Within the circle of care: The patient's lived experience of receiving palliative care

by

Eileen McKinlay

A thesis submitted to the Victoria University of Wellington
in partial fulfillment of the
requirements for the degree of
Master of Arts (Applied)
In Nursing and Midwifery

Victoria University of Wellington
1998

Abstract

I am a Registered Comprehensive Nurse with dual practice interests in the care of terminally ill people, and in quality improvement. This research study originates from my experience of working in a hospice as a clinical nurse then as a quality improvement co-ordinator in the early 1990s. At this time, quality improvement in the health services was relatively new, and there was no locally published research on quality improvement in palliative care. World wide there was a developing body of palliative care quality improvement literature (Higginson 1989, 1993, 1995); however there had been little research undertaken which reflected the patients' perception of the palliative care experience.

As a result of my work experience came the quest to find out directly from patients, the aspects of care which they considered valuable. I chose to use the descriptive-phenomenological methodology particularly utilising van Manen's (1990) phenomenological method. This methodology allows the participants' experience to stand apart from existing health professional defined palliative care knowledge, yet provides a way for this participant knowledge to complement and augment it.

This descriptive-phenomenological study describes six persons' experience of care within a palliative care setting, and discusses the possible significance that this may have for the practice of palliative care. The participants had at least two care experiences within this setting and were interviewed on one occasion shortly after their discharge, within their own homes.

I invited the participants to talk about their care experiences. The anecdotes which the participants relayed, when reflected on, revealed both a pattern of storytelling as well as individual components of care. These components or elements of the care experience as well as informing each other, created a representation, a schematic description of their experience.

The representation 'The circle of care', is orientated around the central component of 'identity', with the encircling valued components of care being: 'keeping control', 'being safe', 'chosen isolation', 'mortality awareness', 'relaxation and relinquishment', 'caring qualities', 'being watched' and 'humour'. The circle of 'palliative care philosophy' contained these components, finally being enclosed by an outer circle of the 'spiritual\aesthetic qualities of the environment of care'.

The reality of people receiving palliative care is characterised by a number of supportive traditional and non-traditional aspects of caring. Although some characteristics have been described within general health and palliative care literature, some appear to have been generated by these particular participants as part their reality. The selected methodological approach and results limit the study to the context in which it was conducted. However the study suggests that patients are valued informants, and that they are able to augment existing palliative care knowledge. Ideally their input should be sought within the current systems of evaluating existing care and in the creation of new models of care.

Acknowledgements

Without the support, help and practical assistance of many people this thesis from conception, undertaking and writing, could not have happened.

I wish to thank the six participants who bravely shared their experience of what it was like to be cared for in a palliative care setting. At a time in their lives when meeting a stranger was probably an inconvenience, they gave wholeheartedly of themselves. They affirmed my belief in the good of humanity, and the transparency that develops when people are dying; their chance to give a final gift to the world.

To my partner and family: John, Hannah, Brodie, Thomas, Jack, and my father Bill, go grateful thanks. They have put up with a very distracted family member at times, one who kept deserting them at night and sometimes during the day to keep company with the computer. I thank them for their love and continued encouragement, and not listening when I said I was going to quit 'now'.

Without research supervisor Joy Bickley, I would still be swimming in the kelp; her timely encouragement and challenge always tempered with warmth and humour kept my eyes on the 'what could be', not on the 'what is'.

My thanks go to the Nurs. 593 Thesis class, Department of Nursing and Midwifery, Victoria University, Wellington, New Zealand; my class study group, and study partner Diana Gunn, who inspired me by their dedication to their chosen subjects, and for the giving of themselves in listening and reflecting on my work. To the other Department of Nursing and Midwifery lecturers at Victoria University who participated in the class: Cheryle Moss, Margi Martin (whose continued inspiration over many years has been gratefully received), and Maralyn Rowley, go my thanks for their focused and insightful comments.

To dear, trusted colleagues Chris Barthow, Gaye Robertson and Australian connection Linda Potts, I offer thanks for insights and gems of 'personal knowing', that only those who have been involved in palliative care would understand.

Without the practical loving support of Elaine Edmonds in caring for Thomas, and the word processing ability of Sharyn Leonard in transcribing the interviews, I would have been unable to undertake the work in a timely way.

Dedication

This research project is dedicated to my mother Peggy (Helen) Moore. Peggy died on July 22nd 1996. Throughout my life, she encouraged me to pursue knowledge. She understood my passion for the care of the dying, and knew of my interest in undertaking this work.

Although she never received care in a palliative care setting, she was cared for by my father, and a loved family, and died in her own home. Peggy was one who passionately loved her life and her family. She lived her life to the full and did not accept her illness or her dying until very late, "raging against the dying of the light" as in Dylan Thomas's (1972, 159) poem:

Do not go gentle into that good night.

Do not go gentle into that good night,
Old age should burn and rave at close of day;
Rage, rage against the dying of the light.

Though wise men at their end know dark is right,
Because their words had forked no lightning they
Do not go gentle into that good night.

Grave men, near death, who see with blinding sigh
Blind eyes could blaze like meteors and be gay,
Rage, rage against the dying of the light.

And you, my father, there on the sad height,
Curse, bless, me now with your fierce tears, I pray.
Do not go gentle into that good night.
Rage, rage against the dying of the light.

Key To Transcripts

The following information contains the key to the abbreviations used within the research findings related to Chapter six, The Results; and Chapter Seven, The Discussion.

Names: All name of participants and health professionals used within the quoted narrative of the interviews are pseudonyms. In Chapter Seven, text referring to the quoted interviews of participants in Chapter Six, is identified by a Chapter Six page number within parentheses.

Italics: *Quoted narrative of participants is given in italics.*

Plain type within the quoted interview narrative: Quoted narrative containing words of the researcher is given in plain type.

...	A pause within the original quoted narrative.
\\	Narrative edited from the quoted material.

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"....if an inquiry is engaged in the service of the development of people, it will necessarily engage with them in dialogue" (Reason 1994, 333).

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Chapter One

The origin of this research, the introduction.

> One of the central difficulties involved in embarking on care of the soul is grasping the nature of the soul's discourse. The intellect works with reasons, logic ,analysis, research, equations, and pros and cons. But the soul practices a different kind of math and logic. It presents images which are not immediately intelligible to the reasoning mind. It insinuates, offers fleeting impressions, persuades more with desire than with reasonableness. ... How many times do we lose an occasion for soul work by leaping ahead to final solutions without pausing to savour the undertones. ... Do we need to expose everything that is hidden? Do we need to understand all mysteries? We are used to hearing about the great revelations of science. ... ...and so we think that mysteries are there to be solved. The alternative seems strange, but at the same time it has its own appeal: use our intelligence and skill to preserve the mysteries.
>
> Moore (1992; 122, 125)

Consider the balance between the ultimate good one can do by 'coming to know' about the existential mystery of dying and death, and conversely, its unnecessary exposure for no good reason. I believe the balance lies in the motivation behind the 'coming to know'.

The ambivalence and tension conveyed by Moore's (1992) initial statement represents the side of me that wishes to respect the desirable mysteries of life and death. There are processes within dying and death which are indefinable and inexplicable, yet have inherent value in their own right at the present time. As much as I respect the need to preserve the necessary elements of mystery, there is also need for me to explore questions of my nursing practice.

This thesis seeks to address questions which originated during my years working as a clinical nurse and then in a quality improvement role within a hospice. These questions arose because I was unable to adequately determine elements which related to patients' experience of palliative care. What was it like to be cared for when one was terminally ill? What value and importance did one attribute to the various aspects of care? Are there unique aspects of the clinical specialty of palliative care which made traditional descriptions of a 'good care' experience, or traditional indicators of quality, inappropriate or redundant?

Researcher's interest

As a student being educated as a nursing professional, I was drawn to caring for those living with life challenging illnesses, and those who were dying. My mother told me that as a child I learned to read by looking at the 'In Memoriam' columns in the evening paper, and trying to 'sound out' the little poems inserted within them.

I undertook my nursing education at the Wellington Polytechnic School of Nursing, New Zealand, in the mid nineteen seventies, when such a method of educating nurses was in its infancy, and remember well that my clinical experience within hospital wards was overtly viewed with suspicion by hospital employees. In balance, I remember the school's inspired and dedicated nurse educators, including Judith Christiensen, and Merian Litchfield, who spent as much time in conveying information and skills, as teaching young women and men what it was like to be caring, interacting, and authentic people, and encouraging us as individuals to realise our potential.

In my twenty years of employment as a clinical nurse and quality improvement specialist, I have spent seventeen years within the acute oncology haematology, and palliative care areas. In the early 1990s, I undertook a role solely focusing on Quality Improvement within a stand alone in-patient hospice. This was a position designed to consider the structures which impact positively and negatively on the quality of care of people who were dying, and also to implement an accreditation process.

Currently I am part of a health quality management consultancy. A major section of our work is to undertake contract work as quality auditors for a funding organisation, auditing the quality of care delivered within licensed rest homes and hospitals. My passion for the care of the dying has extended to this wider sphere of those who die outside the boundaries of the Government provided Core Palliative Care services, including those whose diagnoses best fit them for a chronic remitting form of illness.

For me this work is both intensely personal and political. In this role, I stand in an intersection between the interests of the patient, the constraints of the management, and the impact of regional and central health monitoring bodies. I believe to remain an authentic presence in this arena, I must be visibly consumer dedicated, clinically astute, professionally knowledgeable, a critical thinker and politically aware. The business of improving and assuring the quality of health care for consumers must not be seen as a tool of management, to justify cost or service cuts. My professional integrity and authenticity as a registered nurse working in quality management processes is paramount, in liaising with consumers, clinical staff, management and policy makers.

Philosophical base of the researcher

There will always be a conflict between the known and the unknown; what should be investigated and what should remain hidden. There is a mystery about the journey of dying which situates it in a realm of the only partially understood. This situation is one with which I am philosophically comfortable, both because I believe that it is by nature individually experienced, and that those undertaking this experience should be protected from unnecessary investigation.

Having said this, why did I think that my question examining the lived experience of people undergoing palliative care merited investigation?
As my professional clinical practice developed, I learned that the 'real' work of nursing is not in the undertaking of technical tasks, but the human interaction that occurs alongside, within, or after the moments these were completed. I well remember that this insight occurred during the time I worked with people with acute treatable tumours and blood dyscrasias in the early nineteen eighties.

My world view of clinical practice began to change. Initially there was the overwhelming importance of learning the techniques for administration of cytotoxic chemotherapy, and the complex matters of nausea and pain control, neutropaenia support and monitoring, and septicaemia control. Later there came an awareness of patients' view of the overall experience, and their reliance and valuing of meaningful, caring and individual humanistic interactions. I recognised that although there was informal recognition by staff of this human factor, it was not (and even now generally is not) documented, or described in a measurable or valued manner. However this personal awareness transformed my practice. I began to systematically incorporate a method and time for this type of human to human interaction to occur within the eight hour shift. As well as bringing some comfort to my patients, it brought personal meaning to me in a clinical area which was often fraught with professional distress.

As well as there being glorious moments when patients achieved remission and 'cure' from tumours; acute oncology and haematology treatment areas are characterised for staff and patients alike by physically and emotionally distressing events, and untimely deaths. There is often a 'window' period over several days when the difficult decision is being made to cease 'active' treatment, and the conveying to patient and family that this treatment approach is now inappropriate. Nurses in an intense honest relationship with patient and family, knowing this decision is being made but not yet conveyed to the patient, feel caught between the need to be authentic and honest with the patient and family, yet maintain a professional and collegial responsibility with medical decisionmaking.

It was as a consequence of this shift in thinking for me, that I recognised that patients do not interpret or value what happens to them in the same way that health professionals do. I held on to this thought in moving into the clinical specialty of palliative care, and in further refining and extending my sense of the importance of patient valued care. Although I recognise that palliative care involves the care of not only the patient but also their family and friends, I particularly wanted to know more about how the patient experienced this form of care.

The inherent ethical difficulty in understanding the patient's world view, became apparent. It was in my role of quality improvement that I began to dialogue both internally with my own reservations about questioning people who are dying, and pragmatically of how one would undertake this, and also externally with clinical staff and management about the need for and value of determining the patient's viewpoint. Not surprisingly, hospice health professionals have a keen sense of patient protection, and when I first undertook this work, most staff and especially physicians held a very definite view of what palliative care philosophy encompassed , and how this was experienced by patients. As a result there was resistance to audit or research directly involving the patient.

The impact of this on me was to consider a less controversial method, that of asking relatives\significant others for their perception of how their family member was experiencing palliative care. There are inherent problems in this type of compromise: these are expanded in the literature review section on 'Who speaks the consumer's voice in defining quality in palliative care: the patient themselves or the family\close friends?'

However the conundrum of how to determine accurate measures of patient quality in palliative care without actually eliciting the patient's perspective kept returning. How did clients perceive their care? What elements were of critical value to them? Classical palliative care literature (Saunders & Baines, 1983; Saunders, Summers & Teller, 1981) emphasised the importance of symptom control as being the most important component in palliative care. Although I believe this to be critical, I had long doubted that this was the complete experience of patients.

Is symptom control the aspect of care which clients believe is most important? Do patients go to a palliative care setting believing that they will receive one aspect of care (such as symptom control), yet experience another which becomes more valued or more important?

Only patients experiencing palliative care, can determine and describe its value to them as people. As time progressed in my quality improvement position, I concluded that the only way to find out answers to the above questions and others, was by talking to the patients themselves. Within the organisation I worked in, there had also been a spirit of change. Critical thought and enquiry was infectious, and after two years of active quality improvement, the majority of staff were in agreement with the principles of consumer involvement, and had moved from a position of disagreement to one of being in support of interviewing patients about their experience of hospice service. As part of this process there was also the need to persuade the Regional Health Authority ethics monitoring body that interviewing patients within a hospice setting could be morally justified.

I believe that there has always been a dilemma regarding seeking information from terminally ill people. Their time is limited, and so often they are feeling unwell, and vulnerable. Many can feel anxious about revealing true feelings because of the consequence this might have on their care. However there is a balance provided by others, when they express the need to try and repay the care given to them by palliative care staff. They regard talking to others about their 'dying experience' as a way of doing this.

For me the consequence of this process has been my eventual involvement in this quest for knowledge as an independent university student; not as an employee involved in quality improvement. I believe the timing of this has had impact on both the methodology I embraced to consider the question, and the method used to undertake collecting these very precious and unique stories. It also impacted on the manner in which these stories were entrusted to me in my role of post graduate student and registered nurse, rather than as an employee of the organisation.

The ambivalence I identified in the introductory statement regarding the protection and revelation of mystery, is reflected in the methodology I used to frame this work. My past work had been based in a mostly quantitative mode. I have used questionnaires with linear scales to estimate satisfaction with the selected service, with numbers expressed as percentages for types of responses (McKinlay; 1992, 1993, 1993a, 1994). However I could never quite resist leaving spaces for respondent's personal comments; these always being a fascination to me. When analysing these comments I never knew how to accurately and 'scientifically' represent them. I was always concerned with the validity of the number of responses rather than unique individual stories. Within this study it seemed appropriate to use a qualitative methodology that emphasised the description of the experience, and also attempted interpreting what this description might mean. Thus this methodology seemed consistent with my philosophical base.

In talking to patients who were currently discharged from the hospice, and in the 'safe' speaking environment of their home, I hoped to elicit their impressions of the recent care experience. From this I wanted to determine valued, neutral, and undesirable aspects of care.

Background and justification for the research

The overall value and importance which patients give to components of their care experience is unique and peculiar to each person. Are there however, aspects of this unique response to care which are universally recognised as important? Could there also be aspects of valued care which are unique to a particular area of service delivery or clinical specialty?

There is continued argument by organisations throughout the world regarding both the validity of the consumer's opinion, and the impact of this opinion (Zeithaml, Parasuraman & Berry, 1990; Avis, 1994; Avis, Bond & Arthur, 1995; Gray, Fitch, Greenburg & Shapiro, 1995; Young, Minnick, & Marcantonio, 1996; Fakhoury, McCarthy & Addington-Hall, 1996). This debate has been particularly notable in health care, impacted by the prevailing paternalistic attitudes retained by health professionals regarding the nature of care (Avis, 1994; Avis, Bond & Arthur, 1995; Fitch, Greenburg & Shapiro, 1995; Young, Minnick, & Marcantonio, 1996)

I have always believed that there was a connection between the perceived quality of a service as determined by clients, and their own satisfactory experience of care. It could be concluded from this statement that if one could identify the universal salient elements from a satisfactory experience of care, they could be used as a way to measure the quality of the service; the development and use of *quality indicators* of a service.

Contemporary literature on health care quality has moved towards looking at outcomes or outputs as measures of quality (Bassett, 1993; Nocon & Qureshi, 1996). However many of the outcomes in palliative care are intrinsically difficult to define. Within an acute medical\surgical service, morbidity and mortality as outcomes are used as quality indicators of adverse care. In palliative care a shortened life-span is considered to be within the normal process of dying, and could not be used as a quality indicator of poor care. Process elements within the care experience have only recently been regarded as important (MacDonald, 1995; Nocon & Qureshi, 1996). These process elements are uniquely important to palliative care, often representing for the patient the quality of the dying experience. An example of a process element in palliative care could be patients' perceived value of a caring verbal or physical interaction between them and staff members.

Such process elements are difficult to quantify, and it would be difficult to constitute them as an output. For some patients however these process elements determine the quality of the care experience. The moment of dying; the output or outcome, is not the most important factor for the patient. It is within the journey of going to that moment of death, where the elements of: true human interaction; healing, affirmation and self actualisation could occur. It is very unlikely that all of life's difficulties can be resolved during the dying trajectory, but it is a moment in time when physical and existential peace can sometimes be achieved

Significance and Limitations of this study

This research undertook to describe and interpret the stories of six individuals who have experienced palliative care within a specific locational context. It was my aim to elicit the voice of the patient regarding how they experienced their care, and the elements they did and did not value. Although each experience was different, there were elements which conveyed a collective meaning, with similar language and examples. I have identified these elements as themes within Chapter Six. It is from these themes that I have constructed a representation of people's experience undergoing palliative care. This representation is called 'The circle of care' and is discussed in Chapter Seven.

