contact with the hospice at any time for knowledge and advice; the other was making connections with other patients or family members at the hospice. Two family members spoke of being able to connect and then share with another patient's family member and to know that they had a better understanding than many others, because they were sharing a similar experience. They saw this as being of benefit to both and recognised the value to both in sharing a conversation. One patient valued the opportunity to help someone else, after striking up a conversation in a family lounge. Gourджи et al. (2009) similarly found helping others to be important to palliative care patients and a component of that was that in helping others they felt they helped themselves, they felt useful and of value. Being able to make contact with the hospice at any time was valued greatly.

Many patients and their families found security in the knowledge that advice and help was available on the phone at any time, day or night and also the regular contact from staff at the hospice following up with patients to see how they were going:

That was a big one for me... to communicate with her about how she should be doing things and what she should be doing... she's had a visit from someone from here since she's gone home, a few times... yeah and I feel happier that that happens as well. And I think someone rang her up or something, just to see how she was or something so those little things are a help. (Jono, grandson)

I feel I can ring them anytime... day or night sort of thing... and if they can't help they'll say someone else will ring back... the follow up is good too, that they ring you up and say how are you going this week? (Sue, wife)

Being able to ring anytime is reassuring... the hospice are very approachable... easy to ring in and appreciated when we did, the advice we got... they rang [doctor] and then rang back, it was great... [Community co-ordinator] has been helpful... being on the road... that is great that she is available and in contact. (Gordon, husband)

A few participants noted that being able to talk to others in similar situations was another benefit:

To meet one or two others that were struggling with... to be able to talk to other people and share what they were going through too, was... made you appreciate what you had. (Sally, daughter)

[Patient's wife] came into the kitchen and we just got talking away there, that's not a bad thing to... talk with people who are in similar situations... cos they all have worries and its quite a thing to share. (Gordon, husband)

Frances, a patient, shared a story about talking with a young family member who she had met in the lounge, who was worrying and wanted to ask something. She encouraged her to talk to her own family and then helped that to happen. This also helped Frances, who felt good about being able to help a young person, someone who she thought was in a tougher situation than her own.

Making connections with people who understand a difficult situation was noted as a benefit for those at the hospice. Being able to talk freely with hospice staff and with patients and families in similar situations was seen as beneficial. The added opportunity to help others added a feel-good factor. Regular calls from the community team created a feeling of connection, enhancing the knowledge that someone was not alone at a difficult time. Being able to call the hospice at any time, day or night, was helpful and created a feeling of safety, knowing that advice and knowledge was always available, even if at home and not in the hospice itself.

4.4.4 Not Just a Place to Die

When Cicely Saunders founded the hospice movement, establishing St Christopher's in 1967, the message was "You matter because you are you, and you matter until the last moment of your life. We will do all we can, not only to help you die peacefully, but also to live until you die" (Saunders, 2004, p.xix). Despite this there is still, decades later, a common misconception you only go to the hospice to die, and fear of what hospice means. Broom and Cavenagh (2011), in their qualitative interview study, describe the "misnomer that entering the hospice in-patient unit was 'the end'" (p.101). Thomas et al. (2004) similarly report a fear of transferring to hospice but also note the sense of relief when it is discovered to be more relaxed and comfortable than expected. Many people resist admission believing that they would not get home again. Three of the patients interviewed spoke about this:

It's not [just] a place to die; it's a place to consolidate and to get better. (Paul, patient)

No it's not, [just a place to die] it's a place to go to... to feel better. (Felicity, patient)

I thought that when you went in there, more or less, that you just went there and... you went there to die. When you went in there you never come out again. That was, that was it. Everything was over and, I was amazed that everything's not over, everything's just beginning for you... I knew about it, and that it existed, but it was all bad... and it's not, it's all good! And that's what the public needs to realise... that good things are there.

(Frances, patient)

Frances, who had been fearful of coming to hospice and admitted to delaying her admission until she ran out of excuses, was pleasantly surprised when she first arrived. She now

regrets taking so long to come to the hospice and tries to tell anyone she meets that they should not delay as she did. Stomberg (2009) reported a participant in her study saying, as Frances did, “I should have come here earlier” (p.279).

There is still a strong sense in the community that admission to hospice means death is imminent and along with this is the perception that it must be a rather grim and unhappy place. This makes it very difficult for people to choose to be admitted to hospice when they could well benefit from what it has to offer. Slowly, with repeated successful discharges back to home, the word spreads that hospice is about choosing to ‘live until you die’ but this message must be constantly refreshed in the public’s mind and re-stated frequently in order to decrease the unnecessary fear that some people now experience. Advertising campaigns and publicity opportunities, such as Hospice Awareness Week, held during May each year in New Zealand, contribute to increasing public recognition of the true role and function of hospice but ‘word of mouth’ remains a powerful tool. It can be used to convey the wrong message, and it is vital that this is countered by positive and accurate messages.

4.5 Holistic Care

There is a sense that having time at hospice had given participants the feeling of being supported, that it had in some ways improved the physical and mental well-being of both patients and family members. The intent of the hospice is to incorporate the concept of Te Whare Tapa Wha; that is to “integrate the physical (tinana), social (whānau), emotional (hinengaro) and spiritual (wairua) aspects of care to help the dying person and their family/whānau attain an acceptable quality of life” (Durie, 1994). Participant narrative would suggest that these concepts are indeed important to patients and their families.

4.5.1 Improved Sense of Well-Being

There are a number of factors that impact on a patient’s sense of well-being. Both physical and psychological symptoms can make a difference to how they feel each day. Aspects of life outside of their illness can impact on how they feel, and in turn, how they feel affects their life and family life. That is why hospice care aims to incorporate the concepts of Te Whare Tapa Wha in its holistic care of patients and families. Symptom control is vital but it is only a part of the care delivered in a hospice or palliative care situation and this is recognised and appreciated by the participants in this study.