I believe the results of this study should be viewed at the moment as positioning this work contextual to the organisation from where the participants' were obtained. However there are components of care identified by the participants which have also been reported in other studies (McDonnell, 1989; Arblaster, Brooks, Hudson, & Petty, 1990; Gates, Lackey & White, 1995; Greisinger, Lorimor, Aday, Winn, & Baile, 1997).

I also believe that this study could be viewed as attempting to determine whether a particular methodology is successful in eliciting sensitive information, in a manner that respects the identity and validity of those interviewed, and does not compromise their integrity or safety.

The above limitations are not stated to undermine the uniqueness and validity of the stories of the six who entrusted their thoughts to me. It was an overwhelming privilege for me to be able to finally speak to people who were dying, about their care. It was also a personal adventure to use a methodology which was not in my knowledge or comfort zone at the time when I first envisaged undertaking this work.

Structure of the Thesis.

This thesis is structured to allow the reader to follow my method of thinking through the process of researching my interest.

Chapter One introduces my background and the origins of my interest in the nature of the patient's experience of undergoing palliative care. I briefly outline my personal experience in palliative care, discussing the intersection between clinical practice and quality improvement, thus identifying my interest in undertaking this research.

Chapter Two briefly outlines the development of world wide hospice care, and positions the New Zealand context. I discuss the current situation, including the impact of the health reforms on the funding and development of palliative care services.

Chapter Three and Four encompasses the literature which I use to guide my thinking. Chapter Three: 'Palliative Care, the patient's experience', focuses on literature regarding the patient's experience of palliative care. It examines palliative care literature fort the experience of palliative care, the relationship between palliative care philosophy and palliative care, and the ethical dilemma of seeking patient opinion. In this chapter I highlight the paucity of literature resulting from direct interaction with people who are terminally ill.

Chapter Four: 'Quality and Patient Care' contains a review of the literature related to quality improvement in health care. I review previous work on the nature of quality care, what is measurable about health care, and the value of involving patients in both participating and evaluating their care. Within this chapter I attempt to identify why it is necessary to determine the patient's own experience in evaluating contemporary palliative care practice.

Chapter Five outlines the qualitative descriptive-phenomenological methodology adopted, identifying their philosophical bases, their differences and similarities, and method used to obtain the data.

Chapter Six reports the results; it tells the stories of those who participated in the study, identifying their similarities and differences. From these similarities and differences, themes are identified which comprise a representation of the patient's experience of palliative care.

Chapter Seven discusses, and provides an interpretation and elaboration of the results. The resulting representation called 'the circle of care' is described, identifying its interconnections and relationships.

Chapter Eight provides a conclusion, summarises the results of the study, its limitations, and recommendations for further study.

The Appendices contain a time line of current New Zealand hospices, patient information form, consent form, and information given to hospice staff prior to the research being started.

Review and summary

This chapter seeks to provide the background to undertaking this research project. I have presented you with a glimpse of my background, and why I came to develop this interest in investigating the 'care experience' within palliative care.

The structure of the following chapters of the thesis have been outlined, according to the process I utilised. Chapter Two which follows, focuses on the background to the palliative care movement world wide, and also the origin and current development of New Zealand palliative care services.

Chapter Two

The Background: The origins and history of the hospice (palliative care) movement world wide, and with particular reference to New Zealand.

Introduction

Within this chapter, I will provide a brief overview of the origins and development of key hospices throughout the world, with a focus on the development of the New Zealand palliative care movement. In writing about the history of the hospice movement, I wish to provide a basis for both the subsequent literature review which focuses on palliative care literature regarding the care experience, and also the currently accepted determinants of 'quality' health care; as well as situating the context of the location where the research participants experienced their palliative care.

The origins of the palliative care movement: a historical review

> The (modern) hospice movement arose out of perceived deficiencies in the care of the dying. It was observed that dying patients suffer unnecessary pain and other distressing symptoms, experienced anxiety and depression that were capable of relief, were subject to emotional stress and spiritual unease, for all of which help could be offered. Moreover, the families of the terminally ill were subject to the same emotional upsets..... (Lichter cited in Hospice New Zealand Inaugural Conference Report; 1986, 4).

The term *hospice* has changed its meaning over time. Originally the Latin term was *hospes* which meant 'guest'; later in the middle ages changing to 'stranger' (Talbot; cited in Manning, 1984, 33). Traditionally it has been thought to mean a place of shelter for travellers on difficult journeys. The terms 'hospice care' or 'hospice'; are believed to have a different philosophical base than the more modern term 'palliative care' which reflects a degree of 'medicalisation. However in recent times these terms have come to be viewed as synonymous (Perano, 1988).

The hospice movement has been written of since early times- the third century. Below I have identified key dates to allow the reader to note significant events since that time, using historical work undertaken by Manning, 1984; Snowden, 1985; Perano, 1988; Simpson 1989; and Parr, 1995.

Historically as a philosophical approach, hospice originated in the third century (AD 273-232) when an Indian Emperor Asoke made housing provision for travelling religious pilgrims going to the Ganges. In Roman times, a woman Fabiola was said to care for travellers, including the tired, the sick, and those people who were dying, an approach consistent with modern hospice philosophy (Parr, 1995; Perano, 1988).

By the eleventh century (1065), there was the first evidence of religious organisations (Brother Gerard and the Knights' Hospitalliers) taking particular responsibility for the provision of hospice care (Manning 1984).

The twelfth and thirteenth centuries saw outcast lepers cared for by Brother Vincent de Paul and the Sisters of Charity in Paris. Monastery situated hospices developed in the later Middle ages (1300). There developed a change in the function of these hospices with an emphasis on the care of the traveller rather than with people who were dying (Parr 1995).

The 17th century saw a resurgence in the care of terminally ill people with the formation of the Sisters of Charity by St Vincent. Their mission was to care for the orphans, the sick and those who were dying.

In the 18th century the first Protestant hospice was formed by Pastor Fliedner. Later in Dublin (1815), Irish nuns from the Sisters for Charity founded Our Lady's Hospice for the dying (Mother Mary Aikenhead). In 1842 the first use of the word *hospice* is described in relation to the dying of a woman in France. There was further development of what could be said to be the hospice movement in the 19th century in England, with the founding of St Joseph's Convent in London by the Irish Sisters of Charity, providing beds and homecare (Manning 1984, Parr 1995).

In the United States the first informal home care hospice operated from the house of Rose Hawthorn, New York as a result of the influence from the Irish nuns in 1899. The early twentieth century (1905) saw the formation of St Joseph's Hospice in London, with a number more opening throughout England (Simpson, 1989; Parr, 1995).

In 1957 Cicely Saunders one of the seminal writers and protagonist of the modern hospice movement began to work at St Joseph's Hospice (Saunders, Summers & Teller, 1981; Saunders & Baines, 1983). She researched and began the development of protocols which have provided guidance for pain control, symptom management and psychological support up until recent times. Cicely Saunder's work in palliative care together with the impact of Elisabeth Kubler-Ross (1970) constructs of the stages of loss, grief, and dying shaped a humanistic paradigm of knowledge about the process of dying. This paradigm was in contrast to increasing technology within hospitals and increasing medicalisation within the healthcare industry. Wald (in Anderson cited by Perano; 1988, 25) states:

> The movement stemmed from increasing dissatisfaction with so much technological care and so little concern for human beings with life threatening and life terminating illnesses; it is searching for a unique approach to life and death that will combine scientific medical knowledge with human and spiritual concerns.

The hospice movement in the United States and Canada, although having developed at a slightly later stage, continued to form hospice units, supported by private organisations or trusts (rather than the mainly religious or public hospices of the United Kingdom). As in the United Kingdom, there have been a number of key writers about palliative care such as Balfour Mount (1980), and Bob Kastenbaum (1981), North America.

In Australia the hospice movement began with the establishment of Caratis Christi Hospice by the Sisters of Charity in Victoria, 1938. By 1978 after increased publicity about the hospice movement, hospices were developed in New South Wales, and Queensland; extending throughout Australia by the mid nineteen eighties. Overall the nineteen sixties, seventies and eighties have brought further development in the world wide formation of hospices, the writings on palliative care, and the development of palliative care standards.

Much of the early hospice and palliative care service delivery in Europe, Australasia, (and to a much lesser degree in the United States and Canada) has been characterised by the involvement of religious organisations. Hospice and palliative care philosophy is said to align with the religious doctrine of caring for others who are in need.

Definition of philosophy and intent

The World Health Organisation defines palliative care as

> the active total care of patients whose disease is not responsive to curative treatment. Control of pain, and of other symptoms, and of psychological, social and spiritual problems is paramount.
> (cited in the Draft Position paper on Hospice\Palliative care; 1997, 1)

The NZ Consensus Forum, a forum of health professionals, consumers, and health care administrators, was convened by the Ministry of Health in 1993 to provide a framework for existing and developing hospice and palliative care services (Messervy Report 1993). This Forum described palliative care as:

> ...a quality and type of care for patients with an illness which no longer benefits from curative treatment, an illness which will eventually result in death. Palliative care aims to alleviate symptoms and maintain the quality of life for the dying. Unlike terminal care, palliative care is regardless of life expectancy. Palliative care focuses on the psychological and social needs of the patient and family, and promotes the acceptance of a dignified death.
> (cited in Draft Position paper on Hospice\Palliative care; 1997, 1)

'Hospice New Zealand', the national hospice body formed in 1986, agreed the terms of hospice care and palliative care were synonymous, and described such an approach as providing:

> ...specialised care to patients with active, progressive, advanced disease, unresponsive to curative treatment. The focus of care is on the quality of life for both the patient and family (Draft Position paper on Hospice\Palliative care; 1997, 1).

These statements reflect the ongoing definition of palliative care both world wide and in New Zealand. There has been an emphasis in New Zealand not to constrain palliative care 'admission criteria' to people with certain types of illness. Also there has been a focus on holistic and interdisciplinary care aimed at continued or increased quality of life; rather than solely on physical symptom control (Ministry of Health, New Zealand Consensus Forum, 1993: Messervy Report; Draft Position paper on Hospice\Palliative care; 1997).

The New Zealand Hospice Movement

Of relatively recent origin, the New Zealand hospice movement has its roots in both the religious orders of the Roman Catholic church with the establishment of St Joseph's hospice in the Mater Hospital: Auckland (1977), Mary Potter Hospice in Calvary Hospital: Wellington (1979); and the community based hospices: Te Omanga Hospice in Lower Hutt (1979), Cranford Hospice in Hastings (1982) and the South Auckland Hospice (1983) (Parr 1995).

Since the small beginnings of these original NZ hospices in the seventies and early eighties a great many more have been established. There are now 36 services in New Zealand (see Appendix One). Each hospice runs on a different basis with different financial support and different modes of care; some completely homecare (Otago Hospice Trust), some in patient and homecare service (Cranford Hospice and Te Omanga Hospice), some only inpatient service (Mary Potter Hospice).

It is very difficult to generalise about New Zealand hospices. Each has arisen from community need; each distinct from the other. Three are Crown Health Enterprise based (Waikato hospital palliative care unit; Auckland Healthcare palliative care unit; and South Auckland Health); the rest part Regional Health Authority \community funded. Their philosophical bases too, could be said to be different; all originating from the UK hospice philosophy but now flavoured by the NZ culture, the NZ health service and the individuals, and groups that control them.

The originating hospice\palliative care services were provided by religious orders and a community trust (St Joseph's, Auckland; Mary Potter Hospice, Wellington; and Te Omanga Hospice, Lower Hutt). At that time there was no overall organisation and direction given by the then New Zealand Health Department. Thus ongoing development of the hospice\palliative care movement occurred through a series of ad hoc meetings co-ordinated by government (Ministry of Health, New Zealand Consensus Forum 1993: Messervy Report); the then Area Health Boards (A National Hospice Association, proceedings of a workshop in Auckland 1985); and the developing national hospice organisation ('Hospice New Zealand' 1986).

The majority of New Zealand hospices are affiliated to the national body 'Hospice New Zealand' (Hospice NZ.), which was formed in 1986 after a need was seen to consolidate, share experience, provide education and resources. 'Hospice New Zealand' had as its prime aim, the improvement of the: "...quality of terminal and palliative care in New Zealand" (Barnett & Smith 1992, 12). Currently 'Hospice New Zealand' has an executive officer who co-ordinates communication between hospices, develops policy statements for the organisation, lobby's government bodies, and assists in the yearly conference for New Zealand hospices

In 1995 a working party sponsored by the Cancer Society and chaired by Professor Isbister of the Dunedin School of Medicine (Wellington Clinical School of Medicine) formulated an extensive list of recommendations related to the form and standards which hospices in NZ should follow (1985, Proceedings of the Workshop held in Auckland: A National Hospice Association). This inaugural conference established priorities for 'Hospice New Zealand' to focus on. These were 'Information sharing'; 'Education'; and the 'Establishment of standards'. The first standards were released in 1987 (revised 1994).

At the time of this conference the Area Health Boards were still in operation, and there was an optimistic hope that these boards would provide far more extensive funding and even be induced to: "...establish in-hospital\hospice services through out the country" (Lichter cited in Hospice New Zealand Inaugural Conference report; 1986, 7). However time went on, and the begining of the health reforms were signaled with the release of the 1992 Core Health and Disability Services report. From this report It became apparent that hospices would need to present a strong and ongoing case for palliative care services to be seen as specialist and essential.

Currently although within the health service hospice\palliative care is informally viewed as a specialist and essential service, there remains no guarantee that the service will be available in all areas through out New Zealand. Funding remains precarious; each provider having to obtain as much funding as possible from the local Regional Health Authority, the balance coming from local support- an oft uncertain financial state.

Because there is competition for the provision of funding for services by the Regional Health Authorities, some services such as the Christchurch Burwood Hospice service were not able to compete successfully with local funding services. To the public it appears that competition to provide services is usually based on cost factors, rather than the provision of recognised quality care. It could be argued that the consequence to Christchurch was that a large number of skilled hospice professionals were lost to the specialty, and now work in areas which do not fully utilise their skills.

As well, some hospices suffer a naiveté about their place within the health service, believing that they do not need to attempt to present a compelling financial case to compete. Even now there remains a catch cry for some within the hospice movement, that each wants to be different and retain their own local personalities. However with the coming single purchasing body the Health Funding Authority (mid 1998), there is potential for a more co-ordinated approach. In 1997 a draft Hospice NZ position statement was circulated in an attempt to create dialogue, and state the universalities of the service. The writers of the position statement saw five key factors to the way forward (Draft position paper Hospice NZ; 1997, 8):

1. **Commitment by Government:** the fact that hospice\palliative care services are seen as essential, needs to translate into a committed

funding arrangement.

2. **Recognition as a specialty:** recognition by the College of Physicians that palliative medicine is a specialty service.

3. **Using existing expertise**: recognition of the skilled nature of the palliative care professionals. A quality service means the provision of skilled practitioner, not just the health professionals with generalist experience who are required to provide palliative care.

4. **Appropriate budget holding**: Where there is a recognised level of care and expertise (Level two and three, see explanation at the end of the section on funding N. Z. palliative care), such palliative care services should have budget holding to supply the palliative care services within an area. By doing this they can utilise and co-ordinate the existing skills within a community. In doing this quality standards can be maintained.

5. **Appropriate funding levels**: Initial costings established by the Casemix research from Australia should provide costings for the different aspects of the palliative care service. Within palliative care "the number of users and the timeframe for individual care is unpredictable. Dying cannot be allocated to a waiting list and rescheduled" (Draft position paper Hospice NZ; 1997, 8).

Funding of the palliative care service in New Zealand: A review

The government funding of the New Zealand hospice service has been and is currently allocated on an ad hoc basis. Each individual hospice presents a case to the Regional Health Authority for funding to provide a palliative care service in that area. New Zealand hospices do not provide the same level of service, with some being completely community based using registered nurses and volunteers to provide care in patients' homes, and having no facilities to provide respite day care, physician assessment, or occupational and physiotherapists (Clark 1997, 1998). Others provide a complete inpatient\home care service with a full range of the interdisciplinary team (registered nurse, physician, occupational therapist, physiotherapist, spiritual care, bereavement care, social worker, volunteer, educator, quality improvement, complementary therapists, and administration). Because of the dissimilarity between the range of hospice services provided, and for other reasons which are not clear to me, there is no uniform way in which funds are allocated. Currently up to one fifth of N.Z. hospices do not receive Regional Health Authority funding. The balance receive up to 50% of their funding from the Regional Health Authority.

In all cases community based hospice services rely on community fund-raising, charitable and lottery grants, sponsorships and donations to cover their operating costs. The current situation is little different from prior to the establishment of the Regional Health Authorities.

Hospice\Palliative Care was identified by the Core Health and Disability Services Committee as a core health service. (Messervy Report on the Consensus Forum on hospice\palliative care service; Ministry of Health, 1993, 16). Shipley's (the then Minister of Health) 'Policy Guidelines for Regional Health Authorities 1996-1997' identified in 'Secondary and Tertiary Medical Services: Services to be purchased' (8.10.5), the requirement for: "...hospice palliative services for people with a terminal illness (which may extend over a period of time) and counselling services for the families of those people" (pg. 55).

The Consensus Forum (1993) agreed "...that hospice\palliative care is a core service and that it should be purchased by Regional Health Authorities on behalf of the community", but that "The community should continue to be a source of a proportion of funding for hospice\palliative care services"

(Messervy Report on the Consensus Forum on hospice\palliative care service: Ministry of Health, 1993, 16).

A recommendation was made: "A major proportion of hospice\palliative care services be purchased by Regional Health Authorities. The remaining proportion should continue to be funded from community sources" (Messervy Report on the Consensus Forum on hospice\palliative care service, Ministry of Health, 1993, 16).

Performance indicators were also developed, which were designed to measure quality palliative care: demonstrate evidence of staff seeking quality; show low absenteeism and sickness rates among staff; demonstrate ability to recruit and retain quality staff; meet all the palliative care needs of the population served; and have strategic and business planning cycles.