For some participants this holistic care was a vital aspect that made quite a difference, not only within the hospice but after their return home as well:

I've got a lot more quality than I had prior to going in there. (Frances, patient)

It was nice, knowing that she was coming somewhere, where she'd actually be taken care of and more importantly, taught how to take care of herself in her condition, properly... my grandmother was well taken care of, she was comfortable, she was, you know, happy. Happier actually, happiest than I had seen her for a while. (Jono, grandson)

I came away with such a wonderful feeling... and I've come home with a feeling that I know that I can... do things to help myself... I don't have to be dependent on someone to totally do things for me... I use them [medications] now... to have that knowledge... that I can use these things... and they're helping me... that little bit more energy to be able to live, like a normal life... to help me live a normal life... just that confidence again. (Sue, patient)

For some this feeling better equated to lower stress levels for both patients and family:

Just made her feel at home really... yeah... and no stress. (Colin, husband)

It's a place to go to... to feel better... it's being looked after... the nurses know what they're doing... you can just relax and basically de-stress... and basically start to feel better... any stresses and anything that you had sort of carried into the hospice with you... sort of just slowly disappeared and you felt... you actually started to feel better in yourself... also made my family feel better as well. (Felicity, patient)

For one family whose Dad had been reluctant to enter the hospice, seeing him happy was a great relief:

He still had his sense of humour... that's how relaxed he felt... it was just beaut to see him like that... he was lively and he was enjoying himself. (Sally, daughter)

Spending time being nurtured and cared for helped people to relax and reduce stress levels. Having problematic symptoms resolved improved not only their physical well-being but also their mental well-being. An on-going issue such as pain is exhausting and wearying on both body and mind so if those symptoms can be resolved and control regained, then patients

often feel greater energy and well-being. Often, so do their family, when they are no longer as worried about their loved one.

For some patients, learning techniques for managing and controlling symptoms, other than medication, is also helpful. Techniques for managing such symptoms as breathlessness can increase energy and self-care capabilities which impacts, not only on their physical state, but also on how they feel within themselves. In turn, this impacts on family who care for a patient at home. For Sue, an increased independence meant she was more able to live a 'normal' life, a great achievement for someone who is living with a terminal illness.

Family noticed that when some control is given back and they are able to relax, patients are happier, regain their sense of humour, and are more like themselves when they are no longer overwhelmed by uncontrolled issues.

4.5.2 Family

There were many views on the benefits for families of palliative care. Some of these were from patients who felt better themselves when they found their family well cared for too, or they could see that it was easier for their families when they themselves were well supported. Family members noted that they felt more at ease when their loved one was feeling better or they could see they were being taken care of. Nelson et al. (2010) researched patients' and families' definitions of high-quality care in the intensive care unit and similarly identified care and support of the family as highly valued.

Meals offered to a family member staying were much appreciated. In a mixed methods study Kaarbø (2010) found that looking after the relatives, allowing them to come and go freely, sitting with them, and offering them food and drink was greatly appreciated, and was seen as 'good care'.

Having a loved one looked after eased the burden for tired family members. They were able to rest and recover, even if staying in the hospice with them, without feeling guilty. This gives patients and family members a break, not only from looking after each other, but also time apart which can be appreciated.

Unlimited visiting hours were also seen as important; enabling some to visit that might not otherwise have been able to do so. Staying overnight in the patient's room or in a nearby

lounge was a valued offer, even if the offer wasn't taken up. This allowed family a freedom to support their loved one as best suited each individual. Being able to stay at the hospice and come and go freely was a real benefit for some family members. This was similarly identified by Stomberg (2009) as a vital factor in palliative care. It was suggested that this freedom allowed them to feel more comfortable and relaxed, perhaps feeling a little like being at home. Spichiger (2008) noted that free family visiting contributed to patients retaining connections with their home lives which supported them while they were in a hospital.

Both patients and family appreciated that they were all included in the care:

It was really nice to know that when I went up there feeling so crook that someone was prepared to look after me, to look after my family... You seem to treat the patient and the family... altogether as one unit...and I think it makes a big difference. (Felicity, patient)

There was the fact that you were not only interested in him, but in us as a family. (Sally, daughter)

Having a meal offered to family was a pleasant surprise that was much appreciated:

He (husband) was even offered a meal... you know? How lovely that was. (Sue, patient)

I felt included because I was asked if I would like to have a meal. (Gordon, husband)

Some family felt the pressure on them eased when their loved one was cared for and improvement could be seen:

It... takes the burden off me and I don't feel guilty. (Jono, grandson)

It took the pressure off me... and then as the days went on to see (...) then there was gradual improvement... and that was quite relieving... and then the boys could come and go... and they catered for me to be there when I could. (Gordon, husband)

Some family members noted the value of extended visiting in their acceptance of what was to come:

To make patients and the family comfortable with what's happening, because that not only is helpful and makes the patient more comfortable... it also, I think, helps with what happens next, because you're more prepared for what's happening and you almost start

... kind of... that grieving process a little bit sooner, because you've got that support around you. And you know what's coming... and you got that help there to go through those first initial stages. (Jono, grandson)

It was good for the boys, because they're of an age where they... it was good for them to... to be aware and to learn, you know, it opened their eyes... you could involve them and that's probably a positive. (Gordon, husband)

This was perceived as an advantage by both family and by patients:

It was good for Gordon, that he could come and stay... and it wasn't a problem and the boys could come in (...) at night, and it wasn't an issue and they were happy there... they were quite happy to come and just sit and relax... they'd come in and sit and watch a bit of TV with mum and then go for a walk down to the kitchen and make themselves a hot drink and then come back and sit with mum... He's [husband] come in and stay every second night, with having the farm (...) came in and just stopped... and he really enjoyed the fact that he could do that... it made life a lot easier for him and then he also knew that when he wasn't there, that I was being well looked after... and things like that... that gave him peace of mind... without the stress of worrying about me being in Dunedin and him being here [home] by himself... I think that helps... family as well, knowing that their mums being looked after even if they can't be there which is good... me having family wasn't a burden to anybody else and they could come and go as they pleased... so that for us [...]that was... a benefit from... the hospice, that they include families... doesn't matter if they're older or younger... wee toddlers, the whole lot, cos you got that wee playground and stuff there (...) you seem to treat the patient and the family... altogether as one unit... and I think that makes a big difference. (Felicity, patient)

Children visiting sometimes had unexpected benefits:

The fact that it is so family friendly is very good... our daughter was staying and she's got two little toddlers... and there's the whole playground for them... so that means people can sort of stay longer... really, like family... and you can go away and go for a walk and come back... or just go and play out in the playground for half an hour and you can come back... things like that... how much better it is for visitors... for family... its family friendly

and I can... not worry that the grandchildren are running up and down...although you do though, you don't want to disturb other people . (Sue, wife)

This family had been concerned that their children might have been bothering a very ill patient in the room next door and was pleased when the family spoke to her:

The daughter of the lady next door said "My mother's so enjoyed listening to your children laughing... it really made her day. (Sue, wife)

It was clear that for some people the joys of a child's laughter may outweigh any inconvenience. Sue had noticed the SPCA bringing visiting dogs and suggested that it would be good to have visiting toddlers for patients as well!

Both patients and family appreciated the welcome at any time and the option of staying with the patient:

I did like the way that... and it wasn't just for me... but for anybody that was in there, like how your visitors could just come and go. You didn't have to go by time because otherwise like, with my grandson, he come in every night... well if he had to come in at certain hours... he, he wouldn't have been able to come and see me. And that's important that people can come in anytime. (Frances, patient)

Things in place if the boys wanted to visit... or stay the night they could... I mean... you just can't do that in a hospital. (Gordon, husband)

Being able to have people coming in at all times too, was great.... It was really super not to be rushed out at certain hours. (Sally, daughter)

Sally shared a story about her sister and herself spending an evening with their Dad, recreating some family evenings they had had previously. They enjoyed a wine and pizza while ginger beer (Dad's favourite drink) was used to swab Dad's mouth, and watched a favourite television programme that had been a running joke between them all. This created a special time for the family:

It was just having that memory... that's what [sister] said, 'No-one else has got that memory that we've got'... of being there at that time... having that fun with him and talking to him as if he was with us. (Sally, daughter)

Having meals offered to a family member when they were staying for extended periods had more meaning than might be expected. It suggested care for the family and clearly delivered

the message that they mattered too. This allowed family members to stay for longer, not having to leave to seek sustenance or go home at the end of a long day with a patient and then having to start and cook. It created a feeling of inclusion.

Being able to have a break from caring for a loved one around the clock eases the burden for some family members, and this is a recognised benefit in hospice practice. Being able to have time away from a dependent person is useful; whether to just relax, knowing they are taken care of, or whether it is to catch up on some neglected tasks.

Feeling welcome to spend as much time as wanted at the hospice helped some who intimated that spending time at the hospice was one of the most important things for family members because it helped in developing a sense of understanding, even perhaps the beginning of acceptance, of what was to come.

Children visiting in a health care facility can be a fraught topic, often due to concerns about them bothering other patients. Being able to bring them in to visit and know that there was both playground and lounges where they could play without bothering others was a relief and their chatter and laughter was often a welcome sound for other patients.

Unlimited visiting hours also created the opportunity to create memories that might otherwise have been missed. These memories are precious to families, especially when their loved one is no longer around to create new ones.

4.6 Room for Improvement

In seeking a definition of what was important it was essential also to find if anything was missing in current care. Accordingly everybody interviewed was also asked if there were any changes they would like to see made at the hospice. Was there some important factor that had been missed? Was there anything that could be done differently or better?

One family member's response was about an episode some years ago, of trying to get her Dad admitted to the hospice programme. This had taken some days and been very stressful at the time. Fortunately on this occasion her husband had been admitted very easily. Lessons could still be learned from her previous experience.

Some minor issues were brought up that may seem relatively unimportant. However, as discussed previously, little things can have a big impact so these should not be dismissed but taken as further opportunity to improve:

The one thing I got sometimes is you don't know is who's a nurse and who's ... somebody coming to make a cup of tea from the kitchen... and I understand it's... nicer not to have the uniforms like the white traditional kind of thing... but... (Sue, wife)

But sometimes their badges were hidden under things... and you couldn't really see who they were. (Paul, patient)

The only person who would like something changed is my sister who drove past the hospice six times, trying to find it... everybody else seems to have found it but she was the only person who had to drive past it six times to find it. (Felicity, patient)

Many of the participants could not define any changes they wanted made:

I can't think of one thing that I could say bad about [the hospice] and that is, that's a fact... I can't honestly see a thing that you could change... I mean, I can't fault anything. (Frances, patient)

No, not at all. Not at all. [in response to the question would you like anything done differently?](Sue, patient)

I wouldn't like to change it. (Felicity, patient)

I wouldn't change a thing about that place, not one thing... just keep going the way [it's] going... absolutely first class... don't tell them I said that but just... but that's the way I feel about the place, you see... It's a cracker wee place. (Ron, patient)

I wouldn't change anything. (Jono, grandson)

Couldn't do much better really. It was just superb wasn't it... yeah... the attention to everything yeah... we couldn't fault it... just blown over by it really. (Colin, husband)

You couldn't fault what was already there in place really. (Gordon, husband)

This is rewarding for the hospice involved but should not be taken as a reason to stop aiming for progression and improvement. Remaining open to feedback, both positive and

negative, and continuing constructive critique of practice assists in ensuring consistently high standards of care are maintained.

4.7 Conclusion

This chapter has reported a number of important themes within palliative care, as heard from the participants. These themes will be discussed in further detail in the following chapter.

Chapter 5: Discussion

5.1 Introduction

This research aimed to hear the patient and family priorities in palliative care; to understand what is truly important to someone in palliative care from their and their family's perspective; to find out what is being done well at hospice so that it can be shared with others and to find out what needs to be changed or improved. The literature review revealed a wealth of information on palliative care and meeting the needs of patients and their families. What was not commonly found was the actual voice of the patient and the family themselves. There was valuable guidance on symptom control and concepts such as truth and communication but little to be found on the detail, the 'essence' of palliative care, directly from the patients and their family members.

This research asked people who had been in-patients at a hospice, and their families, what it was that had made a difference to them, why it made a difference, and what was important for staff to know when caring for a dying person and their family. It has taken their answers and reported them, in their own voice, so that anyone who reads the research can hear, direct from the people who know, what it is that matters when you or someone you love is receiving palliative care. Some of these answers may seem inconsequential or trivial, but when you are dying it can be the trivial or 'little things' that matter the most.

The knowledge gained from this research can be used to enhance the care given to patients, and to their families, while receiving palliative care. Patients and families were willing to share their experiences and discussed what had made a difference for them or their loved ones while they were at the hospice. They have described events, actions and care that affected them in some way. Their voices can be heard in the previous chapter. They have explained ways in which their needs "physical (tinana), social (whānau), emotional (hinengaro), and spiritual (wairua)" (Durie, 1994,) have been addressed and they have shared what that meant to them, and why it was important. There is an opportunity to pay attention to what they have said and to incorporate their thoughts into daily practice in the care of the dying.

The responses from the participants have been grouped into themes that showed consistently through their replies. Although there were twelve themes that came out of the research, none of these themes stood alone. Each of the themes was interconnected with some of the other themes, some of them connected with many other themes as Table 1 illustrates.