Despite the recommendations of the 1993 Consensus Forum, the critical issues facing the palliative care\hospice funding dilemma remain in 1998. These include 'lack of equity in government funding' being a problem recognised by policy makers; consequently leading to lack of equity in patient access, and lack of uniformity of hospice service provision from area to area (Clark 1997, 1998). Other factors include constraints caused by geographical features of the service areas; financial concerns; limitations of the existing patterns of palliative care service delivery including availability and distribution of volunteer workers and specialist health professionals; and availability of community funding (Carter, MacLeod & Hicks; 1997 in press).

To address the question of uniformity, Hospice New Zealand have endorsed three levels of hospice care (similar to other countries).

The first level refers to the application of palliative care principles by health professionals and volunteers. The second level is the provision of care by trained and accredited health professionals in both community and inpatient settings. Third level refers to care in the community, and in-patient settings by specialised health professionals with post graduate training in palliative care.

The disparate nature of New Zealand hospices makes any attempt to develop a standardised funding approach difficult. An Australian Casemix classification system developed for the sub acute\non acute category of patients using measures such as functional status, physical and psychological problem severity and phase of care to classify patient groups may provide a solution. This provides a far more sensitive measure than the Diagnostic Related Groups used within the acute care areas within some New Zealand Crown Health Enterprises. However there are still difficulties in using the current Australian Case Mix model to account for the level of input by some services including volunteer staff and day care services, because such services have not been addressed within the setting up of this model (Carter, MacLeod & Hicks; 1997 in press).

What do people need in order to 'die well' in New Zealand?

Is there such a thing as a good death? This immensely complex philosophical question cannot be answered within the scope of this research; however it is important to make an attempt to gather together what is known about the care of the dying that could enable a 'good death' to occur.

The burgeoning literature on both the mechanics and personal experience of palliative care, surface several distinct themes. This consistency and frequency situates them as key aspects with those who work in the field. They are quality of life; the mode of care; the place of death; interdisciplinary care; patient\family\supporter as unit of care; and education and research.

Quality of Life:

There is a crucial moment for all who are ill, when the question becomes: “what are the treatment aims”? For the health professional worker the questions are: “At what cost are we trying to prolong a life”?; “Is the treatment likely to bring remission”?; and “What does the ill person want us to do”?

My professional observations lead me to believe that there is a time when death is certain, and approaching, and “...when further attempts to cure become irrelevant, unkind, and indeed bad medicine” (Hanratty & Higginson; 1994, 2). It would be simplistic to say that this moment is easily recognised. It can be the person, the family or the medical\nursing team who are unwilling to recognise that the ill person cannot or will not respond to more aggressive treatment. There is a certain indescribable tension in this moment of time, with a sense of relief when the decision is made that the treatment options and focus must change.

Quality of life is an unquantifiable notion, yet it is often spoken of with little thought for how it can be achieved. It can be said that it is an individual goal; individually defined, and differs between people. Twycross (1997, 4) says: “Quality of life is what a person says it is”. Health professionals are in the fortunate position of seeing how people can operationalise quality of life, and sometimes can persuade the ill person that they are settling for less than they could be; but in the final analysis it has to rest with the ill person’s self definition. Factors which can affect quality of life can be physical symptoms, psychological distress, family dynamics, spiritual issues, and environmental concerns: all the factors that constitute a person’s way of being.

Palliative care workers and supporters must remain vigilant in preserving the political importance of’ ‘Quality Of Life’. In my opinion it would appear that as the funding of publicly provided health care diminishes, there is a very real threat to the ‘public value’ of the ‘incurable’ or ‘dying’ person.

The provision of and equitable access to quality palliative care is viewed by an increasing number as a basic human right, based on the moral reasoning that there are some types of health care that must be provided without the requirement to justify a productive output (McGilly & Haines 1995).

A Mode of Care:

The second factor contributing to a 'good death' is the way the ill person is cared for. There is no prescriptive 'right' way. In my view it is for the person\family to decide. Their 'way of dying' should be accommodated if at all possible. Such things which could lead to a good death are: co-ordinated care, holistic care, family\group centred care, available care, quality care, and contemporary palliative care (Draft position paper Hospice NZ 1997; Doyle, 1994).

A Place of Death:

Palliative care writings have always focused on the environment of the place of dying and death (Saunders, Summers & Teller ,1981; Doyle, 1994; Hanratty & Higginson, 1996; Twycross, 1997). It has always been thought that a person should ideally wish to die at home, with suitable care and support. However those who work in the palliative care field recognise that this cannot always occur for reasons of the individual's personal choice, adequate control of symptoms, and family\supporter need for assistance. In recognition of the necessity to provide an environment where people can die if they are unable to at home; hospices have always focused on being built as 'homelike' structures, in fact often described as more like a hotel, often providing accommodation for family\supporters to stay.

Interdisciplinary care:

Palliative Care has long been established on the premise of interdisciplinary care (West, 1990; Twycross, 1997). Such things as collaborative management of patient care and interdisciplinary assessment and management are key factors. Use of spiritual care counsellors, volunteers, physiotherapists, occupational therapists, bereavement counsellors and complementary therapists such as the aromatherapist, art therapist and music therapist, to complement the traditional nursing and medical care is universally accepted within contemporary Hospice practice.

Patient\Family\Supporter as unit of Care:

The patient is not cared for in isolation but as part of a dynamic group, including their family and/or supporters. This wider unit of care requires holistic assessment, flexible support, and appropriate referral within the interdisciplinary team. It is recognised that a person cannot be devolved into body systems to be 'treated', or cared for in isolation from their significant others. This aligns the hospice movement with humanistic concern rather than the positivistic reductionist models of traditional health care organisations.

Education \ Research:

Cicely Saunders(1981) from the inception of the modern hospice movement has actively promoted education not only for health professionals but the community at large (often through advertising for funds); and since that time (1950s) hospice care has proactively attempted to educate. Research into alleviation of symptoms, the process of grieving, support for staff under stress has also taken place; this being predominantly in the UK, the USA, and latterly in Australia. Palliative Care has been early to grasp the model of Quality Improvement with published standards released in the United States and the United Kingdom in the early to mid nineteen eighties. Irene Higginson (UK) has published widely in this field (1989, 1993, 1994, 1995).

Review and summary

In this initial chapter, I have attempted to identify the philosophical basis of hospice\palliative care, the origins and brief overview of the world-wide development of hospice\palliative care services, finally focusing on the development of palliative care services within New Zealand.

In describing how the New Zealand Hospice\Palliative Care Services have evolved, I have identified the political (funding), and ideological influences, and have attempted to identify the characteristics of services that people need to potentially 'die well'.

To refine and focus the research question onto the patients perception of palliative care, chapters two, three and four work together to provide a framework of understanding. Chapter Two discusses the development of the hospice movement world-wide, with particular reference to New Zealand, thus giving the reader a historical, political, and sociological perspective of palliative care. Chapter Three will go on to describe research undertaken with and about patients having palliative care, particularly looking at work undertaken to enlighten health professionals about the patient's 'being' within palliative care. Chapter Four focuses on how the quest for quality palliative care can focus the way forward for health professionals and others interested in the further development of patient centred palliative care.

Chapter Three

A review of the literature on the patient's experience of palliative care.

Introduction:

Within this chapter, I wish to discuss and position research undertaken within the specialty of palliative care in relation to the patient's experience of care. I shall review literature relating to the care experience which speaks the voice of health professionals, carers and patients. In reviewing the literature, I wish to identify the different perception of the value given to acts of care between those who are ill in acute care (medical\surgical) hospitals, and those who are ill being cared for in a hospice. I also wish to highlight the lack of research undertaken directly with patients who are terminally ill regarding their care. In order to expand on how patients may perceive 'valued care', I have reviewed literature which relates to what may be considered a 'social construction' of palliative care. To conclude the review I discuss literature which identifies the need for researchers to speak to the patient themselves, in order to gain an authentic voice regarding the perceived value of care.

Palliative care specialists have been criticised by some for being slow in undertaking research, especially involving patients (Broadfield, 1988; Davis, Cowley, & Ryland 1996; O'Henley; Curzio & Hunt, 1997). There have been genuine ethical debates between palliative care health professionals regarding research involving direct interaction with people who are terminally ill (Mount, B. Cohen, R. MacDonald, N. Bruera, E. Dudgeon, D. 1995).

The art and science of quality palliative care. What is measurable about care?

Quality Improvement\Quality Assurance and the measurement of quality is in its infancy within the health care setting. Within palliative care there is continuing discussion regarding a relevant model of quality. Hospice as an ideal was set up in response to poor quality patient care for the terminally ill (Higginson, 1989; MacDonald, 1985). As demands for quantifiable outcomes and other quality measures began, some workers within this field have become disgruntled that they have had to prove their worth.

In a study of quality improvement systems in the hospices in New York state, the sentiment of a 'poor fit' between established quality philosophy and hospice philosophy was recorded, with the response that: "...quality is defined differently in hospice than in other health care settings" (MacDonald; 1995, 23). Comments such as the intangibility of measuring a patient's sense of well-being, the holistic nature of hospice care, and 'quality' itself being a subjective concept based on a patient's perception of care rather than objective measures, were identified.

> ... there may be elements of the quality improvement paradigm- its methodology, its assumptions, and its business- orientated conception of organisational goals- that are to some extent inconsistent with the philosophy and mission of the hospice, as understood by many hospice workers....Particularly lacking are valid quality indicators for the more intangible aspects of hospice care, such as psychosocial and pastoral interventions. Practical methods must be developed to use descriptive, rather than quantitative data, to verify beneficial outcomes in these vital areas of holistic care
>
> (MacDonald; 1995, 28. 29).

Nocon & Qureshi (1996) discuss the problem of focusing on 'outcome' rather than 'process' measures of quality care; outcome measures not being sensitive to the intangibles such as the skills of health professional relationship:

> ...long-term care may sometimes involve interventions directed at the achievement of specific outcomes, aspects of process often represent important and continuing influences on user and carer satisfaction and quality of life (pg. 134).

I have an ongoing interest in developing quality indicators for palliative care. Nocon & Qureshi (1996) provide an alternative focus on process elements of quality rather than the output or outcome measures which have characterised quality management literature (Donabedian, 1988; Zeithaml, Parasuraman, Berry 1990; Koch & Fairly, 1993). These process elements perhaps appear to align more appropriately with the nature of palliative care. It is my hope that this assumption will be partially tested within my research.

Morris, Sherwood, Wright, & Gutkin in Mor, Greer, & Kastenbaum (1988) studied over 1000 patients (and their relatives) who had received hospice care. They asked the question: 'Does hospice make a difference?' The findings showed that: "...patients are fairly satisfied with the medical and nursing care they receive ... terminally ill patients are as generically satisfied with health care providers as are all patients" (pg. 131).

Whilst it is also known that interviewing patients when they are still receiving care can make them feel too frightened to honestly say how they really feel in case their care is compromised (Snyder, 1993; Avis et al 1995). Morris et al (1988) suggested that patient's have an indiscriminate 'satisfaction' with health care. This 'satisfaction' masked the information that health care providers with a committed interest in quality care could obtain from patients' experience. Morris et al (1988) suggested the development of a programme designed to raise patients' expectations of care as well as the construction of a safe environment in which to complain or provide constructive feedback. The results of this study are surprising to me and are inconsistent with quality improvement literature suggesting that patients intuitively discriminate between 'good' and 'mediocre' care (Spitzer, 1988; Bliesmer & Earle, 1993; Synder, 1993). This study undertaken ten years ago would possibly not produce the same results today, given the rise of the health consumer movement during this time.

Ivan Hanson (a terminally ill health professional) when interviewed, gave insight into how he viewed quality of care. When asked to comment about his care, he responded that what he wanted was: "Ask me what I want, and what I need. A lot of times that doesn't even get asked. Most of the time they expect to just tell me" (Schmele; 1995, 35). Other significant factors he identified were: the lack of knowledge about how people get ready to die; how they make peace with this task (this comment made even though this man was familiar with contemporary writings on the process of dying); the important use of establishing significant rituals with the dying; the importance of giving timely and accurate knowledge; and how the presence of unrelieved pain could slow or impede the process of getting ready for death (Schmele; 1995, 36-38).

It is this type of interview process and verbal and non-verbal experience that I wished to engage in with my participants. Although Ivan Hanson, the man interviewed, was a health professional, and as explained was familiar with death and dying literature; his narrative reported a different sense of 'personal knowledge'; the result of the living reality of his journey through the dying process.

What is the care component of palliative care? A review of the notions of 'care' and 'palliative care'.

Having discussed what possibly might constitute quality palliative care, I shall go on to look at the notion of 'care', to determine what has been written about this element within palliative care. Considerable study has been undertaken within nursing to determine what constitutes or indicates the generalised notion of care or caring (Mayeroff, 1971; Leininger, 1981; Paterson & Zderad 1976; Watson, 1985). Other than to outline these positions related to 'care' in general, it is my intention to focus and examine how 'care' given within a palliative care setting is experienced.

There are many models of care. Johns (1994, 23) viewed care as a configuration between the variables of: relationship \ intervention \ patient \ outcomes \ nurse. Watson (1985) developed a classification system for nursing actions of care, defining them as instrumental or expressive; instrumental being those which focus on physical or treatment interventions, expressive being those which describe psychosocial activities.

In an attempt to expand the knowledge of what constitutes good care in general terms, various health professional behaviours have been identified by patients and families as being helpful actions in providing care and support (Brown, 1986; Scanlon, 1989; Degner, Gow & Thompson, 1991; Herbst, Lynn, Mermann & Rhymes, 1995).

In a study focusing on patients being treated for acute oncological diseases, (which one could suggest would be similar to patients within a terminal care setting), Larson (1984) administered an instrument (Caring Assessment Instrument CARE-Q) to 57 acute oncology patients. She asked them to rate 50 behavioural items relating to care, from most important to least important. The results of this study show that the first eight items were *monitors\ follows through*: rated first and second- (knows how to give I.V.s etc., and knows when to call a doctor); third- *accessible* (responds quickly to patient's call); fourth- *monitors\ follows through* (gives good patient care); fifth- *accessible* (gives patient's treatment on time); sixth- *trusting relationship* (puts patient first); seventh and eighth- *comforts* (listens to patient, talks to patient). Larson (1984, 49) relates these results to two previous studies on care; one a doctoral study of medical surgical patients (Brown; 1982 cited in Larson; 1984), and Ford's (1981 cited in Larson 1984) doctoral thesis on how professional nurses describe caring processes. She found consistency between her study and Brown's (1982) study for the first two items; and between her study and Ford's (1981) study on the identification of listening as an important caring activity. She concluded:

> ...for the majority of the patients in this study, demonstrated competency of skills precedes the patient's need to be listened to by nurses. Listening and talking, psychosocial skills highly valued by nurses, appeared to become important to these patients only after their basic 'getting better' needs were met
>
> (Larson; 1984, 50).

Brown's (1986) study of fifty medical-surgical patients examined examples of reported 'caring' experiences given by a nurse. Eight themes were described: *recognition of individual qualities and needs; reassuring presence; provision of information; demonstration of professional knowledge and skill; assistance with pain; amount of time spent; promotion of autonomy; and surveillance.*

Forrest's (1989, 819) phenomenological study of the caring behaviours exhibited by nurses identified two main themes: *Involvement* and *Interacting.* Theme clusters relating to *Involvement* were: *being there* (putting the patient first); *respect* (acknowledging the patient's presence); *feeling with and for* (responding to the patient's perspective); *closeness* (an attitude of confidence, hope and positiveness). Theme clusters relating to *Interacting* were: *touching and closeness* (testing for the need for physical contact and intimacy); *picking up cues* (how far to go); *being firm* (saying 'no'); *teaching* (telling patient's what they need to know); *knowing them well* (continuity and long term contact).

Brown's (1986) and Forrest's (1989) studies even though from the different perspectives of being-a-patient; and being-a-nurse appear to be similar in valuing more highly the expressive rather than instrumental qualities (qualities defined by Watson 1985); but contrasting with Larson's (1984) study (quoted above) where patients valued instrumental qualities.

Both Brown (1986), and Forrest (1989) used qualitative methodologies asking patients and nurses to describe their experiences; Larson (1984) used a quantitative tool requiring patients to rate aspects of care already defined.

The results therefore, do not suggest a consistency in patient opinion on care within the realm of 'general health care', reflecting that this is an area of great complexity.

In becoming familiar with these studies which have attempted to describe the type of care patients value, I am not convinced that they necessarily reflect how people who are terminally ill view and value their care. I believe that Larson's (1984) study using patients who had cancer does have some similarity in the type of diagnosis with people who are terminally ill. However the type, nature and focus of care given in a 'treatment' or 'cure' oriented model such as in acute oncology care, is vastly different from 'palliative care', and therefore the perception of valued care is resultingly different.

There is also a seminal and growing body of literature on the nature and explication of care within a palliative care institution (Saunders, Summers & Teller, 1981; Gilmore & Gilmore, 1987; Mor, et al 1988; Higginson, 1993; Hanratty & Higginson, 1994) .

However the experience and elements of care in the palliative care setting are not well defined (Fleming, Scanlon & D'Agostino, 1987). The hospice is said to be intrinsically involved with the notion of care and caring, the: "...agenda for caring for the dying ideally aims to promote living and even facilitate growth during the dying process" (Moller; 1996, 40). However Schmele (1995) expresses palliative care as a form of humanistic interaction which does not lend itself well to analysis. Helping people get ready to die is not well articulated. The interaction he described as caring, was undertaken in a: 'casual manner', and often by staff who were not seen as particularly highly educated (Schmele; 1995, 36). "They're not coming from a big body of literature, they're coming from their own life experiences" (Schmele; 1995, 36). Morris et al in Mor et al (1988) believe that the type of people that work in palliative care reflect an attitude of hope in their manner of caring: "This confidence may be further translated to the families and patients" (pg. 122).

"Care begins when difference is recognised" (Frank; 1991, 45). There is no one formula of action to suit all peoples. "The activities of caring have their basis in the carer's perception of the individual's needs or in the self articulated needs of the individual in a given situation at a given time" (Fealy; 1995, 1136), or as Fleming et al (1987, 234) say all people with cancer have very: "...individualistic needs, what they have in common is the universal need for comfort". Fleming et al (1987), and Bottorff, Gogag, & Engleberg - Lotzkar (1995), both establish comfort as being the major component of care in the field of palliative care.