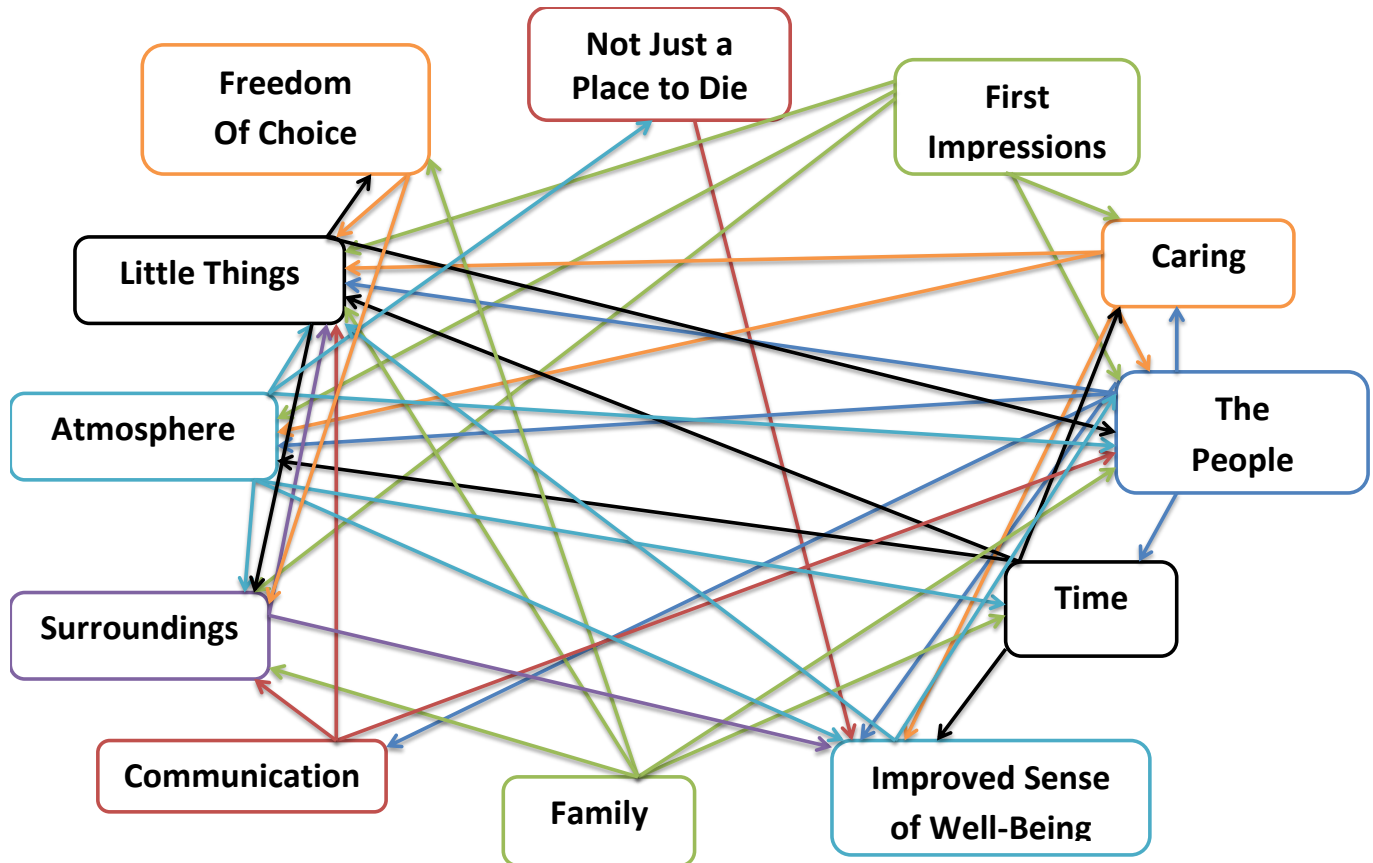


Table 1

On analysis it was observed that reference was made within each theme to many of the others and these references are shown in the table as arrows connecting the theme being analysed with those that were referenced. Often there are arrows in both directions indicating that each theme referenced the other. The diagram demonstrates the web of interconnectedness.

In particular, 'The People' and 'Little Things' were both interconnected with nearly every other theme. This indicates that although they had relevance and importance in their own right, they also had importance within other themes, signifying a greater importance and relevance to the study participants than might be understood from a singular theme.

The groupings of themes that developed during analysis seemed coherent and a natural progression of what had been identified by the participants but the interconnections between the themes created new groupings that are explained in the discussion in this chapter. The original intent was to separate patient and family responses but, as in the interviews, the responses from both groups of participants were similar and interwoven and that is how they been presented here.

5.2 First Impressions

It is important to be mindful that for people who entering the hospice for the first time, the reception needs to be warm, friendly and welcoming in order to allay the fear, stress and anxiety about coming to hospice. Other researchers (Broom & Cavenagh, 2011; Thomas et al., 2004) have noted that misconceptions about hospice can make it difficult for people to enter a hospice. Some of the comments made by participants were about supplanting their previous fears or misconceptions of what hospice meant to them.

By creating a welcoming atmosphere from the moment of arrival, for both patients and family, whatever preconceptions they may have had can begin to dissipate and they can begin to relax and accept whatever the hospice has to offer. First impressions were noted as important by many participants. No direct questions were asked regarding first impressions, yet several participants spoke of what it meant to them that they were so warmly welcomed on each arrival at the hospice, regardless of whether they were patient or family. Several participants commented on how the warm greeting on arrival made them feel welcome immediately. The personal recognition, the friendly atmosphere and the warm welcome, whether for the first time or for subsequent visits; these are an indication of the culture of the facility. It is created by all members of the team and signifies the importance of 'people'.

5.3 Family

The World Health Organisation (2009) and the New Zealand Palliative Care Strategy (2001) both define palliative care as including caring for the family. In non-palliative health care the focus is on caring for the patient, while in palliative care it is generally accepted that supporting the family is also a part of caring for the patient. The participants in this study appreciated the care and attention shown to the family members in a number of ways.

Families being allowed to freely come and go around the hospice was a part of feeling included. Patients felt that when their family members were cared for, such as being offered meals with the patient, it eased their concern for their family. Spichiger (2008) similarly found that sharing meals with family was, amongst other supportive gestures for family, greatly appreciated by patients. Patients in this study suggested that if their family were being looked after then it was seen as an extension for the care they themselves were receiving. Some acknowledged that this inclusion of family made a big difference to how they felt. Similar rationale is acknowledged by other researchers (Kaarbø, 2010; Nelson et al., 2010; Stomberg, 2009) who all report valued aspects of families being supported in palliative situations.

When the family were supported at the hospice it helped them make steps towards understanding and acceptance of their loved one's death. Two family members described a deeper awareness, understanding and acceptance of their loved one's death, for themselves and extended family members, because of the free time they could spend in the hospice with them.

5.4 Environment and Atmosphere

Warmth, friendliness, informality, laughter; all have been identified as important facets of the atmosphere which was a part of the hospice experience for the participants in this study. Participants appreciated the relaxed feeling of the surroundings that enabled them to also feel more relaxed. Often hospitals were unfavourably compared, but at the same time there was recognition that this was a different situation with different requirements. This peaceful, friendly atmosphere offered an opportunity to open up about any concerns and many participants suggested this was easier to do at the hospice than in the confines of a busy hospital. It would be interesting to note how much of patient perception is affected by the usual practice of staff at this hospice, particularly doctors, to sit while with patients, rather than standing in the room. Patients in this study acknowledged that feeling that the health professionals had time for them was important. They felt more able to express their worries, even little 'niggles' and this was a contributing factor to an improved quality of life. Stomberg (2009) had similar results from the participants in her study who noted the staff having time for them, and appreciated it.

Physical surroundings had been identified as an important factor by a number of other researchers. Several research articles studied in this research project (Broom and Cavenagh, 2011; Gourdji et al., 2009; McKinlay, 2001; Rasmussen and Edvardsson, 2007; Stomberg, 2009) all noted the value study participants had placed on their surroundings. This was supported by the participants in this study who noted many facets of both the physical surroundings and the atmosphere within the hospice. The ability to have private space was greatly valued by both patients and families. Having the choice to close themselves off was appreciated; it gave the chance for peace and privacy and helped in creating a feeling of peace and of calmness. However having shared spaces was also appreciated and generated opportunities, for family members especially, to meet and connect with others who may be in similar situations. This offered the chance of support and understanding at a different level, and for some, the opportunity to give something back to others. Gourdji et al. (2009) had also noted in their qualitative study that being able to do something for others made life worth living for some patients.

Creating a relaxed, friendly atmosphere is reliant on both physical surroundings and the people who work there. Comments showed that allowing for private spaces; building design allowing for quietness, yet also allowing for gathering together; garden or pleasant views all contributed to creating a “warm, cosy, friendly place to be”. But the comments also demonstrated that part of that perception was dependent on the people who were in the building. Several participants used the word ‘friendly’ in a sense that indicated their relationship with the staff was an important feature to them. McKinlay (2001), Spichiger (2008) and Stomberg (2009) all discussed the value of warm, friendly, approachable staff to patients in palliative care. Feeling welcomed at all times, being able to talk to anybody, approachable staff in every role; these were all key facets of the atmosphere that were valued by participants in this study.

The environment and atmosphere were factors in allowing, or even encouraging, patients and family members to make connections with other patients and families and also with staff. This ability to make connections was recognised and appreciated by participants for a number of reasons. Developing a comfortable relationship with staff not only made it easier to talk while at the hospice it also made it easier to make contact from home when questions or concerns arose. Similarly the connections made with other families or other

patients in the lounge areas were seen as a benefit to all parties, and these may have been missed without a gathering place being available.

5.5 Not Just a Place to Die

There is a common misconception that hospice is just for they dying, (Broom & Cavenagh, 2011; Connor, 2009; Murray, 2002). Accompanying this is the thought that it must be a grim and dark place, forbidding and, as well, very depressing. An indication of this is the researcher's and colleagues' experiences of frequent negative responses when divulging their place of work to the general populace.

This image creates a challenge that must be overcome. It creates a resistance to admission; it is difficult for a person to accept admission to hospice for symptom control if their perception is like those above. It can be difficult for family to hear that a loved one is to be admitted to the hospice if they have a negative view of all that may entail. An example of this is provided by a recent experience at Otago Community Hospice when an elderly lady was admitted for some symptom control with clear expectations of returning home. On informing her out-of-town family that she was being admitted to the hospice, they immediately rushed down to be with her. She was bemused to hear they were all on their way and wondered why. It transpired that after she told them she was coming into the hospice but would only be there for a week, their interpretation was that she only had a week to live. The misperception cost this family a lot of unnecessary distress, financial impact and worry.

This image persists for a number of possible reasons. Connor (2009) suggests that the term 'hospice' is associated with negative connotations; that some associate the word with death and this causes discomfort. For those who have not experienced hospice first-hand, there is often a fear associated with the fear of death and dying. Perhaps it is an indicator that society remains death-denying and would like to avoid all indications to the contrary. Positive images emerge only slowly as patient by patient, family by family, it becomes clear that many return home from hospice. And yet still there are those, like some of the patients interviewed, who are told by caring friends 'You can't go there. You only go there to die!' Broom and Cavenagh (2011) report the trepidation many feel on transfer to hospice and

suggest that this fear is related to the myths surrounding hospice rather than the hospice itself.

Stomberg (2009), as in this study, found participants who would have come to hospice much earlier if they had not been frightened of what it meant. There is often pleasant surprise, as Thomas et al. (2004) found, on experiencing hospice, that it is actually a lively, warm and pleasant place to be. Further study would be worthwhile in an attempt to understand how to change people's perceptions of the hospice before they need its services. This could include investigation into ways of increasing public understanding in order to avoid the fear and trepidation of admission.

5.6 Little Things

Consistent throughout this research was the value of the 'little things'. Numerous factors identified by patients throughout all the themes could be also described as little things, perhaps individually thought of as having little importance but they made a difference to the participants; enough of a difference that they noticed them, thought enough of them to remember them and then related them to the interviewer. This is supported by many of the authors previously noted (Arman, 2007; Arman & Rehnsfeldt, 2007; Barnard et al., 2006; Janssen & MacLeod, 2010; MacLeod, 1994; Pearcey, 2010; Perry, 1996 and 2005) who all describe the effects and benefits for patients, of little extras being done. Some of the 'little things' observed during this research, such as easily accessed tea and coffee facilities, nice artwork, cheese and crackers for morning tea, crocheted bedspreads, flowers in the rooms and on meal trays, simply saying hello on arrival, all contributed to an overall feeling of caring and support.

Many of the features described by participants are easily replicated in other situations; it may just be a matter of realising their importance to the people living in those locations. It is easy to put a picture on a wall but taking the time to source pictures that appeal to the eye or have personal meaning, perhaps a scene that has significance to an individual, can have greater impact than realised. Most of the features remarked on by participants are also features that are often found in people's own homes, but less often found in healthcare facilities. This is a part of creating a welcoming environment that enables people to be more relaxed. Likewise visiting pets made a difference to a number of participants. Whether it

was a patient's own pets coming in to visit or a visit from the SPCA visiting dog service, the presence of animals was greatly appreciated and was a key ingredient in helping create a homely atmosphere.

Perhaps seen by some as a small thing, is having the freedom to make choices. This may seem unimportant to those who have never lost it, but to those whose lives have become limited by ill health, the freedom to make small choices is greatly valued. A number of authors (Frankl, 2006; Strohbuecker et al., 2011; and Teno et al., 2001) all acknowledge the value of being able to make personal choices and its effect on a person's quality of life. Being able to choose to go for a walk, when or if to have a shower, when and what to eat, to have visitors or not, these are all freedoms many people take for granted until they are lost. Many choices are taken away in healthcare facilities simply because of their size, but for those who have little left, being able to choose when to eat may be just as important as choosing to eat or not, or when and whether to take walk in the garden. Many participants noted the significance of being able to make choices. The ability to go for a walk in the garden at any time is a simple choice for most people, but is significant for someone who has little control.