Kubler Ross's (1970) stages of death and dying have been critiqued for placing people's dying process in a mould of sameness (Moller, 1996). From a historical viewpoint the stages were an enlightened and liberating model. Now we see that when the 'particulars' in a care situation are recognised that true care starts. "Care is inseparable from understanding, and like understanding it is symmetrical. Listening to another we hear ourselves" (Frank; 1991, 49). An individual's dying trajectory has its own 'particular shape', moving in its own time and matching no other individual (Glaser & Strauss cited in Moller; 1996, 63).

Frank's (1991, 1995) work has influenced my thinking from when I first listened to him speak in Hamilton, New Zealand in 1994. Frank speaks predominantly from his experience as a person who has faced two life challenging illnesses. He describes both his personal experience of treatment, and the facing of the threat to his mortality. Frank's (1991, 1995) writing arouses in me a sense of authentic experience, in relation to the life challenges I have faced. It is that sense of authentic experience that I wish to describe in this research. As with Frank, authentic experience can only be revealed by dialoguing with people who are currently experiencing being terminally ill.

But what is palliative care? Latimer (1991, 13), speaking about palliative care, believed that: "...care results in the patient being informed, comfortable, reasonably alert, and at peace, surrounded by a family that is receiving support and caring". There is research which supported these beliefs about the perception of palliative care (Sykes, Pearson & Chell, 1992; Bergin, 1992; Fakhoury, McCarthy & Addington-Hall 1996).

Four studies on the notion of the 'care' needs of patients where information is derived from patients (McDonnell, 1989; Arblaster, Brooks, Hudson, & Petty, 1990; Gates, Lackey & White, 1995; Greisinger, Lorimor, Aday, Winn & Baile, 1997), and a model of palliative care derived from care exemplars given by 'expert nurses' (O'Berle & Davies 1992), result in a different paradigm view of 'care'.

In McDonnell's (1989) qualitative descriptive study of patients' perceptions of care; when interviewed for the second time shortly after their admission to a hospice, *patients focused on their feelings and perceptions to a greater extent, rather than their physical symptoms.* McDonnell (1989) questioned whether this was because their physical symptoms had been successfully treated or was it: "...that patients found themselves in a system of care that was person-orientated rather than disease orientated?" (pg. 49). McDonnell's (1989) study bears some similarity to my research interest in that it focuses on the experience of palliative care within an in-patient hospice although using a different methodology and method.

Arblaster et al (1990) asked 40 patients to rank a representative range of nursing behaviours by Q-sort cards, attempting to determine helpful nursing activities, allowing the patient to make comments if they desired. The results indicated that patients favoured nursing behaviours which *were responsive to their individual needs*, including the need to *retain dignity and decisionmaking*. Patients also indicated the desire to be able to *remain at home as long as possible.* They favoured the use of *humour* in their care, and for the nurse to *be sensitive to them if they were 'down' or depressed.* Least favoured behaviours were attempts by the nurse to talk about death and dying, and sexuality.

Gates et al (1995) compared the needs of acute treatment cancer clinic and hospice patients using the 'Cancer Patient Need Survey'. Hospice patients identified their need of: *support, listening, communication, a patient caregiver, maintenance of dignity, practical support, how to cope with loss of control and needing something useful to do.*

Greisinger et al (1997) study, a three phase study, (two of which are completed); is designed to elicit by interview the major concerns of terminally ill patients. Phase two of the study required 120 patients to rate already identified concerns. The patients rated in order: *existential concerns,* including, sense of hope, life having meaning, having had a productive life; *spiritual concerns*, strength in beliefs, comfort in faith; *family concerns,* appreciation of family, being able to say goodbye to family, expression of feeling to family, knowledge that family will be all right without them; *physical symptoms*, knowing symptoms that could be experienced, knowing prognosis, being able to discuss prognosis with doctor; and *emotional concerns*, feeling restless.

O'Berle & Davies (1992) as a result of analysing exemplars of care related by recognised 'expert nurses', constructed a model of palliative care featuring '*preserving integrity'* as the central notion whereby nurses must maintain their personal wholeness before giving care; *'preserving integrity'* is surrounded by '*connecting'*- forming a bond with patients, *'empowering'*- helping patients build of find strength; *'finding meaning'*- assisting patients to make sense about their experience in the health system; and *'doing for'* - actions which maintain the connection between patient and nurse. Encircling these concepts is *'valuing'*-which is the context within which this relationship occurs (pg. 763).

There appears to be some consistency between the studies by McDonnell (1989), Arblaster et al (1990), and Gates et al (1995), in the valuing of the expressive aspects of care. Krakauer (1996) believes that the provision of palliative care is exceedingly complex requiring constant interdisciplinary re-assessment, and "...may require an intensity, aggressiveness, and ingenuity rivalling that of an intensive care unit" (pg. 30). Greisinger's et al (1997) study suggests this complexity of dynamic patient need includes the expression of existential needs; the measurement of which can be very difficult (Twycross & Dunn cited in Ling, 1997). O'Berle and Davis's (1992) model of palliative care appears to attempt to integrate a 'valuing' environment where both instrumental needs (the 'doing for' actions), and expressive needs ('connecting', empowering, and 'finding meaning') could be met.

A social construction of Palliative Care?

There are those who would question the philosophical underpinnings of hospice care and the claims that palliative care outcomes (e.g. symptom control, comfort) are better than those in other settings (James & Field 1992;

McNamara, Waddell, & Colvin 1994; Seale, 1989). Is it possible that people who have been cared for in a hospice are socialised to evaluate their care in a positive way? Moller (1996, 43) suggests a number of unanswered and searching questions about the nature and effect of palliative care similar to these below:

Does a certain 'type' of person choose to be cared for in a hospice? Does their personality dictate the experience of dying?

Do hospice patients pretend satisfaction with hospice care because it is expected of them?

Could it be that there are different meanings to care or caring, or could the different responses to care be a reaction to how people view their illness? Is there a social construction of caring; in particular a social construction of terminal care?

It seems significant that in McDonnell's (1989) study that the participants in their second interview focused on their perceptions and feelings rather than on symptom control which has been traditionally been considered to be the main output of palliative care.

Could the patients' past experience of illness and associated care affect their perception of the palliative care experience?

> Several authors have hypothesised that the meaning of illness directly affects a person's coping behaviour to that episode. The meanings of illness to an individual vary from episode to episode, but most people reflect their past personal experience, knowledge and personal background
>
> (Pfifferling; 1981, 215).

There is a relationship between how persons view their illness and care resulting from a previous experience of somebody else with that condition (Pfifferling, 1981). As the palliative care movement develops and expands further, and with an ageing population, there will be even more potential for a personal contact with another person receiving palliative care; thus both disseminating the principles of palliative care, and that of the individual experience of palliative care, both good and bad. Outcomes of this personal exposure may be that: "...meaning is often influenced by feelings a patient harbours towards someone significant in his past, especially if that person had similar symptoms or disability" (Stoeckle & Barsky; 1981, 225). Does this mean that people will be socialised to act in a prescribed manner when receiving palliative care?

In future times in assessing patient need, we may need to be: "... taught to elicit and "decode" patient's semantic networks, to uncover the personal and evaluative meanings that provide the context for the patient's experience"? (Good 1977 quoted in Good & Good; 1981, 166).

Lipowski (cited by Pfifferling, 1981), Rogers(1991) and Kleinman (1985), amongst others have constructed ways of understanding the meaning of illnesses. They suggest the response that a person makes to illness, (and I suggest too, the ultimate experience of a terminal illness), is exceedingly complex, involving all manifestations of the human response: physical, psychological, spiritual and emotional.

> ...we experience symptoms not just with sensations of pain and deliberate choices in help seeking, but with unsettling questions of bafflement and suffering that are freighted with feelings, beliefs and relationships that cannot be divorced from sickness, because they are integral to psychophysiological processes constraining both the course of the disorder and the response to treatment
>
> (Kleinman; 1985, 140).

Lipowski (cited by Pfifferling; 1981, 215) suggests categories as a way of understanding how people view their illness and which strategies (both positive & negative) they utilise in response. Parker (1992) similarly discussed the roles people adopt when faced with the challenge of hearing a cancer diagnosis. Rogers (1991) suggests a similar model whereby people evaluate their viewpoint towards illness and health; thus adding a layer to the notion of a social construction of care and terminal care, and the power values attributed to the notion of care vs. cure.

My research has no direct focus on the social construction of palliative care. However the suggestion that palliative care has a social construction informs my interest in pursuing the notion of hearing the patient's authentic voice. It is from the patient's individual experience that questions of the expectation of care, and behaviour related to environment and care might be addressed.

It appears to me that the community in general have played a unique role in the development of palliative care. The originating hospice movement relied on proponents to advocate the merit of its work in order to gain social acceptability. As well, these people were relied on to raise large amounts of money to support the giving of care. Many were ardent volunteer supporters who wholeheartedly and uncritically accepted the philosophy of the hospice.

Initially hospices had strong links with religious organisations (particularly Roman Catholicism: Sisters of Mercy, and the Little Company of Mary in New Zealand). As I discussed in the previous chapter, I believe there are similarities between the accepted 'hospice philosophy' of care, and the Christian doctrine of unconditional loving care. However these religious links have until recently contributed to an unchallenging attitude by supporters and palliative care health professionals, regarding the structure, organisation and philosophy of palliative care.

Palliative care services in New Zealand in the last decade have become increasingly independent of both the community and religious proponents of care. Some hospices would say they still rely heavily on both these sources for support, and that such support is integral to their philosophy of care. Some hospices appear to have attempted to rely more heavily on government funding and corporate sponsorship. What overall influence has this had on the development of the hospice and palliative care service in New Zealand and world wide? It is possible that these questions will only be answered with the passage of time. I believe that over the last decade and probably accelerated by the health reforms of the nineteen nineties, hospices and palliative care services in New Zealand have voluntarily placed themselves within a more critical gaze in terms of examining the provision and evaluation of care.

To this overall analysis, must be added the political dynamic. Waitzkin (1981) believed that within the last century: "...the goals of medicine shifted from caring to curing" and that the "...emphasis moved away from the nuturant support for a person under physical and emotional stress" (pg. 339). Implicit within this statement is the change in focus from care to cure, with resource allocation favouring 'cure', and as well the bureaucratic and political devaluing of care. Ironically, the number of diseases that we can cure has been dramatically reduced, and those that we cannot cure but can give continued care for, the chronic health problems of the world has escalated (Waitzkin; 1981).

As in other countries, Aoteoroa\New Zealand has fought for the provision and equitable allocation of funding of palliative care (see Chapter Two); those who work with and alongside people who are terminally ill, have taken on the advocacy voice to ensure the survival and development of this core service.

Who speaks the consumer's voice in defining quality in palliative care; the patients themselves or the family\close friends?

What is the responsibility of the ill?

> It is to witness their own suffering and express this experience so that the rest of us can learn from it. Of course others must be willing to learn; society's reciprocal responsibility is to see and hear what ill people express. ... Life without illness would not be complete, it would be impossible
>
> (Frank; 1991, 122\128).

There is only a small body of palliative care literature which speaks the patient's voice or describes their unique experience (McDonnell, 1989; Arblaster et al 1990; Bergin, 1992; Gray, Fitch, Greenburg, & Shapiro, 1995; Schmele, 1995; Gates et al 1995; Bullivent & Reeve, 1996; Halldorsdottir & Hamrin 1996; Greisinger et al 1997).

There has been great concern that patients in the last days of their lives should not be troubled by interviews about aspects which will have no long term impact on them. It has been felt that their own personal and existential concerns were paramount. Ethical issues have been identified similarly. Interviewing patients at this stage in their life is argued to be too intrusive and unfair. As a consequence of this thinking, family and friends have been asked to make judgement for the patient on many aspects of terminal care (Addington-Hall, MacDonald, Anderson, & Freeling, 1991; Sykes, 1992; Field, Ahmedzai & Biswas, 1992; Kristjanson, & Ashcroft 1994; Fakhoury, McCarthy, & Addington-Hall, 1996).

> ....the majority of studies of satisfaction with palliative services has used carers as their information source. In the context of terminal illness this avoids the clear methodological and even ethical difficulties raised by using the patient to gain information

(Sykes; 1992, 233).

However, and with justification another argument is put forward. Only patients undergoing care can describe their own experience. Mermann (1996, 55) says: "...if anyone knows the need for compassionate care, and how to provide it, it is the patient who is seriously ill". The experience of the family is different and represents other influences such as anticipatory grief, conflicting pressure of other responsibilities, and the sensory impact of not only the dying loved one, but other patients within the setting (Gray et al 1995; Wakefield & Ashby, 1993).

Gray et al (1995) when describing their experience of seeking the collaborative viewpoint of people with cancer, stated:

> The desire to speak accurately on behalf of as many consumers as possible was tempered for some participants by concerns about potential for inappropriate representation. ...one cancer survivor recommended that family members never attempt to represent patient\survivor concerns, because of critical differences in perspective. A community representative spoke of her inability to speak for patients\survivors or family members. (pg. 30)

Giordano (1994) in an editorial entitled 'Quality is in the eye of the consumer' says: "...we must remember that consumers do not always define quality of care the same way we (the nurses) do and that consumers' perceptions of their care are the actual outcomes" (pg. 795).

Review and summary

Within this chapter, I have focused on literature relating to the philosophy and social construction of palliative care, and how palliative care is perceived by its patients. Palliative care originated in response to a need for quality terminal care of the dying; it was quality driven. However contemporary quality management philosophy and measurements do not appear to 'fit' well with the indicators required to measure quality palliative care.

Patients and health professionals are beginning to describe their perception of quality palliative care. There are some similarities and generalisations that can be made. Many palliative care health care professionals believe that patients should be allowed to participate in research about their care, and recognise the benefit that increased knowledge could provide (Mermann 1996; Gray et al 1995; Wakefield & Ashby, 1993).

Discussion regarding the social construction of patients' response to palliative care adds another dimension to the interpretation of quality care. This discussion cannot be ignored; it augments the need to further understand patients' lived experience of palliative care.

Within Chapter four, in order to explain the influence that my interest in health quality improvement has had in the development of the research question, I include a discussion of contemporary quality improvement literature. I review the patient's experience of care; the significance of understanding the patient's experience; quality- technical competence or caring; and participation and power in care, highlighting the need to include patient evaluation in the improvement of service delivery.

Chapter Four

A review of the literature on quality and patient care.

Introduction:

This chapter reviews quality management literature related to consumer satisfaction with service, particularly relating to the health care service. In deciding to separate this literature from that which focused on palliative care, I have attempted to provide a background and elaboration of my particular interest in generic health quality management, and provide some detail of the current issues which could inform the development of palliative care quality management. I firmly believe that knowledge of the principles of quality improvement augment the ability of health professionals to make informed decisions about the method for, and necessity of evaluating patient care. This belief influenced the literature reviewed in this chapter because it focused particularly on the consumer.

The chapter focuses on the importance of the patient's experience of care; the significance of understanding the patient's experience of care; quality- is it technical competence or caring?; and the issues of participation and power in care.

The patient's experience of care; how important is it?

The connection between caring, quality, and outcome is firmly established within contemporary nursing literature. Caring is said to have a direct connection with the clinical outcome. If patients feel cared for, they exhibit a high degree of patient satisfaction (Miller 1995; Snyder 1993; Price 1993; Sykes, Pearson, & Chell, 1992; Young, Minnick, & Marcantonio 1996).

In a study of older adults within hospitals (Bliesmer & Earle; 1993), the subjects rated their 'quality' criterion as: "Good staff attitude, nurses attentive\cheerful\listening" (pg. 31); which is the caring component of nursing practice. Thomas, MacMillan, McColl, Priest, Hale, & Bond (1995, 153) in developing a patient defined satisfaction scale found nurses' manner, attentiveness, availability, and reassurance ranked most highly. This vital connection between quality and nurses has been emphasised and supported by many other studies which show consistency in their results (Bliesmer & Earle 1993; Fine, 1988; Miller, 1995; Snyder, 1993; Price, 1993; Sykes et al 1992; Beck & Larrabec, 1996).

However there is reservation expressed on the causal connection between quality, caring and outcome by Ludwig, Ryan, Johnson, Hennessy, Gattuso, Epsom and Czurylo (1993). They believed the: "...relationship between caring and quality is unclear ...and the effect of caring on patients' outcomes is not well understood" (Ludwig et al; 1993, 43). The authors proposed that further work needed to be undertaken to establish the patients' definition of quality, care and caring; and to compare patient satisfaction with quality care. It is this link that I have had concern with, and that concern influenced me to undertake this research. Are patients satisfied with care that is less than ideal? Are 'vulnerable patients' such as people who are dying, so grateful because of the relief of their physical symptoms, that they do not question other aspects of their care?

There is a concern that standardising care and auditing to a given measure, which is demanded in traditional quality assurance, will stifle the creativity essential in respect of individual circumstance or need. "Consumer focused care must be individualised. Standards and rules developed to reduce errors and ensure safe care may, therefore, inadvertently restrict or prevent this process" (Snyder; 1992, 209). This concern with respect to individuality is specifically addressed in the previous chapter of the literature review in relation to the specialty of palliative care. As a health professional auditor, I share this concern as well. In general terms I believe that an undue emphasis on auditing, and the devising of prescriptive standards and protocols of care characterises immature quality management systems. It is part of an evolutionary process where a health care organisation uses these processes in an attempt to involve all staff, and to create clinical 'best practice' guidelines; moving onto a fully integrated quality management approach whereby all practices within an organisation are critiqued. I am always pleased to see health professionals creatively incorporating quality improvement principles, positively critiquing their professional work, and developing their own quality improvement projects without relying on auditing processes alone to identify deficiencies.

Of concern to me as well, is the need to validate 'caring' aspects of the health professional's work by quality improvement theorists. These 'caring' aspects are often process related, and difficult to quantify; an aspect that I have discussed in the previous chapter. It is these unquantifiable caring acts which characterise the nature of palliative care. Nursing as a professional group, has as well been challenged to define these aspects of 'caring'; as they have been said to be key expressions of nursing (Watson 1985).