5.7 The People

It was the people who helped make the first positive impressions; people who demonstrated caring and were a part of creating the atmosphere; people who made 'little things' happen; people who created the sense of time for patients, so they felt heard and did not feel rushed; people who made the connections happen and who helped patients 'live until they died' so that the hospice was not just a grim place of death; people who helped improve health and symptoms so that patients could enjoy an improved sense of well-being, and make the most of the time they had; people who also supported family members and made them feel as welcome and cared for as the patients they were with. The most consistently reported factor, a theme that was interwoven with most themes throughout this research, was 'the people'. This was the one identified theme which every participant had directly noted and, when hearing the voices within the other recognised themes there was a link to 'people' in many of these also.

The people were a key component of the 'little things'; the people who were behind them or who performed them. From the first impression participants found when they walked in the door, the attitude of the staff at the hospice made a deep impression. Being remembered on return visits was important; being greeted like an old friend on a first arrival was seen as very welcoming.

Spichiger (2008) and McKinlay (2001) both found that the people who worked within a palliative care area were an important feature and were instrumental in creating a therapeutic environment for their patients. Participants' commented on the open friendliness of the staff that made them approachable and yet had a recognised professionalism which was also appreciated. An interesting comment from many was on how the staff would stop for a chat, just to talk with patients and their families. It appeared that this is no longer expected from health professionals and was much appreciated by those who commented on it. This was experienced as staff having 'time' for patients and family members. This gave people the opportunity and feeling of safety to talk about concerns. People felt they were heard and felt acknowledged as real because they were not rushed. Instead of the sensation that a staff member had to move on to someone else, each person felt they were the one that mattered at that time and that the focus was on them, not on what the staff member had to get on to next.

The personal touches such as putting a family photo on a wall or going out to get particular favourite foods for a patient, while little things in themselves, were seen as indicators of good care. People doing little things made a big difference to those on the receiving end. It is likely that these things were seen as so unimportant by the staff member concerned that they have forgotten them, while the person for whom they were done has never forgotten how it made them feel.

Caring was perceived to be demonstrated by all members of the team at the hospice. There were many observations on the caring attitude of all staff and this was clearly valued. This caring was seen as giving respect to patients and helped to preserve their dignity, something that was greatly appreciated by patients and by family. When people feel cared for by those that are around them, they feel safe and are able to trust that their needs will be met. As with feeling that staff had time for them, caring also meant it was easier to open up with

health professionals and be honest about concerns they have had. Being able to open up with health professionals must be an advantage and can only improve their care and subsequently their health status.

It was clearly acknowledged that 'the people' included not only the health professionals but all those who worked at the hospice – the cleaners, the cooks, the administration, the volunteers – all were identified as caring by one or more of the participants. Health professionals can seem to dominate the discourse around palliative care but cannot afford to ignore the valuable contribution made by other staff. It is easy to become entangled in the concept of a 'specialist' service but the patients and the families equally identify the importance of the other staff. There is a risk of undervaluing the importance of the whole team and continuing to regard 'professionals' as of greater value than support staff. There is much talk in palliative care about working as a team; it is vital then that all components of that team are acknowledged. Their value and importance to the patients and the families was clearly identified in this research. This suggests that there is a 'human to human connection' that defies any professional limitations and focuses more on the person than the specialist training. Perhaps we should be open to balancing the professional with the 'ordinariness' of everyday living – after all the maxim of New Zealand Hospice is "Living Every Moment". Randall and Downie (2006) believe that ordinary activities represent a meaningful end of life to a very sick person. Everyday life is important in hospice or palliative care and dying is a natural, normal part of living.

Chapter 6: Concluding Thoughts

6.1 Strengths and Limitations

The small number of participants allowed for in-depth understanding of their lived experiences and their insights of what is truly important in palliative care. Purposeful sampling would have allowed, if necessary, a spread of ages and genders of participants. However this naturally occurred with an even mix of male and female participants. The age range of the participants, although not specified, reasonably reflected the age range of the patient population enrolled at the hospice. The direct reporting of participants' voices allows for rich insight into their priorities of care in a palliative situation.

It is also important to acknowledge possible limitations of this research. This was a small study from one hospice in New Zealand. In acknowledging this limitation it is also recognised that the results could be used as a guide for a variety of settings where palliative care is situated. Therefore findings from this research may have application for health professionals and leaders in other settings. The findings could supply a foundation from which to consider possible improvements or changes to be considered, or at least a basis for discussion by interested parties.

A limitation of this study is using only participants who spoke fluent English. It needs to be noted that the non-English speaking patients at the Otago Community Hospice where this research took place are small in number so to exclude them could be considered acceptable in this instance. It should also be noted that during the literature search almost every research article cited the same limitation within their selection criteria. If this is not rectified the voices of non-English speaking palliative care recipients, patients and families of different cultures, are in danger of not being heard.

The researcher acknowledges that although she was not involved in the care of any of the participants in the study, it was known that she worked at the hospice involved and therefore may have been presented with a biased view. Attempts were made to ameliorate this during the interviews by reminding participants of the need for honesty if the research

was to have value, and by asking directly for any criticisms about the hospice, changes sought, or any unmet needs or wishes.

It is also acknowledged that as the researcher I am a registered nurse, therefore I cannot help but write from a nurse's perspective, it is embedded within me. I remain aware of other health professionals and the hospice team members with whom I work closely and hope that I can speak for them too, but I remain a nurse.

6.2 Recommendations for Future Research

As acknowledged previously, many of the articles acknowledged in this study described research that was limited to English speaking participants. This lack of voice for other cultures and ethnicities means they are at risk of remaining unheard. This could lead to a significant gap in the knowledge of those working in the field of palliative care and, more importantly, could lead to a lack of appropriate care for many people. Consequently this would be an area open to further research which could greatly benefit the multi-cultural society that comprises New Zealand's population, as well as palliative care world-wide.

There is also evidence of a need for changing perceptions of hospice to avoid delayed admission due to unwarranted fears. Research into why perceptions remain negative and what can be done to change this image of hospice could prove invaluable and not only enable people to accept hospice or palliative care earlier but remove the unwarranted trepidation that many experience currently.

The literature search identified a gap in research into compassion in palliative care. There was considerable writing on the topic from a number of established literary authors and health professionals who have an understanding of the topic (Johns, 2009; Kuhl, 2005; Watson, 2008; Youngson, 2011) but no research articles were discovered on the topic. It would be valuable research to discover an understanding of both patient's and health professional's perspectives on compassion and its place in palliative care.

There would also be value in further developing this current study into a larger one and to ask the same question of a larger group of people from a wider geographic base, without losing the detail to be found through the in-depth interviews using one's personal voice that

is identified as the hallmark feature of qualitative methodology by Sandelowski (1997, 2000).

People wishing to improve care in their own facility can take from this what is relevant to their own situation. Perhaps some of the comments resonate with them and there is realisation that some of the findings may be applicable to their facility. This research can be used to trigger discussion with staff about what care is given and how it is given, or perhaps be used as a basis for other hospices doing research with their own patients and families to find what is important in their context.

6.3 Acknowledging the Participants

Each of the people who contributed to this research thought that they had little to offer. However, what can be clearly seen in the preceding chapters is that each one had much of value to share. Their insights offer a great deal to those who want to learn and understand how to best care for the dying. Just as the key to the success of palliative care is the insights the staff give to the service, the key to the success of this research is the insights the participants have given. These people who generously gave some of their time to this research, at a period in their lives when time was very precious, shared their personal understanding of what is important in palliative care. This research could not have been accomplished without them and their willing participation is gratefully acknowledged. Their insights will help anyone working anywhere in palliative care enhance the lives of other patients.

6.4 Room for Improvement

Although the feedback from this research was overwhelmingly positive for the hospice involved it is important to not become complacent and feel there is no room for improvement. Exemplary health staff will always review practice, and participate in ongoing training, education and assessment to ensure that standards of practice remain at the highest level; thereby ensuring patients continue to be cared for in the best possible way.

6.5 Final Thoughts

The key to good palliative care is the people who deliver it. It is a whole team of people: a receptionist who warmly greets everyone in as if they are being welcomed into his own home; a cook who cares enough to cook tasty morsels and not be offended if they are appreciated but not eaten; a cleaner who doesn't just wipe down a table but leaves the whole room looking fresh and inviting; a doctor who sits down with the person so even if she really only has a few minutes she makes them feel like she has all the time they need; a nurse who responds to calls and understands that the pain might not be physical and that holding their hand might be as helpful as analgesia; anyone who is involved with caring in any way for a dying person, who recognises the value of even the smallest action to that person.

It is not only about the people who deliver it, it is also how the care is delivered. The two strongest components of this study were the people and the 'little things'. Together they related to all other themes except 'Not just a place to die'. Studies of exemplary nurses, discussed in Chapter two, suggested that a part of their skill was the ability and willingness to go the 'extra step', to notice the opportunity to perform little acts and then to do them. This does not apply only to nurses. Exemplary staff in any position will see and action those same opportunities. In palliative care those actions may take on greater meaning. As life becomes limited, it also perhaps condenses and smaller actions can have much greater meaning than might otherwise be noticed in the busy outside world. The people who notice and action those 'little things' may offer much more to the person receiving them than it seems at the time. The person who performs those 'little things' with grace and pleasure offers something of themselves and this use of self or 'being' may affect the person more than the action itself. When this care is then offered to the family as well as to the patient, the benefit magnifies as both appreciate not only their own care, but seeing their loved one cared for too.

Dame Cicely suggests that while there are some who will require palliative care in a specialist or stand-alone unit many people will continue to die elsewhere, and by adopting the knowledge and experience of palliative care experts good care can be given wherever patients are dying (Saunders, 2006). What has been learned from this research can be put into practice in any setting that cares for people who are at the end of life. People need not

leave their home or their current place of care to be well cared for when they are dying. Specialist palliative care needs will require a specialist palliative care unit but beyond that, support, education and willingness to meet patient needs, will enable good care to be given at the end of life, wherever a person may reside. This research extends beyond the hospice where it was conducted. The dimensions of good practice, sometimes overlooked and under-valued, that have been documented in this research are of wider application than just the hospice movement. This hospice approach to practice can easily be adopted wherever the dying are cared for.

I began this research because I questioned, in our care of the dying, if the little things actually made a difference to people and I wanted to discover what patients and families thought was important. This study confirmed my view that little things made a big difference. Much of what was described to me could easily be defined as little things but I also found a lot more. I found detail about those little things, I began to understand why they made a difference and I discovered that what really mattered to patients and their families were the people who delivered the care. What mattered was not only who they were, but how they did what they did, their manner, their empathy, their caring, their humanity in caring for those who are dying. This affected not only those who received their care but also made the journey easier for families when they saw their loved one cared for in a loving way. Many were astounded to find that loving care extended to them also. Patients and families would no doubt agree with Mother Teresa who said "It's not how much we are doing, but how much love we put into doing it" (Doig, 1976, p. 158-159).

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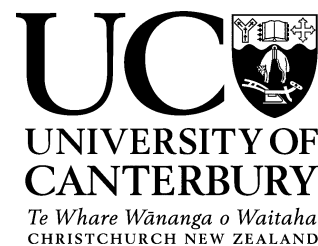
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Appendix 1

Health Sciences Centre

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Email: healthsciences@canterbury.ac.nz



Letter of Invitation

Research Project: The Important Thing Is...: Finding What Really Matters to Patients and their Families in Palliative Care (Working Title)

You are invited to take part in this research project, conducted by Denise van Aalst to complete a thesis for a Master's Degree in Palliative Care.

The aim is to discover what is really important to people who are receiving palliative care. I would like to know in what way hospice could, or does, make a difference for patients and for their families. Can you think of any actions or happenings that have impacted on your experience while at the hospice? Has it been a little thing? A number of things? Or maybe something really big that has affected you at this time? What has made a difference for you?

The research would involve a one-on-one interview with you, discussing your perceptions of hospice and would last approximately thirty minutes to one hour. This interview would be audio-taped to ensure accuracy. The research will also involve a group meeting with whichever members of your family would like to participate, where we could discuss together what their perceptions are, of their hospice experience.

There is no obligation to participate in this research. It will not affect your care here, at the hospice, in any way. And if you do choose to participate you can freely withdraw or change your mind at any time, simply by telling the researcher or any staff member at the hospice.

Would you and your family like to participate? If so please tell your nurse and she will arrange for the researcher to visit you, answer any questions and, if you decide to be involved, organise a time to suit you for the interview.

For further information please contact the researcher, either through your nurse, or directly at email: denisev@clear.net.nz

phone: 4885 992 (H) or 027 384 2903 (cell).

I would be pleased to discuss any concerns or answer any questions you may have regarding this research project.

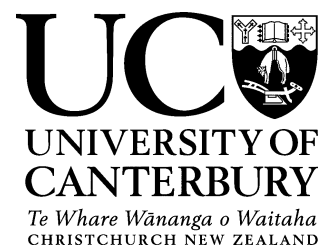
Denise van Aalst

RN, PG Dip Heal Sc (palliative care).