> Because standards have been easier to define and data have been more readily available, more attention has been given to the technical aspects of care than to the neglect of the interpersonal relationship. However the provider's success in meeting the client's values and expectations is reflected in the client's satisfaction or dissatisfaction with his or her care, compliance with suggested treatment modalities, and subsequent outcomes
>
> (Meisenheimer; 1991, 41).

A contemporary aspect within the discussion on patient outcomes and quality care, and which I only briefly outline within this study, is the intersection between quality patient outcomes and the cost of 'caring' (Nyburg, 1989, Nyburg, 1990; North, 1995; O'Connor, 1995; Valentine, 1997). This is a complex area, resulting in what is viewed as inherent conflict between health professionals and health administrators; yet as Valentine (1997, 71) states:

> the economic forces of health care are integral to the effectiveness of nursing care delivery... both costs and quality need to be addressed because they relate to patient outcomes.

Nyberg (1989, 1990) states her belief in retaining of the principle of quality health care: "Economics and human care must be viewed as interrelated forces within today's hospital environment ...in the final analysis, there is no substitute for professional commitment and accountability. Quality of care remains our highest mission" (pg. 17). I believe that Nyberg is adopting a moral position, although not a popular position with health policy makers and health administrators. Nyberg's position aligns with my discussion in Chapter Two, The history of the hospice movement, where I discussed the changes wrought by the health reforms in New Zealand (1991- ongoing), and identified my belief in the need to provide certain types of care (including terminal care) without undue emphasis on the output.

The significance of understanding the patient's experience

Literature reviewed on patient and consumer satisfaction highlighted the current debate about the perceived importance and significance of obtaining and using patient feedback to effect change within health care structure and delivery.

On the one hand it is believed to be critical to the survival of the contemporary health system. If administration and clinical health professionals listened to the voice of the patient, both would benefit (Chaston; 1994). Patients have always been expressive about their experiences but until recently, health professionals have not consistently listened or given value to their opinion. "We are hearing the same stories but with new ears and with new research methods and we are gaining new insights" (Morse & Johnson; 1991, 341).

It could be argued however, that at present, the management of the health service determines what the patient should want, and develops their service quality standard accordingly. Zeithaml, Parasuraman & Berry (1990, 51) say: "Despite a genuine interest in providing service quality, many companies miss the mark by thinking inside out- they know what customers should want and deliver that- rather than the outside in". Young et al (1996) agree that there is a 'gap' between: "...patients' actual values and what health professionals perceive as patients' values" (pg. 18). This results in a mismatch of service delivery where health providers': "...motivation to meet these expectations does not closely approximate the value their patients' place on these aspects" (pg. 18). In my experience, it is well meaning yet paternalistic health professionals, particularly medical practitioners who have made these judgements. Medical clinical education until recently has placed a disproportionate time on diagnosis and the administration of correct clinical practice, with little emphasis on how the patient may view the experience of health and illness within their world (Pfifferling 1981).

Many are convinced that even though the health consumer is not always able to make a textbook objective judgement of 'quality care', that doesn't mean that they can't make an excellent intuitive judgement (Spitzer, 1988; Norman, Redfern, Tomalin & Oliver, 1992; Avis, Bond & Arthur, 1995; Mahon, 1996).

> The fact that there is no standard measure of quality of care does not mean that people do not know what quality is. A hospital may be the

> best in town, but if it is perceived as a loser, consumers will stay away in droves
>
> (Spitzer; 1988, 33).

The involvement of patients in determining the priorities in their care is paramount. Unless there is a 'fit' between the 'expressed' needs of patients (their definition of quality care), and the need of the health care staff to provide care according to patients' health status, dissatisfaction with the service will be perceived (Bliesmer & Earle; 1993). "Satisfaction with nursing care occurs when the consumer's health care expectations are congruent with his or her perception of what he or she actually received" (Megivern, Halm & Jones cited in Snyder; 1993, 206).

Nurses, administrators, and consumers have different perceptions of quality. Nurses ranked it as: technical\physical care competence; information source; leadership abilities; and professional creativity (Hinshaw & Oakes in Meisenheimer; 1991, 45. Health administrators believe satisfaction to be "...an attitude that reflected the degree of congruence between clients' perceptions of nursing care received: the ideal versus the real" (Risser cited in Meisenheimer; 1991, 45). Three aspects of 'satisfaction' have been identified by Risser: technical-professional factors, skills to perform the task; educational relationship, ability to meet the patient's education needs; and trusting relationship, the essence of care.

Patients perceive that quality care by nurses is the providing of: personalised care; information source; technical competence; and professionalism (Meisenheimer; 1991). There is not one single bench mark of quality care; patients perceive it at as a variety of aspects (Young et al; 1996).

It is this aspect of patients' perception of care which I wish to look at in this thesis. I too question whether care and particularly palliative care, is viewed congruently by 'funders', 'providers', and 'consumers'. The differences between perception of quality of identified within the literature could reflect different 'gazes' on the same reality, or could the reality of care be conceptualised in different ways?

It is also important to consider what influences patient expectations. Research has shown that patients' expectation is altered by their previous experience with a service provider, their experience with a competitor service provider, and their experience with service providers in general (Avis et al 1995). Zeithaml et al (1990, 125) say we need to let "...customers know what is, and is not possible and the reasons why". Thus a realistic expectation is established prior to admission, however this must never be used to provide excuses for poor care.

> If the patient is to be served, then he or she must have a voice in the process of medical care. Satisfaction has therefore come to be seen as a legitimate and desired outcome in itself, not solely as a means of improving compliance. It has become an attribute of quality, a legitimate health goal
>
> (Williams; 1994, 510).

This is of relevance to the patient's anticipated experience of palliative care. Patients usually have had a previous experience of care (usually for diagnosis and acute treatment) within a public or private acute care health setting, thus colouring their expectation of what might be provided by another health care agency. Other contributing factors may be media messages regarding palliative care, and the personal experience of another person receiving palliative care.

At present, many healthcare agencies base their service quality in response to patients' 'complaints' regarding care (Kock & Fairly 1993). An oft quoted piece of research undertaken in Washington D.C. revealed that only 4% of clients complained regarding poor service, but these 4% told 9 or 10 others of their bad experience (Zeithaml et al; 1990, 54). "When patients are disappointed in their personal relationships with the physician, nurse and other providers of care, they may be more likely to be unco-operative in their own treatment. This non-compliance in turn may have negative consequences on patients' quality of life" (Morris, Sherwood, Wright, & Gutkin in Mor, Greer & Kastenbaum; 1989, 111).

Conversely, there are those who apply a degree of cynicism to the process of patients being able to affect change, declaring it tokenistic and misleading (Gray, Fitch, Greenburg, & Shapiro, 1995; Avis 1994; Avis et al 1995; Fakhoury, McCarthy & Addington-Hall 1996. In speaking about consumer involvement Gray, et al (1995, 31) said:

> Alongside the dominant hopeful messages were many other messages, qualifying success and cautioning about how consumer participation can easily be compromised or derailed. These messages must be attended to, so that an uncritical and naively optimistic perspective does not continue to dominate the literature related to consumer involvement in health care.

Fakhoury et al (1996, 728) were even more direct saying that caregivers often give false\misleading information on satisfaction surveys, because they believe: "...that nothing will change as a result of complaining about the services".

Although I believe that the above experience will resonate with some heath management personnel who give lip-service to the process of surveying their patients, I believe the opposite predominantly exists in the New Zealand health service. I have noted that in health care organisations committed to quality management practice, administrators and senior clinicians were genuinely interested in the comments that patients made in patient satisfaction surveys. I have seen attempts to contact patients and family members if able, and the investigation and rectification of a concern or problem if possible.

Criticism is also made of the process of surveying patients (Williams 1994; Fitzpatrick & Taylor, 1994). Williams (1994) stated consumer satisfaction tools are constructed on a false premise and force:

> ..service users to express themselves in alien terms; consequently, inferences made from their results may misrepresent the true beliefs of service users. The original motivation behind satisfaction surveys was to introduce some element of consumerism and accountability to health care; however through high levels of relatively meaningless expressions of satisfaction, an illusion of consumerism is created which seldom does anything but endorse the status quo (pg. 515).

Patients are often asked to rate or rank items which may not have held any relevance for their particular care e.g. food or parking, whereas the important issues to them such as communication, and discharge planning are not included in the survey. The patient can be led to believe that because their concerns were not included within the survey, they are not considered important by management, as Fitzpatrick & Taylor (1994, 35) say: "...they assess service performance against criteria which may not be sensitive to the concerns of the patients".

In fact the survey may be entirely incorrect:

> ...the expression of satisfaction may not necessarily mean that a critical evaluation has taken place: it might just as well be an expression of the non-existence of opinion and/or an acceptance of medical paternalism... While some patients might critically evaluate their care the majority of studies suggest that most service users are very uncritical of it, allowing care to be of very low quality before expressing

> dissatisfaction
>
> (Williams; 1994, 513).

It was noted too by Williams (1994), and Avis et al (1995) that quantitative measures of patient satisfaction were often high. However the accompanying narrative revealed a disturbing level of disquiet with diverse aspects of the health service. In my experience with patient satisfaction surveys, I would agree. Thus a patient may on the one hand score the service highly by quantitative survey, but on reading accompanying comments have many significant and unresolved issues.

> Compelling reasons have been advanced for involving the patients' perspective. One of the reasons is that publicly funded health services are often in a seller's market where patients are restricted by financial mandates to select alternative services based on consideration of cost and quality
>
> (Kerssens (1994, 344).

"...consumer reactions can provide prescriptions for action for improving services that are beneficial to clients and the health care system as a whole" (Taylor et al cited in Price; 1993, 34). However what the patient wants from service and care is often very different from what the professionals and the administration believe they do (Bullivent & Reeve, 1996; Snyder, 1993; Young et al, 1996). Young et al (1996) believe that an increasing number of hospitals utilise customer satisfaction measures within their quality improvement processes. They believe that an "...error in definition" may cause patients' goals or needs to be unrecognised or unmet (pg. 19). This error in definition results from staff inability to recognise what aspects of care patients truly value. Snyder (1993) encourages the development of collaborative and congruent goals between patients and health professionals to redress the definition of valued care:

> When the focus of care is directed toward what the consumer views as important, interventions are more likely to be perceived as supportive. A match between perception of what is needed and what is actually received affords the consumer a sense of confidence in the care provided by the nurses
>
> (Snyder; 1993, 206,207).

The most successful businesses and service industries harness the power of the client to direct their services:

> ...goals set by these companies are based on customers' requirements and expectations rather than internal company standards....sometimes service companies are measuring and monitoring standards for features that customers do not care about while ignoring features customer do care about
>
> (Zeithaml et al; 1990, 83).

It is said that the giving of previously restricted health information such as the results of national hospital quality indicators including morbidity, accident, and nosocomial infection rates gives the patient far more power than in the past (De Back & Waite; 1988). "This information places the consumer in the role of evaluator of the services ... consumers have increased their confidence in identifying hospitals which provide good service" (Fine; 1988, 68).

This may be so in the United States where private medical care predominates, with consequent increased competition among providers and resulting choice for insured consumers. Within New Zealand quality indicator information has only recently been collected by the Crown Company Monitoring and Advisory Service (C.C.M.A.U.), since 1993. Some of this information is available to the public; some is available only to Crown Health Enterprises. Private health care is becoming increasingly competitive, but mainly to those who have medical insurance. The majority of New Zealanders would see themselves as having no choice but to use public health facilities. Certainly there is minimal choice in palliative care services. There would be few situations in New Zealand because of our small widespread population, where more than one palliative care service was available.

Nocon & Qureshi (1996) cite Hirschman's (1970) belief that the patient has two ways of exerting power within the health arena: 'Exit', the ability to take their business elsewhere (not possible within the New Zealand palliative care service), and 'Voice', using the democratic process of being able to influence the providers by request. Nocon & Qureshi (1996) take this latter position in actively advocating the empowerment of patients, by restructuring the health service in order to redress the position of power held by health providers. In this way:

> ...users and carers will be enabled to exercise the same power as consumers of other services. This redressing of the balance of power is the best guarantee of a continuing improvement in the quality of service (pg. 48).

Some argue however, that patients and the general public do not want to be involved in their care, but only 'to be done to' (Avis 1994; Williams 1994; Toms 1992). One impediment to participation derives from: "...patients' lack of demand for involvement ... This inconsistency may be related to the inherent paternalism of centralised health services, where the patients' role has often been defined as the grateful and passive recipient of care" (Klein in Avis; 1994, 290). "...although the role of the patient is changing gradually, most people receive health care passively, rather than actively participating in it" (Sharf in Toms; 1992, 1493). Fatigue and lack of energy characterise terminal illness, yet it is my experience that people wish to be given information and offered choices.

Quality: technical competence or caring?

The literature reviewed was inconsistent in its conclusion of how patients describe 'quality care'. Health care professionals, particularly nurses are reported as thinking that caring aspects rank more highly than technical skills (Miller, 1995; Hinshaw & Oakes in Meisenheimer, 1991). Literature reviewed referred to patients in a variety of health care settings, homecare to psychiatry (Miller, 1995; Price, 1993; Ludwig-Beymer et al, 1993; Sykes, Pearson & Chell, 1992; Meisenheimer, 1991).

The complexity of 'quality' is shown in definitions of quality care. Parents in a study describing quality in paediatric care talk of: "...an assumed trust in the technical abilities of the nurse" (Price; 1993, 39). Whereas in Miller's (1995) study the discrepancy or 'gap' between health professional and patient 'view' is highlighted: "...although professional nurses sometimes view themselves as providing quality care through technical competence, patients define quality as combining competence with caring skills" (Miller; 1995, 31). In Hansson, Bjorkman, & Berglund's study (1993, 41) patients rated the most important qualities of care as: "...staff empathic qualities: being caring, interested and understanding, respecting patients, devoting time to patients, and creating a safe treatment environment". In a study of caregivers of terminally ill people, family members giving care said: "The professions and services caring for the dying people judged as much on their degree of humanity and honesty as on technical or clinical excellence" (Wakefield & Ashby; 1993, 536). The quality improvement study referred to in the introduction and undertaken by Stroh (1995) in New Zealand, revealed a similar theme of caring which Stroh described as "...a quest to put patient and family first at all times and for excellence in practice" (pg. 4).

Leino-Kilpi & Vuorenheimo (1994) believe a major challenge for nursing exists in developing an evaluation tool which elicits and measures the human-orientated activities such as respect and care. They say: "...given the obvious difficulty in measuring the human element of the quality compared with the technical element, it is clear that new innovative measurement tools are needed." (pg. 93).

Participation and power in care

It appears that patient satisfaction with caring and therefore quality, is reliant to a greater extent on the congruence of needs being identified and met by the care givers as stated above, and to a lesser extent by the encouragement of the patient to participate in their care (Avis, 1994; Klein in Avis, 1994; Snyder, 1993; Jewell, 1994). Participation in determining the mode of care, given and received, is believed to result in empowerment of the patient, greater compliance in care, and therefore to greater patient satisfaction (Jewell 1994). "Participation has been demonstrated to help patients, and their relatives, manage health problems more effectively" (Avis; 1994, 290).

For some patients it is not a problem to insist on involvement in care. "...people who receive health care today want to take an active part in deciding what they need and the type of care they will require. They are consumers of a product with which they are intrinsically involved" Snyder (1993, 206). However for some, the influence of the paternalism of the medical and probably other health professionals is very strong, and inhibits them from participation (Avis et al 1995).

> Even individuals with the capacity to speak out and act assertively, described difficulties in overcoming perceived lack of status ...Facilitators need to be especially aware of any disrespectful behaviour of professionals towards consumers and must intervene to ensure a context of safety and mutual respect.
>
> (Gray et al; 1995, 32)

Although there are limitations in the ways that those who are terminally ill can participate in their care; it is my experience in clinical palliative care, that even in the last days of life people still want to take part in (limited) aspects their care. Often these aspects of care relate to personal aspects of physical care such as washing their own face, or in relation to a loved member of the family, such as asking to be woken when their partner arrived.

Review and summary

Within this chapter I have attempted to identify the quality management issues associated with the location of the patient's opinion, their expectation of care and quality clinical and administrative issues.

Although there appears to be agreement that an organisation should seek patient opinion regarding care, there is debate about how honest and appropriate the results are, and how this information should be used. Contemporary literature suggests it is very important to both the satisfaction of the patient, and the survival of each health provider

There is also differing opinion between health providers and health consumers regarding the constituents of quality care. Nurses particularly appear to favour the expressive elements of care. Patients in general health care tending to favour instrumental (technical) aspects, or a mixture of instrumental and expressive.

In chapter five I will discuss the nature and components of the qualitative-descriptive-phenomenological methodology; particularly looking at van Manen's (1990) method, and why I decided it was appropriate to adopt this approach. I shall follow by describing the process through which I undertook the research.

Chapter Five

The Research Process: the methodology

Human science seeks to know the reality which is particularly our own: "...the questions merging from clinical experience frame conversation and determine research design..." (Miller & Crabtree; 1994, 341).

> ...research is always personal, political and spiritual: knowledge is always from a perspective and for a purpose
>
> (Reason; 1994, 333).

Introduction

In this chapter I will discuss the theoretical framework underpinning the qualitative-descriptive-phenomenological methodology I have used, and describe the method I used to collect the data. To explicate these methodologies, I shall briefly outline my understanding of qualitative methodology, focusing on descriptive methodology, and then phenomenology particularly as defined by van Manen (1990), finally discussing the use of both. It was my hope to use a methodology which created

> ... an open research space that celebrates qualitative and critical approaches to the clinical world providing the tools necessary for discovering and confirming clinical stories and knowledge within this space, identifying and describing the means for sharing the stories and the knowledge
>
> (Miller & Crabtree; 1994, 341).

Qualitative methods:

> ...(allow) exploration of humans, by humans in ways that acknowledge the value of all evidence, the inevitability and worth of subjectivity, the value of a holistic view, the integration of all patterns of knowing into the whole of knowing, the limitations of empirical evidence in relation to studying humans, the value of ethical justification, esthetic criticism, and personal introspection and the limitations of the meaning of statistical significance
>
> (Chinn, cited in Taylor; 1993, 173).

> ...(are) convincing if the methods are appropriate for the question and the investigator's relationships with informants, data, and audience are clearly addressed; if the audience recognises itself in the findings; and if the question and results matter to the clinical participants
>
> (Miller & Crabtree; 1994, 349).

The underlying ontology, epistemology, and methodology of quantitative and qualitative methods differs. The ontology of quantitative methodology is based on humans being able to be examined by component (bio\psycho\spiritual), and who are seen as a sum of their parts. In contrast the ontology of qualitative methodology described humans as unitary, in constant process with the environment and universe as a whole; and are different from and greater than the summed parts (Parse, Coyne & Smith; 1985). Epistemologically, quantitative method constructs variables which allow for comparison. It is considered value- free, maintaining objectivity; whereas qualitative method views the descriptions of participants as patterns of a whole. The goal of quantitative methodology is to test hypotheses, to provide a non-biased approach to testing theory. Qualitative methodology is viewed as the process between researcher and participant, with minimal control by the researcher, aimed at uncovering meaning or recognising themes\patterns thus giving a description of humanly lived experience.

The qualitative methodology used in this research is *descriptive* informed by *phenomenology* (specifically the hermeneutic-philosophic approach developed by van Manen 1990).

Descriptive methodology

Qualitative descriptive method originated within the social sciences and is not governed by a specific ontology, however it is said to be generically phenomenological (Parse, 1995).

The aim of descriptive research is to reveal information about a group of people, a situation or a procedure (Carter, in Cormack, 1996). Parse, Coyne & Smith (1985, 92) defined the result of the descriptive method as "...yield(ing) findings based upon conversations and observations". It is designed to focus on the meaning of an event in time, including its location within the past and prospectively towards the future. It examines the contextual and individual perceptions of the event or phenomenon. Typically the method is exemplified as a case or exploratory study. The type of information revealed can range from objective facts such as demographic information about a group; to: "...subtle and personal realms of human experience such as feelings or attitudes" (Carter in Cormack, 1996, 180).

The descriptive method is said to contain five elements (Parse, Coyne & Smith 1985; Porter in Cormack, 1996).

1. Identifying the phenomenon. The phenomenon which can start as a general idea, provides the context and basis for the evolution of the study.

2. Structuring the study. A conceptual framework is identified or developed, including all aspects of the study design. The conceptual framework of the study design: "...describes the phenomenon from a particular paradigmatic perspective of nursing and, as such, guides the subsequent phases of the study. The conceptual framework is a creative synthesis invented by the researcher It arises from disciplined persistence in coming to know and understand the phenomenon" (Parse, Coyne & Smith 1985, 93). In qualitative research the question is skeletal in form; waiting to be filled in, and filled out by the expression of the participant's lived experience (Oiler; 1982).

3. Gathering the data. Interviews are open-ended and directed toward uncovering the meaning of the lived experience.

4. Analysing the data. The participants' narrative is examined looking for themes which explicate the objectives of the study. In analysing and interpreting the lived experience of others the researcher must be intimately involved in the setting being studied. "Qualitative researchers are required to interpret as accurately as possible the experiences, meanings and motives of subjects, from the perspectives of those subjects" (Porter in Cormack, 1996, 117).
Acknowledging one's own understandings that may cause an effect on the interpretation of the data is an important component of creating authentic writing. The reader does not need to make assumptions about the researcher; there is a clear route of understanding.

5. Describing the findings. The major themes are transformed to a higher level of discourse in the move from the subjects' language to the language of the researcher (Parse, Coyne & Smith 1985).

Phenomenological methodology

Phenomenology is a philosophy, a philosophical approach and a research methodology. Husserl (1970) the originator of phenomenology, focused on the epistemological question of: "How do we know what we know?" (Ray; 1994, 118). Phenomenology as explicated by Husserl (1970) attempted to respond to the claim that: "...scientific knowledge had somehow wrenched itself free of subjectivity" (Anderson, Hughes & Sharrock, 1986, 83).

Husserl (1970) examined the notion of *a priori* knowledge; that which exists in the mind which does not derive from inductive (subjective) thought and concluded that all knowledge is rooted in the conscious. "Reality is to be found in people's minds, rather than in external objects" (Porter in Cormack; 1996, 115).

Husserl (1970) postulated there were two means of thinking, the natural attitude whereby there is a world of knowledge which can be obtained, and the philosophic mind. The philosophic mind is based upon the questioning of all presumptions: "By extending the premise of doubt to all presuppositions, philosophy can transcend the natural attitude" (Anderson et al, 1986, 85). Such transcendence from the natural to the philosophic attitude, Husserl named epoche or phenomenological reduction (Ray; 1994, 119). Embedded in this notion is 'bracketing' whereby pre-existing theory about or attitudes to, the phenomenon under study are overtly stated and deliberately put aside whilst the research is undertaken (using a presuppositionlessness approach). Thus Husserl's overall aim: "...was the avoidance of all conceptually bound and theoretically constructed beginnings" Ray; 1994, 119).

Heidegger, a student and critic of Husserl, further developed phenomenology upon Husserl's original assumptions, but focused on the ontological question: "What is being?" (Ray; 1994, 118). Heidegger however did not believe one could abstract the notion of consciousness (bracketing) and examine it as separate from the world. In contrast to Husserl's construct of presuppostions, Heidegger believed these should not be: "...eliminated or suspended, but are what constitute the possibility of intelligibility or meaning"; they are legitimate aspects of Being (Ray; 1994,120). He believed that there were essential or primal notions of being which could not be ignored: "...our separation from others, our anxiety about the future, our fear of the uncertainty of death" (Anderson et al 1986, 95). To him human reality was the possibility of existing within the world.

'Dasein'; 'being there', was the term he used; 'being' used grammatically as a noun. Such being exists in a historical sense; it is communicated in language which itself is historically driven. Because our being is located within the past, and the here and now, it cannot be abstracted. Because of coexistence as humanity; we share meanings and an understanding of the world and its practices. Heidegger defined this phenomenon as "the clearing" (Heidegger; 1927\1962 cited in Plager; 1984, 69).

In later times Heidegger refined and redefined this concept to encompass local and focal clearings that are unique for groups of people or individuals. We are: "...dialogical beings engaged in our world through a shared community understanding that is for the most unarticulated" (Taylor in Plager 1994, 70). For Heidegger, interpretation was the key to the development of understanding and reality.

Other philosophers who have written about phenomenology such as Gadamer (1975), Ricoeur (1981), Merleau-Ponty (1974), and Van Manen (1990) have extended and advanced the notions of 'lived experience'.

Van Manen's phenomenological approach is said to be a blend of: "Husserlian and Heideggerian philosophical underpinnings..." (Plager; 1994, 78); reflecting a background in the Dutch (Utrecht school) and German philosophic traditions. The research method: "...clearly articulates the relationship of phenomenology, hermeneutics, semiotics, and a research process of textual reflection that contributes to understanding practical action" (Ray in Morse, 1994, 122). Thus it interrelates description, interpretation, language, and the research process of considering 'lived experience', integrally linking the results to everyday living.

Van Manen's method *(1990: 30-31)*

To explain van Manen's (1990) method further, I have detailed its components, and as well my response as a researcher in considering their use.

> 1. *turning to a phenomenon which seriously interests us and commits us to the world (pg. 30)*

The phenomenon is often a subject that has puzzled or intrigued the researcher for a substantial period of time. For me as I have explained, this study is part of an unfinished quest; that of finding ways to assure myself as a health professional that I have given patients both high quality, and appropriate 'patient desired' care.

> 2. *investigating experience as we live it rather than as we conceptualise it (pg. 30).*

For me this has meant considering becoming involved in the phenomenon in an inclusive way using literature, personal involvement, and forms of narrative expression to exemplify the phenomenon.

> 3. *reflecting on essential themes, which characterise the phenomenon (pg. 30).*

There has been a conscious act of preparing myself for a process which takes time; being prepared to listen and re-listen to, and absorb the taped narrative of my interviews thus preparing to use the narrative of the participants to reveal the phenomenon.

> 4. *describing the phenomenon through the art of writing and rewriting (pg. 30).*

Van Manen's (1990) approach focused on using the creative medium of writing to reveal the essence of the narratives; finding, and describing the essential components in a way which preserved the original meaning yet conveyed the researcher's interpretation.

> 5. *maintaining a strong and orientated pedogogical relation to the phenomenon; balancing the research context by considering parts and the whole (pg. 31).*

For me there is an emphasis on the preservation of the integrity of the stories, to remember to whom they belong, yet to maintain the original balance of highlighting the importance of asking and hearing what patients value about care.

> 6. *Balancing the research context by considering parts and whole (pg. 31).*

For me this will be the maintenance of perspective; to maintain the original goal of revealing patients' experience yet preserving the veracity of the participants' stories.

Phenomenology seeks to answer questions of understanding (Smythe; 1997). By design, phenomenology will not provide rationalistic answers or solutions, but it will: (give an) "...understanding of the deeper meaning or significance of an aspect of human experience, in the context of the whole human experience" (van Manen; 1990, 51).

The phenomenon chosen for consideration can often be one that is taken for-granted, 'something that has always been like that', 'been done like that', or not viewed as important, or having relevance (or the spark for me; the experience of the patient receiving care has been written of, given value, and described by the people who were not the recipients of care).

Smythe (1997, 17) suggested that "...phenomenology can share stories that draw you into the experience of others, (and) stay within you in a way that no collection of ideas or statistics will; ... the researcher can interpret the stories in a way that enables you to understand the phenomenon with new insight".

If reading the insights: "...helps them to clarify their understanding, if it provokes them to wonder, if it sets them thinking new thoughts, then it has been worth doing" (Smythe; 1997, 17).

Narrative is the essential component for such understanding. Phenomenology demanded that the context and content of the interview arise from the participant. Narrative captures an expression of an event or viewpoint. Because it is a verbal response to a question, it has an immediacy and authenticity which cannot have been pre-conceived (van Manen 1990). The individual defines his own reality. Reality is layered by culture, social and political influence and because of this: "...we lose sight of our being from existing within this familiarity" (Plager; 1994, 65).

Phenomenology in the philosophical sense refers: "...to an approach which implies that the researcher studies the phenomenon as it is lived in a natural setting using processes that lead to narrative descriptions" (Parse; 1996, 10). Its main interest is the illumination of the basis of an experience; that is the 'being' (Swanson-Kaffman & Schonwald, 1988; Bishop & Scudder cited in Ray;

1994). This illumination occurs through the: "...engaged reasoning and imaginative dwelling in the immediacy of the participants' worlds" (Benner; 1994, 99)

"Phenomena are described as they are consciously experienced without theories about their cause and as free as possible from unexplained preconceptions and presuppositions" (Merleau-Ponty; cited in Beck; 1994, 500). Such experience is always a remembered thing; to be able to describe experience one must turn one's gaze to the past , to remember it; thus it is historically inspired (Oiler, 1982; van Manen, 1990).

> The successful outcome of the phenomenological method is centred on the ability of the researcher to engage with the informant's reality compared with quantitative methods which utilise distance, logic and rationale ....the body, the word and the concerns, unique to each person, are the context within which that person can be understood
>
> (Burns & Grove; 1993, 64).

Van Manen (1990) postulated that undertaking the research, subsequent reflective writing, and resulting practical action were intimately linked; one informing the other. Embedded within this notion of writing and re-writing is to make explicit the description of the phenomenon under discussion. "Writing is part of the intellectual work of doing interpretation.......there are false starts, but a rejected false start is an advance on understanding" (Benner; 1994, 101).

The descriptive-interpretive methodology

To say one is going to be using the Descriptive method informed by Phenomenology could appear to be contradictory. How can one describe and interpret at the same time? Descriptive, implies the writing down of a happening as it has been observed, yet phenomenology viewed from a Heideggerian perspective, is interpretive, going beyond pure description to the underlying meanings.

Van Manen's (1990) phenomenological approach blends the descriptive (eidetic approach) and the interpretive approach. In addressing this apparent conflict van Manen (1990) said the term descriptive relates to the: "...description of the lived through quality of lived experience" (pg. 25), the written expression of the happening. He elaborated:

> A good description that constitutes the essence of something is construed so that the structure of a lived experience is revealed to us in such a fashion that we are now able to grasp the nature and significance of this experience in a hitherto unseen way
>
> (Van Manen; 1990, 39).

The phenomenological basis arises from the description of the meaning of the expressions of lived experience, a perhaps more symbolic description at a later time, which may be viewed as an interpretation of the happening.

Spiegelburg (cited in Taylor; 1993, 173) similarly described six types of phenomenology including descriptive phenomenology; being the: "...direct description of phenomena aimed at maximum intuitive content".

Other writers (Farber, 1966; Merleau-Ponty, 1956) stated that it is impossible for writing to be entirely descriptive, as the event being described has already passed by and interpretation is inevitable. Farber (1966) spoke of this dilemma:

> It is the aim of description to give an account of the pertinent facts, because the facts are infinite in number... There are not only the difficulties resulting from the individual or the group which conditions

> him, but also the problems caused by the facts themselves; and there is the necessity of weighing the evidence of events which continue to recede in to the past (Pg. 45).

Merleau-Ponty (1956, 62) cited in Farber (1966) explains 'weighing of the evidence' as:

> ...the basis from which every act issues and it is presupposed by them. The world is not an object the law of whose constitution I possess. It is a natural milieu and the field of all my thoughts and of all my explicit perceptions (pg. 45-46).

It is apparent that descriptive and phenomenological methodologies are similarly aligned, although with differing ontological bases. There are commonalties between the descriptive and phenomenological methods in the structure of the method, in the identification of the phenomenon; the gathering of the data; and the describing of the phenomena. There is however variance in the philosophical underpinnings and how the data is analysed; the descriptive method following a defined pattern; the phenomenological method allowing the lived experience to speak its own agenda.

Knowledge resulting from a qualitative descriptive method informed by phenomenology is not static, fixed and predictable. It is not enough to be able to uncover environmental or human patterns within a lived experience, but the realisation that these patterns: "...are in mutual process, and are both changing together" (Phillips; 1993, 16).

Along with this process too, is the mutual, interactive and resonant relationship between the researcher and the participant (Phillips, 1993; Oiler, 1982; Miller & Crabtree, 1994). "The observer is not separate from the observed. Subject and object are united in being in the world" (Beck; 1994, 501). Within this notion too, is the sense of mutual, interactive learning: a "...reciprocal relationship" (Lather; 1991, 63). Meaning emerges from this interaction: it is an: "...intersubjective phenomenon" (Beck; 1994, 501). It is not devised from the reduced unit components of positivism. Therefore the preconceptions of the researcher are acknowledged, valued, and utilised within the research process.

Oiler (1982, 179) believes that what the researcher brings into the relationship depends on her\his "...position within the world" and that this "...knowing shapes experience". This is an explicit knowing; one that is held up like a mirror to reflect a perspective; able to be described. Van Manen (1990) said a good phenomenological description is "...collected by lived experience and recollects lived experience- is validated by lived experience and it validates lived experience" (pg. 27); or as Miller and Crabtree (1994, 348) said a "...rhetorically convincing story".

The process of obtaining this is a combination of description, thematic interpreting and metaphoric insight. Lowenburg (1993) offers a critique on the integral relationship between researcher and participant, and suggested the position of inherent power and influence that the researcher has, must always be acknowledged and given credence too, within this process.

Language is only one part of the interaction between participant and researcher (Polanyi in Bunkers, Petardi, Pilkington & Walls, 1996; Phillips, 1993). "... there is more to human phenomenon than we are able to see. There is more to what people experience and know, than what they are able to express and we are able to hear..." (Halldorsdottir & Hamrin; 1996, 30). This can be both a conscious and unconscious mechanism; there is a lack of facility in being able to express in some way everything as it is experienced: "...we know more than we can tell" (Polanyi cited in Bunkers et al; 1996, 33). Lived experience itself is unconsciously experienced. It: "...is an awareness of life without experiencing it..." (Dilthey cited in Taylor; 1994a, 2). It is only through verbal description of these experiences, that humanity gives life too, and understands the experiences themselves (Taylor 1994b).

There is an emphasis on reporting the experience as described by the participant, given the underlying philosophy that multiple truths and beliefs exist even within a very defined group. Miller and Crabtree (1994, 348) described this as: "...local context and the human story of which each individual and community story is a reflection", rather than "...validity, reliability and generalizability". Such multiple truths and beliefs are a result of social, cultural, spiritual, physical, historical, and personal experience, and can only be demonstrated in language (Lowenburg; 1993, 63).

There is however an inherent problem in the use of language, which can be culturally, politically situated, to convey the description and interpretation. "Language is the terrain where differently privileged discourses struggle via confrontation and/or displacement" (Lather; 1991, 8). Because humanity has tended to communicate experience within a research context by discourse or text, communication can become distorted or corrupted from the start, because expression and interpretation of experience usually occurs through: "...existing categories of thought, all of which lie open to radical deconstruction" (Reason; 1994, 333)

Finally, there is recognition given to variance between each research design. Flemming (1997); Oiler (1981); and Leonard (1994) believed the design of phenomenological method altered depending on the nature of the question in order to preserve the individuality of the person's lived experience.

I was introduced to van Manen's (1990) work some years ago. I was immediately gripped by the honesty and clarity of his writing, and the value it gave to each individual's unique experience. Such an approach resonated with my personal value system, and my own interest in understanding how people experienced their world. The descriptive-phenomenological methodology (utilising van Manen's method) as defined above fitted the aim of my research; that being to elicit people's lived experience of receiving palliative care. As well as describing a number of individuals' lived experience in a similar environment, it employed a phenomenological reflective engagement with the participants' stories and utilised a phenomenological approach in the analysis and interpretation of the narrative.

The method

The first section of this chapter focused on the philosophical underpinnings of my research. Within this section I will explain the processes which explicated the methodology including: the research proposal, ethical considerations, access to the organisation, recruitment of participants, data collection, the semi structured interview, role of researcher as interviewer, data analysis, trustworthiness of the research, concluding with a summary

The research proposal

The proposal for this project was developed within a research methods paper I was undertaking at the Department of Nursing and Midwifery, Victoria University: Wellington. Over a period of months in collaboration with my fellow students and lecturers, a period of refining the research question occurred. Within the proposal there was a broad literature review, as I was uncertain of the boundaries of the research, and was ambivalent about the degree of involvement that my interest in quality improvement should take. As well there was an outline of the aims of the study, the proposed methodology, and a budget which I hoped by making application to funding bodies I might obtain some financial support for the project.