Appendix 2

Health Sciences Centre

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Information for Participants Sheet

Research Project: The Important Thing Is...: Finding What Really Matters to Patients and their Families in Palliative Care (Working Title)

This research project is being undertaken as a thesis requirement for an MHSci in Palliative Care at University of Canterbury. The principle investigator in this research project will be Denise van Aalst, RN, PG Dip Heal Sc (palliative care). This study has approval from the Lower South Regional Ethics Committee.

Denise can be contacted via: Phone (03)4885992
Cell (027)3842903
Email: denisev@clear.net.nz

The aim of this research is to discover what is really important to people who are receiving palliative care. To know and understand in what way hospice could, or does, make a difference for patients and for their families. Can you think of any actions or happenings that have impacted on your experience while at the hospice? Has it been a little thing? A number of things? Or maybe something really big that has affected you at this time? What has made a difference for you?

You are invited to take part in this study because you have been a patient at the Otago Community Hospice for more than a week. Five or six patients will be involved in this study, along with their families.

The research would involve a one-on-one interview with you, lasting approximately thirty minutes to one hour. The interview will be audio-taped to ensure accuracy. This audio-tape will be transcribed and you may, at the end of the research project, have a copy of the transcription if you would like to do so.

The research will also involve a group meeting with whichever members of your family would like to participate, at a time that suits them, where we could discuss together what their perceptions are, of their hospice experience.

There is no obligation to participate in this research. It will not affect your care here, at the hospice, in any way. And if you do choose to participate you can freely withdraw or change your mind at any time, simply by telling the researcher or any staff member at the hospice.

If at any time during the interview you feel like taking a break or stopping altogether, or if you would like the tape turned off just ask. It is important that you remain comfortable with the interview process and do not feel any distress at all. If you develop symptoms or become tired the interview can break for a while, stop for the day, or if you wish, cease altogether.

You have the right to determine time, place and general conditions of your interview and you may have a support person if you like. If you identify as Maori, the researcher will endeavour to follow your wishes regarding consultation with appropriate whānau, hapu or iwi.

The results of this research may be published, or presented at a conference. You may be assured of complete confidentiality regarding all information gathered in this research. As part of writing up this project the researcher will probably use direct quotes or stories in order to illustrate significant episodes. In this instance what you said will be written for all to see. If you would prefer your real name or a pseudonym of your choice to be alongside the example it is important that you sign the consent to this.

Recordings of interviews and any personal information will be held securely locked in a filing cabinet in the researcher's home until the research is complete and then destroyed. The responsibility for the safety and security of the data is the researcher's responsibility.

Your informed consent means you have read this information sheet and are happy with all the details in it.

Please do not hesitate to contact me. I would be pleased answer any questions or to discuss any concerns you may have regarding this research project.

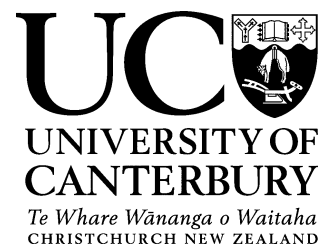
Denise van Aalst

15 May 2012

Appendix 3

Health Sciences Centre

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Consent Form

The Important Thing Is...: Finding What Really Matters to Patients and their Families in Palliative Care (Working title)

I have read and understood the information for participants' sheet, dated 15 May 2012, for the study designed to establish what is important to patients and their families in palliative care and have had the opportunity to discuss this with the researcher. I am satisfied with the answers I have been given.

I have had the opportunity to use family or friend support to help me ask questions and understand the study and I have had time to consider whether to participate.

I understand that taking part in this study is voluntary and that I can withdraw at any time from the project, including withdrawal of any information I have provided, and that this will in no way affect my future health care.

I understand the interviews will be audio-taped and that these tapes will be held in a secure location, along with written transcripts, until completion of the research project when they will be destroyed.

I understand that my participation in this study is confidential and my identity will remain protected throughout the study process and through any potential publications and presentations. I am aware that stories or direct quotes from my interview transcripts may be used to illustrate points during the writing up of this project and subsequent publication or presentations.

I know whom to contact if I have any questions regarding this study. YES/NO

I wish to receive a copy of my transcript YES/NO

I wish to be informed when the thesis is available to be read YES/NO

I wish to use my own name in any potential publication of this project YES/NO

I wish to use a pseudonym in any potential publication of this project YES/NO

Pseudonym _____

I consent to taking part in this research project

NAME (please print).....

SIGNATURE.....DATE.....

RESEARCHER.....

SIGNATURE.....DATE.....

Appendix 4



Lower South Regional Ethics Committee
c/- Ministry of Health
229 Moray Place
Dunedin
Phone: (03) 474 8562
Email: lowersouth_ethicscommittee@moh.govt.nz

7 July 2011

Denise van Aalst
Otago Community Hospice
293 North Road
NEV
Dunedin 9010

Dear Denise -

Ethics ref: LRS/11/EXP/017 (please quote in all correspondence)
Study title: The Important Thing Is...Finding What Really Matters to Patients and
 Their Families in Palliative Care

This expedited study was given ethical approval by the Chairperson of the Lower South Ethics Committee on 7 July 2011.

This approval is valid until 30 June 2012, provided that Annual Progress Reports are submitted (see below).

Amendments and Protocol Deviations

All significant amendments to this proposal must receive prior approval from the Committee. Significant amendments include (but are not limited to) changes to:

- the researcher responsible for the conduct of the study at a study site
- the addition of an extra study site
- the design or duration of the study
- the method of recruitment
- information sheets and informed consent procedures.

Significant deviations from the approved protocol must be reported to the Committee as soon as possible.

Annual Progress Reports and Final Reports

The first Annual Progress Report for this study is due to the Committee by 7 July 2012. The Annual Report Form that should be used is available at www.ethicscommittees.health.govt.nz. Please note that if you do not provide a progress report by this date, ethical approval may be withdrawn.

A Final Report is also required at the conclusion of the study. The Final Report Form is also available at www.ethicscommittees.health.govt.nz.

Appendix 5



Health and Disability Ethics Committees
1 the Terrace
PO Box 5013
Wellington
6011

0800 4 ETHICS
hdecsc@moh.govt.nz

17 September 2012

Mrs Denise van Aalst
12 Centennial Rd
Fairfield
Dunedin 9018

Dear Mrs van Aalst

Re:	Ethics ref:	LRS/11/EXP/017
	Study title:	The Important Thing Is...Finding What Really Matters to Patients and Their Families in Palliative Care

Thank you for submitting a Minimal Dataset Form (MDF) for this study. This letter is to confirm that responsibility for on-going review of this study has been assigned to the Southern Health and Disability Ethics Committee.

Please don't hesitate to contact us for further information. We wish you all the best for your on-going study.

Yours sincerely,

Administrator
Health and Disability Ethics Committees