At this stage I began to undertake the process of revealing to myself and to others beliefs that I had about the question under study, and how these beliefs might be affected by, or affect the methodology chosen. This process of autodialogue, and dialogue with others has continued to the present day. I am extremely grateful to the challenges of my supervisor and professional colleagues in saying: "Well have you looked at it this way", or, "...it could be viewed like this".

Ethical concerns

Within the literature review I have discussed the ethical dilemmas inherent in the interviewing of those who have a terminal illness. In summary they were:

Vulnerability of the participants: There were established ethical risks in interviewing people who were terminally ill; these being the interviewing of a recognised 'vulnerable' group of people who were probably frail and unwell; imposing the research process upon people who were terminally ill and unlikely to benefit directly from the results; and using a hospice, which is considered a 'place of safety' to recruit patients (Aranda, 1995). Recognising these risks I established systems to ensure the recruitment process protected the most vulnerable patients (see section on recruitment).

Informed consent: Recognising that this research would require recruitment from a hospice which should be a place of rest for people who are terminally ill, there needed to be a mechanism whereby I did not directly approach patients. I decided that the interdisciplinary team of staff were best positioned to decide who fitted the inclusion criteria I had defined. I obtained access to the staff by approaching the hospice management team, explained to them my research and sought their assistance. Staff first identified patients who fitted the inclusion criteria, and were considered 'least vulnerable' in terms of holistic health. The staff approached these patients to gauge their interest in the research, and only if they were interested passed on their names to me. I visited each potential participant, encouraging a support person to be present to act as a patient advocate and allow for wide questioning about the project and the requirements of the participant. At the end of this session, the patient was asked to consider participating in the research, and informed that they could let me know then or later of their decision, prior to signing a consent for interview (see appendix three). Four of the six participants agreed to take part immediately, and signed the consent for interview at the initial meeting, the other two signed when I visited them at home. The participants were informed that they could withdraw from the research at any time before, during or after the interview.

Anonymity and Confidentiality: Despite use of pseudonyms; requiring other people viewing the researcher's work to sign confidentiality statements (my transcriber); and the careful protection of data which might identify patients; I had a concern that because of the small geographical size of the country, and relatively small number of people terminally ill at any one time, the participants might be recognised. To address this, I decided to alter identifying characteristics to reduce the chances of this occurring.

Emotional support: I recognised that the patients (or support persons if present) could become distressed by the recounting of the hospice experience because it might surface feelings about the dying process and death. A confidential referral process to a bereavement counsellor was established. It then became possible for me with the patient (or support person's consent) to refer them for counselling (see Appendix Six for details of how this was established). As it happened I suggested this service to one husband and wife, but they declined saying they were already receiving counselling.

Application for ethical approval from the Regional Health Authority Ethics Committee

My application for ethical approval was structured to include a comprehensive discussion of the ethical debate within the literature, as well as my own understanding of the ethical concerns. The inclusion criteria to be used by the host organisation's interdisciplinary team was designed to include only patients who were not in the 'actively dying' phase of their illness, and who were considered 'well' enough to participate by the team.

I deliberately sought to have another family member or friend present at my initial meeting with the patient to ensure both parties understood my intention. Family members or friends could intervene to protect the patient's interests if they considered this necessary.

I sought to interview in the patient's own home after discharge to ensure a sense of safety and confidentiality.

I made the decision to interview the patient only once, thereby reducing the risk of being intrusive. I was aware however, that in doing this I would not be able to validate my findings with the patients.

I made an assurance to alter the name and details of each participant to preserve confidentiality.

My application for ethical approval from the Regional Health Authority Ethics Committee was accepted with the requirement that I extend the range of time for interviewing up to 45 minutes, in order to allow people to speak longer to me if they wished.

Access to the host organisation

Access to the organisation where the participants were to be sought had been discussed with the medical director in the year prior to beginning the research, and was formalised by the general manager prior to the research starting.

I was aware that these discussions had been conducted with only the senior members of staff and management, and that I needed to ensure that all the interdisciplinary staff understood my research study; what our mutual requirements would be, and how the information gained might benefit them. I was concerned that the 'working' clinical staff be comfortable with my presence, the purpose for the research, and the interview method I would use with patients. I met with as many of the team members as I could on four occasions, excluding only the permanent night staff, as I did not require them to approach participants. I left information sheets designed for each staff group who might be involved with the study (see Appendix Five, Appendix Six).

Recruitment

Patients were recruited according to the inclusion criteria I had established within my application for ethical approval. I sought between 4- 6 patients to take part in the study. The clinical staff were to apply the inclusion criteria to any patients being considered for discharge, and approach the patient to ask whether they would like to meet with me and explore taking part in the research. If they agreed, I would meet with them and a family member or friend, discuss the research, and if they were agreeable seek their consent.

The patients were to be adult in age, and have had more than one experience within the hospice. This may have been inpatient admissions or a mixture of out-patient\ in-patient services, and to be cared for on discharge by a home care team, so researcher concerns about health status could be referred with the patient's permission.

The patient would be in the palliative care phase of a terminal illness i.e. conscious, able to speak, semi-dependent, lucid, and considered to be able to sustain a conversation for 15 min by the interdisciplinary team caring for them.

The clinical reasons these type of patients would have been receiving care was for symptom control, or respite relief for relatives.

The exclusion criteria were also defined to clarify who should not be approached, these criteria being applied by the interdisciplinary team at their daily meeting. These criteria were: all patients not in the above category; children and adolescents receiving care; patients requiring an interpreter; patients whose mental state (either organic or psychologically) would cause them to be unable to participate; and patients whose physical state would cause them to be unable to participate.

An arrangement would be made to meet soon after discharge preferably within the first ten days of discharge while memories of the experience were fresh. The consent to participate and \ or use resulting data could be withdrawn at any stage in the phase of research even after the interview was undertaken. Patients would be interviewed in their own home or nursing home; an environment considered 'safe' to speak. I would also ask when consent is sought whether the patient wished to be interviewed in private or with a support person present (such as family or friend). This would be checked again on the day of interview, when I arrived at the participant's home. As it was, two participants asked to have their spouses present, and specified that they wanted them to stay for the interview. I recognised this might alter the content of the interview, but wanted to allow an environment where the patient felt safe to speak.

Given that these patients were terminally ill, and that their own personal time was very precious, I would not interview them more than once. I would however phone that night to thank them, and check on their well-being, and re-check if they would like a transcript of the interview. This written transcript could form an important part of their life history.

The semi-structured interview

I chose to use the semi-structured interview as a method of obtaining the lived experience I was examining. I believe it was consistent with the methodology which underpinned this study in that it was:

> ...used as a means for exploring and gathering experiential narrative material that may serve as a resource for developing a richer and deeper understanding of a human phenomenon
>
> (van Manen; 1990, 66).

Minichello, Aroni, Timewell, & Alexander (1995, 65) state that the semi-structured interview allows the researcher "...using the broad topic in which they are interested to guide the interview". Thus the interview is based around a number of areas which the researcher is interested in but does not adhere to fixed order or wording allowing the researcher to explore further within conversation each individual's unique experience. The outcome being a narrative rich in the participant's own language, narrative and story. The participant having been able to guide and explore their own direction within the question leading to a: "...valid explication of the informant's perception of reality" (Minichello et al; 1995, 65).

In the process of designing the method I established two key questions and several prompts which were included within the interviews depending on the response of each person.

Key Questions:
What services have you been involved with at the hospice since you first started to go there?"

I'd like to go on to talk about your experience of care at the hospice. It may be difficult for you to talk about that directly; you may find it easier to tell me a story or to describe a situation which remains in your mind about your care at the hospice. It may have been good or not so good.

Prompts:
Tell me about when you first came to the hospice?; "What has it been like for you since you started coming to the hospice for care?; Could you describe how you felt about your care since you came here?

The interview always concluded by inviting participants to make some final comments, and asking whether they wished a copy of the transcript, a copy of the taped interview or both- all but one requested either tape, transcript or both. Once I had left the participant's home, I drove on a little way, stopped, and jotted down notes in my research journal both about the process of interviewing, and anything that was said before or after the interview. That night or the following day I rang to thank these people for their part in the interview, then wrote at a later time sending the tapes and transcripts.

Data collection

As well as the collection of data by the process of interviewing the participants, audio-taping the interviews, and transcribing the interviews; I began in the year prior to beginning the research to read widely (fiction and non-fiction), about what it was like to die. This literature was not new to me, as I had always been interested to learn about how the process of terminal illness was experienced. However because I was undertaking this research using a phenomenological approach, I looked at it with fresh understanding, and as the interviews commenced, with new insights. I collected a file of books, magazine articles, poems, and hastily written down phrases and references. At the time I had no idea of using these except that they would help me frame another person's experience.

I conducted the interviews, over a period of nine weeks, interviewing three women and three men in their own homes between eighteen hours and ten days after discharge from the health care organisation. The interviews took between 20 min. and 55 min., with a median of 40 min. All interviews were taped by audio-tape after having gained consent. Time was allowed to make field notes directly after each interview about the interview process, and conversation considered relevant before and after audio-taping.

One participant was admitted to the public hospital with a vertebral collapse three days before I was due to interview him, and on visiting him in hospital he declined to continue being part of the study, and withdrew. He was replaced by the next available person who fitted the criteria defined in the proposal.

Within the research proposal I had stated I would interview those who were admitted for respite care or symptom control rather than the terminal phase care occurring in the last days of life. After interviewing my first three participants who happened to fit the respite care category, I realised I might not be eliciting information that was consistent with both the categories of respite and symptom control care. I discussed this with the staff, and we agreed that the next three interviews would be requested only from people who fitted the symptom control type criteria. Thus three participants had been admitted for respite care, and three for symptom control care.

Although I instructed staff at the health care organisation regarding the criteria for participant selection; comments were made when they rang to tell me of a potential participant's availability, that the person was a 'good talker', or would be 'good to talk to'. It is possible that I may have received different interpretations of *care* had I spoken with people who were withdrawn and inarticulate.

The participants were aged between early fifties and eighty years old. Diagnosis was irrelevant to me as it was their categorisation of requiring palliative care which fitted my criteria. Usually through the courses of the conversation on initial meeting or at the subsequent interview I learned what their illness was.

Pseudonyms have been used for all patients, and identifiable details have been changed or omitted. However as stated, I have felt concern, that because of the relatively small number of people who die subsequent to having received in-patient hospice care, that readers may recognise the person whom I speak of. I would ask readers to look at the story and the spirit of these wonderful and brave people that I wish to convey in this study, and not to attempt to discern their identity.

Brian was a man in his late seventies whom I interviewed with his wife. Brian was retired, and had had a tumour for at least six or seven years. He had had several admissions to the hospice for respite care. Brian died several months after the interview.

Frank was a man in his late fifties. His main caregiver was a devoted friend with whom he shared his cottage. Frank appeared very debilitated and bedridden by his illness and had had two admissions to the hospice for respite care. Frank died several months after the interview.

Helen was a women in her late fifties who lived alone in the centre of the city. She had been living with her illness for three years, and had had several admissions for both respite and symptom control care. Helen died shortly after the interview.

Rose was an eighty year old woman living alone. Her husband had died in a hospice several years before her illness started. Rose's extended family were closely involved in her care, as well as many devoted friends. She had had several admissions for both respite and symptom control care. Rose died three months after I interviewed her.

Vance, a man in his late seventies was interviewed after only one in-patient admission although he fitted the criteria by having been seen as an outpatient prior to his in-patient admission. Vance was interviewed with his wife. Vance had been admitted both for emergency respite care, and then stayed for assessment and symptom control.

Carol, in her early eighties lived with extended family. She had had a terminal illness for some years, and was receiving regular respite care at the hospice.

Role as Interviewer

I considered my role as interviewer very carefully prior to interviewing; using the principles developed in Minichello et al (1995, 61-104), and van Manen (1990, 66-68). I attempted to keep my comments and interjections to a minimum; using open-ended questions as encouragers and prompts. Being conscious of active listening skills, I attempted to allow the conversation to develop, being sensitive to silence and space. I was aware of trying to both encourage conversation on the notion of care, and also narrative that was unique to each person. These principles worked well for four of the participants; those who had given time to thinking about what it was they wished to convey. In contrast, I found that two of the interviews did not follow that process; one being with Frank who was extremely tired and weak, and Carol the oldest. With these two participants I found using open ended questions and silence was not helpful, and had to use incremental questions and prompts to elicit details of what 'care' was. I would suggest that this style of interview occurred because of debility and frailty.

I believe interviewing these people who were terminally ill, had several unique difficulties; mainly related to the nature of physiological decline. All were enthusiastic about taking part in the interview when I initially visited to seek consent in the hospice prior to discharge. However when I phoned them at home after discharge to confirm the time of interview; two of the participants stated they were tired, or unwell. On offering the choice of withdrawing or rescheduling the interview; both chose to re-schedule. I did not actively encourage this option, and suggested to these participants that I was more concerned about their well-being than interviewing them if they were tired or unwell.

With these participants I rescheduled two and three times, to the point of having to reschedule an hour before visiting. This caused me some anxiety, and made me wonder whether I should gently decline continuing to reschedule the interview. However each participant was so insistent that they did want me to visit (but not on that particular day), that I continued. When this happened it was a relief for me to finally be able to see the participants in their homes, and to assess their physical and emotional state.

I wondered whether people had felt obliged to be interviewed when initially asked at the hospice, and then became ambivalent, or on the other hand they were feeling the effects of being at home or feeling unwell. I was unable to fully explore these thoughts during the interviews although fatigue was mentioned twice as a limiting factor in undertaking activities.

One participant had been difficult to contact to arrange a meeting time when first discharged, and then on my final confirmation phone call the afternoon prior to interview was uncontactable. I deliberated about travelling to his house at the prearranged time of interview the next morning even though he lived a considerable distance away. On the morning of interview I was able to contact his wife who told me he had been admitted to public hospital three days previously. This typified the difficulties which were in no way attributable to the people themselves but as a result of their illness. I was always aware that they might unexpectedly decline and die before interview; or become much more ill.

As does happen, I arrived at the interview to find areas of practical concern, which as a registered nurse I could not ignore, and which I tended to with the best of my ability. On arriving at Rose's home I found her subcutaneous syringe pump almost empty, with the district nurse about to arrive to change it; but with no medications available to do this because the discharge prescription had been incorrectly written. After several phone calls to the G.P., pharmacist, and district nurse, the difficulty was overcome, with the new medications being delivered by the pharmacist before I left.

Helen was clearly uncomfortable when I arrived. She had been in her lazy-boy chair for several hours before I arrived. With a visiting friend's help, we were able to stand Helen up, assist her with a short walk, and reposition her on her sofa.

After my interview with Frank was finished, he expressed concern about his medication instructions, and asked me to look at them and tell me what I thought they meant. We were able to discuss what was written down, and for me to validate that Frank was taking the medication as it had been prescribed.

Trustworthiness and rigor

The trustworthiness and rigor of qualitative research relies not on numbers and statistical analysis as in a quantitative analysis; but upon the detail given to the reader regarding how the interpretation was made, and the audit trail of the overall research process (Sandelowski 1986, 1993). Criticism of qualitative methodology includes such factors as the influence the researcher may have had on the participants especially if an unstructured form of interview occurred; and the method by which the data are selectively described, reported, and interpreted. Sandelowski (1997, 127) says that many qualitative researchers still measure their work by quantitative measures of rigor: "...validity, reliability, and generalization".

Ray (1994, 131) cites Buytendijk describing the credibility of phenomenological methodology: "...as the 'phenomenological nod'- where the description and interpretation of experiences are something we can nod to and recognize as experiences that we had or could have had"; or as Polkinghorne (1988 cited in Bailey, 1996, 188) calls it *verisimilitude*: "...results that have the appearance of truth or reality" and are "...well grounded and supportable". Guidnon (cited in Plager, 1994, 77) believed: "...truth is envisaged as the emergence of a clearing or opening that releases entities from hiddeness... The description is measured not by criteria of correctness, but by criteria pertaining to its consequences for our lives."

Although I believe this study to have limitations because it is situational to one specific organization, and that the results could be said to be limited because of my decision to interview the participant only once; Sandelowski (1997) challenges researchers who make such claims to not undervalue the results that they find:

> ...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 (pg. 127).

Bailey (1996, 189), in speaking of Polkinghorne's (1988) notion of verisimilitude said:

> ...reliability refers not to the reproducibility of a similar story on a subsequent occasion but, rather, to the dependability of a one time narrative database.

This outlook highlights the outputs of qualitative research which should be; "...meaningful or important" (Bailey; 1996, 189) or whereby knowledge is able to cause:

> ...changes in the way people and events are configured or thought about.... Knowledge is 'used' when it informs and even emancipates thought and when it permits sense to be made of previously incoherent and nonsensical events
>
> (Sandelowski; 1997, 126).

Review and summary

In this chapter I describe the qualitative methodology as being descriptive, informed by van Manen's (1990) phenomenological stance. I discuss why this seemed an appropriate methodological stance to utilise with people who were terminally ill, attempting to describe a lived experience.

Following this, I describe the method I used to gain the participants and also a summary of the interview process. I outline the use of the semi-structured interview approach identifying aspects which worked well, and also those which created some difficulty because of the acuity and age of the participants. I give a brief description of the participants, discussing my desire that they are not recognised. Finally I briefly discuss the notion of trustworthiness as particularly applied to qualitative methods.

In the following chapter, chapter six, I will report the results of the research. The results are expressed as a discussion about the way the 'storytellers' conveyed their anecdotes to me, and secondly the themes which arose from these conversations.

Chapter Six

The Results: How patients reported the experience of palliative care.

> Ill people need to be regarded by themselves, by their caregivers, and by our culture as heroes of their own stories.
> As storytellers ... their testimony is rather that you can be sick and remain not just in love with yourself but in love with the humanity that shares sickness as its most fundamental commonality
>
> (Frank; 1995, 134, 40).

Introduction

This chapter seeks to discuss further the process of descriptive-interpretive analysis with which I used to approach the data. I wish to expand on the way these stories or anecdotes were conveyed to me; the possible meaning behind the story telling. Following this, I will describe how the process of interviewing the participants proceeded, and how I undertook to determine the themes from the data.

The analysis

In the process of attempting to make sense of the narratives of lived experience, I attempted to follow van Manen's (1990) phenomenological reflective process, the purpose being to "...try to grasp the essential meaning of something" (pg. 77).

The process of gaining insight into, and explicating the essence of a phenomenon involves: "...reflectively appropriating, of clarifying, and of making explicit the structure of meaning of the lived experience" (Van Manen 1990, 77). It is not a systematic coding and counting of phrases that appear similar, but to uncover the true 'meaning' of an experience; ultimately meaning that the themes become the experiential structures of the experience.

> Making something of a text or of a lived experience by interpreting its meaning is more accurately a process of insightful invention, discovery or disclosure- grasping and formulating a thematic understanding is not a rule-bound process but a free act of "seeing" meaning
>
> (Van Manen; 1990, 77).

The process of data analysis involves the 'selection of anecdotes' (Van Manen; 1995, 8). Lincoln & Guba (1985, 332) said: "Data are, so to speak, the *construction* offered by or in the sources; data analysis leads to a *reconstruction* of those constructions". To elucidate this reconstruction or uncovering, I chose to work in accordance with the methodological approach already described; that is qualitative descriptive methodology informed by phenomenology. In this way I would work with narrative, people's stories. I was very conscious that these were very precious stories. For some (those who have died) it was probably the last 'formal' interview that they gave to a stranger. I was aware that they were attempting to convey a message, and to honour this there are some comprehensive portions of quoted narrative in this chapter.

> Ill people's storytelling is informed by a sense of responsibility to the common-sense world and represents one way of living *for* the other. People tell stories not just to work out their own changing identities, but also to guide others who will follow them. ... The idea of telling one's story as a responsibility to the common-sense world reflects what I understand as the core morality of the post-modern (Frank; 1995, 17).

Polkinghorne (1988) said with regard to narrative, that it is: "...the primary form by which human experience is made meaningful" (pg. 1), and can be used by practitioners to "...understand why the people they work with behave the way they do" (pg. xi). He stated the end result of using narrative is that it: "...creates its meaning by noting the contributions that actions and events make to a particular outcome and then configures these parts into a whole episode" (Polkinghorne; 1988, 6). As well as researchers 'creating meaning' using stories, the storyteller does also. "To think with a story is to experience it affecting one's life and to find in that effect a certain truth in one's life" (Frank; 1995, 23). This becomes especially relevant when I remembered that five of the six participants requested copies of their interview tape and\or transcribed interview.

In asking people to use narrative descriptions about their experience of palliative care, I was asking them to experience a phenomenon which Astrom, Norber, Hallborg & Jansson (1993) in discussing Tappen's writing (1989, 1990) described as :

> ...when it is necessary to report the way it really happened, the natural impulse is to compose a narrative, ... in some kind of temporal sequence. By narrating, meaning is given to lived experience (pg. 184).

or as Frank (1995, 3) said there is a need for:

> ...ill people to tell their stories, in order to construct new maps and new perceptions of their relationships to the world. ... From their families and friends, from popular culture that surrounds them, and from the stories of other ill people, storytellers have learned formal structures of narrative, conventional metaphors and imagery, and standards of what is and is not appropriate to tell.

As already described in the previous chapter, the method for my undertaking this research was to meet the potential participants whilst they were still in the hospice, talk to them about the study, and determine whether they would take part. If they agreed, formal consent was obtained, and an arrangement to make contact after discharge was organised. Once the participants had been discharged, I phoned and confirmed an interview date and time, ringing on the day of interview to check on their well-being and confirm our arrangement.

When we met initially at the hospice, the participants were all keen to be interviewed, assuring me that they would have plenty of time to do so once they were at home again. I had thought that these people newly discharged from the hospice would 'rest-up' a bit before going out and resuming their social contact with others, but I was mistaken. It often took some juggling for them to fit me in. As discussed within the previous chapter within the section on the method used to undertake the research, two of the participants delayed the interviews through being fatigued, and busy. I carefully thought about other contributing reasons for this happening. I wondered in retrospect whether there was a secondary reservation about going ahead with the interviews despite being reassured by each person, that this was not the case.

The six interviews of these people were very exciting for me, because it fulfilled a long sought ambition, yet also because I immediately warmed to my participants on first meeting, and wanted to get to know them better. Although I had some anxiety about the process of conducting the interviews, not missing any cues, and tiring the participants, I found I enjoyed each one in a different way.

As each interview was completed I had each tape transcribed immediately. I wanted to return a copy of the transcribed narrative, if requested by the participant, as quickly as possible. I knew that people who are terminally ill can decline and die unexpectedly.

My aim before beginning the written reflective analysis, was to engage with the audio-tapes, the written transcribed narrative, and the field notes after each interview.

As soon as the tapes were transcribed, I relistened to and verified the transcribed narrative, finally rereading them alongside the playing of the tape. In doing this I recognised the precious nature of the linguistic medium. Polkinghorne (1983) describes this as:

> Linguistic data, like the human realm, are held in vehicles of expression ... the data are the meanings themselves. Linguistic data are fragile, and they are affected by their transformation of the mode of their expression. Thus the researcher needs to take care and to understand when linguistic data are transferred from the oral mode to the written mode (pg. 268).

Van Manen (1995, 5) when speaking of phenomenological process, stated: "...phenomenological human science dares us to live with uncertainty, without absolute truth, without certainty, without sure method". The methodology may be stated, but researchers must design their own method of revealing the phenomenon. Before beginning I looked at my own knowledge and experience, and tried to become very clear about any feelings I had about both the process and outcomes of the research. Van Manen (1995, 35) believed this is necessary to:

> ...overcome one's subjectivity, private feelings, inclinations that may tempt or seduce you to come to premature habitual or one-sided understandings of the experience. It allows you to come to terms with the phenomenon as it is lived through.

Although palliative care had been my area of specialisation both in clinical practice, and in quality improvement work, I was clear that the whole area of how patients experienced their care was unknown.

I followed a process of seeking to uncover the essential aspects of the phenomena by reading and re-reading the narrative; listening and re-listening to the taped interviews, recognising that: "...the realm of meaning is best captured thought the qualitative nuances of its expression in ordinary language" (Polkinghorne; 1988, 10). I wished to enter into each individual's story as a whole, and as parts of this whole; going on to look at a collective of people sharing a common experience- that of undergoing palliative care. In this I was aiming: "...at elucidating those phenomenological structural features of a phenomenon that help to make visible, as it were, that which constitutes the nature or essence of the phenomenon" (Van Manen; 1984, 27).

After much time, a lot of thought, there came a new sense of what these stories meant, how they were different from each other, how they were the same; and whether even within the difference there was sameness. In attempting to discern this I was giving meaning to the ideas of: "...different kinds of reality", and "...the emergence of multiple realities" (Polkinghorne; 1988, 1), rather than the belief that there is only one interpretation or experience of reality. Frank (1995, 58) describes the phenomenon of 'multiple realities' as the 'interrupted story'. Such interrupted stories, those that can appear inconsistent or hold dual meaning, can make researchers and clinical health practitioners feel uncomfortable. "Disease interrupts a life, and illness then means living with perpetual interruption (Kaysen cited in Frank, 1995, 56).

> The stories are uncomfortable, and their uncomfortable quality is all the more reason they have to be told. Otherwise the interrupted voice remains silenced. The illness story faces a dual task. The narrative

> attempts to restore an order that the interruption fragmented, but it must also tell the truth that interruptions will continue
>
> (Frank; 1995, 58 59).

Thus a phenomenological reflective process was undertaken. At this stage I had developed a document with exemplars, anecdotes and phrases of narrative taken from the written transcripts which were similar and different. As well there were multiple conceptions of ideas about how these might constitute themes. Benner (1995) described this as:

> The goal is to find exemplars or paradigm cases that embody the meanings of everyday practices. The data are participant observations, field notes interviews, and unobtrusive samples of behaviour and interaction in natural settings. Human behaviour is treated as a text analogue and the task is to uncover the meanings in everyday practice in such a way that they are not destroyed, distorted, decontextualised, trivialised, or sentimentalised (pg. 5-6).

The Data, and the Themes

Within each interview, and between each interview there were similar statements, or ways of describing a series of experiences; which reflected the multidimensional experience of care. Within this too, were personal and individualised statements.

In attempting to understand what this meant, I grouped what was similar within each interview and between each interview together; and also what was dissimilar. Then I looked to find a way of naming this collection; to become the consideration of a theme. In this way I wanted to find voice for narrative which was consistent and authentic.

Overall the process by which the participants told the story was similar. There was a statement about the most recent admission; the one where I had met them at the hospice; going on to a positioning story from whence they had come. For most, this was the story of their illness; sometimes from the start, but mostly from their time of admission to the hospice. For one woman it was from the dying of her husband at another hospice many years ago. Within this positioning, there was a need to inform me and perhaps themselves, about their individual current physical capabilities- how I am now, and how I was then. After this initial positioning was undertaken; the conversation moved to the specifics of their interpretation of what constituted the experience of care. For some this was done with some hesitation, with comments such as: "Am I telling you the right thing?"; "This is what you want to hear, isn't it?" I attempted to reassure the interviewees that I wanted to hear anything of what they believed was their care experience- good and bad.

The themes

Overall the themes described aspects which spoke firstly of the individual's response to or requirement from the care process, and secondly of the individual's response or reaction to those giving the care: the staff. I shall discuss the themes which relate to personal response first, followed by those which relate to staff.

Identity:

As stated within the introduction to this chapter there was a consistent pattern in the way people spoke to me about their palliative care experience (Tappen in Astrom et al, 1993). There were positioning statements of how they came to be ill: the illness history; who else had been involved: the caregivers- family, friends, significant others; how has this illness and subsequent care affected their physical, emotional, spiritual, and relational capabilities: 'Can I do more or less now than I could before'?

Overall in the stories of what care meant to each individual was the central theme of the importance of being regarded as a human with unique and individual preferences. Within this there was a strong sense that each person's individuality and dignity had been respected.

Rose, a very elderly, but sprightly and vivacious lady who at our initial meeting at the hospice had expressed her difficulty in finding the right words or images to describe what it was that made the difference between public hospital and palliative care said: *"...you're not just a patient, you're someone and that in itself makes you feel different, you feel as if you're worth something".*

Helen too, found recognition of her as a person integral to her satisfaction with her care. When asked about what she valued in her palliative care experience she said:

> *I think its the interest I've had taken in me personally, you know that they have gone to the trouble to ask, to. To really keep tabs on you if you like, they ask how's everything going, and they've met my family....*

For Helen too, there was a sense of continuity and completeness: "They keep following me you know-that's very special don't you think- I'm not a statistic or anything like that".

Staff's ongoing interest was expressed in comments Helen made over their interest in her activities and her two sons. To her this meant they were wholly interested in her as a real person. She highlighted that there was no distinction made of her status when she came in acutely or as a booked admission for respite (intermittent) care: *"...you don't get treated any* *differently if you're sick or you're there as an intermittent patient you get the utmost devotion and care".*

Trying to retain or regain a normal existence was part of the domain of maintaining one's dignity. This was illustrated by Brian's comment:

> *I'm going down to bowls on closing day... A fortnight away. And I spoke to someone and said I'm going to play ...... I said, I'm going to play that day. And I said even if you've got to carry me up the darn rinks. I'll be down ..*

Frank described the manner in which the hospice staff had attended to his physical needs; the major part of his care. He was almost entirely dependent on others:

> *Their professionalism I think oh straight into it and um,..... still only carried on, you know so professional.. just the way they spoke to you even- they don't even treat you like that ..I'm a real person you know.. They treat you like a human being straight....yeah. they do everything nothing is too much effort for them.*

As part of this valuing of the identity of each individual were the tangible reminders of the uniqueness of each, symbolised by using Christian names. Carol in her eighties and not necessarily of an age to be called by her Christian name expressed her opinion on this. There could have been some initial ambivalence in her reaction to being called 'Carol', rather than 'Mrs Sowry', but she expressed an awareness about the underlying reason why staff did this; that of being friendly, and creating a sense of closeness: *"...you know you'll be walking along the passage and they'll say "Hello Carol, how are you?" I like people to be friendly. They call you by your Christian name- I don't mind at all."*

Carol was entirely at home at the hospice where she went every few weeks for respite care. She had been widowed within the last year, and moved from Hamilton to live with her daughter, and son-in-law, yet despite these massive changes in her life had adjusted:

> *...you have every attention, its such a good place to go to, its another place you feel comfortable in. I don't have any qualms about going there at all because they're so good, I had a lovely bed. They never leave you for very long....never leave you to find out something for yourself. They're all so pleasant.*

At our initial meeting in the hospice, I had noted in my field notes Carol's comment of appreciation for the way the staff always placed her in the same bed in the same room every time she came. She knew where she was, and where she would be next time.

Another aspect of the respect for identity was how the hospice functioned in its measured degree of informality: Brian thought that one: "*...of the things that has helped has been a really informal atmosphere where the nurses are not wearing uniforms and things like that.*"

He went on to expand on informality:

> (Brian) *But knowing that they're there, They're caring very much so an um, peace of mind I'm having a break, but I'm being looked after they're not having to fuss over me. I think peace of mind would be the thing.*
>
> (Researcher) What do you think it is about the environment there that makes it like that? When you say the environment makes you relax. Can you ....

> *(Brian) I still can't put my finger on it....I think the informality of the place...Yeah. Um, ..the big thing I like is that they're not fussing over you...*
>
> (Researcher) Mmm. Not fussing.
>
> *(Brian)..they .leave you to your own devices but if you need them you got the call button and that's it. But the whole atmosphere.. I suppose what makes it so good are two things. One is the informality...*

Vance developed this idea further and explained some of the details that he had noted which were significant to his viewing of palliative care and also of him as a person who might not have followed all positive health practices:

> *I think the informality of the place........the fact that nobody uses surnames. ... going into the hospice with what is after all a terminal condition, they have an obviously different attitude... a lot of little things take on an importance. Some of the things, that some of the things - the nice things, you know, this business of coming around with a drinks trolley... you know the smallest whiskey I had .. I like a drink... the smallest drink was the one I poured myself. I was very generous. And ah, but that's a nice idea. And it is things like that, you know, this acceptance of the fact that an awful lot of people are there because they've been smokers, and ah, the fact that one can smoke and you know, sort of becomes a sort of accepted thing.*

Care is what I tell you it is.

The notion that 'Care' was difficult to describe, emerged frequently. It was as if people felt they had to describe the physical activities of caring, when what they actually valued was something far more intangible yet real. This intangibility of the care encompassed the culture, the environment, the laughter, the 'watching'.

Keeping control

To be able to retain some control when all control could seem to be being taken away by the physical effects of the illness, and the processes of diagnosis, treatment, and health professional involvement was a notable aspect in several anecdotes. Vance had known about the services that the hospice could offer several months before he was admitted acutely. Throughout his life, he had had severe illness, with numerous admissions in Scotland, his country of birth, and also in New Zealand. Vance's experience in public hospitals had at times been difficult; not so much the technical aspects but the admission and re-admission process. He knew each time what was wrong with him and what he needed, and his conversation was knowledgeable about his disease and its treatment. I sensed there had been hesitation to subject himself and his wife, to another round with a different and unfamiliar bureaucracy: the palliative care service. As it eventuated it was a crisis that plunged Vance into seeking help, with the collapse of his wife:

> *I had a......I'll make it as brief as I can...a serious condition of my heart - inoperable and that sort of thing, and that has been mine for years a limitation to activity. Fairly recently ahh, can't remember quite when - it's a sort of subtle change - my health became much worse. My breathing became very much more difficult. Activity became much more difficult and eventually I had very serious difficulty in breathing. Very serious,*

> *and ahh, I was examined those and they found I had an effusion. Well that was really what started it all and explained why my health was deteriorating so quickly and (they) took a vast amount out of my lungs, ahh, and I had the pleuradesis, and um, and my breathing and that sort of thing has improved enormously since then. In the process of all that - they found I have cancer. So that's the rundown on that. ....had um, ahh, there's the connection with (the hospice), we had a lot of recommendations to become involved with (name of hospice)....*

Vance went on to detail many family and social connections

> *The initial... the initial thing (the diagnosis) was.. and obviously this was all a bit of a shock for the both of us, I mean of course of course. The business of the treatment was somewhat unpleasant but generally it seems to have worked out pretty well, you know, but as I say they found the cancer. If anything we were rather overwhelmed with offers of help, you know.. right, offers of district nurses and everybody saying, get in touch with(the hospice) (It) really was... it was.. really was overwhelming - all well intentioned .But anyway the, well it was sad because we, everybody said, you contact me...Ah but um, but it all seemed to work out wrong. Gradually (we) came around and that came round and ah, then I I'm getting confused- how did I get to go to (the hospice). It was the thing it was real wasn't it- ah, that's right - it wasn't me at all, it was her (pointing to his wife). The whole thing... the whole thing, okay, just neither of us really have adapted and obviously the shock that you go through, physical, mental and all that sort of thing, and.. and.. and well I think she was exhausted- upside down*

Vance was trying to attempt some control in his life by the cautioned management of his drug regime, even if from the health professional's perspective it may have compromised his symptom control:

> *I've got a thing about drugs and being given drugs I don't like the idea of sort of saturating oneself in painkilling drugs, so that you're not really aware of what's going on in your body. I knocked off one this morning. I phoned the doctor at (the hospice) and I said this one for my leg.. so I don't think I need ... and ah she said, well it's probably keeping it (the pain) down, so I said well, you know, if its starts again, I can start the tablet.*

Frank, one sensed, had investigated alternative forms of treatment. When talking about the use of meditation I said:

> (Researcher) Did you try some of those things at home yourself?
>
> *(Frank) Yeah, yeah.*
>
> (Researcher) Before you went in?
>
> *(Frank) Yeah.*
>
> (Researcher) Did you teach yourself or someone come and help you?
>
> *(Frank) Oh, sort of pick things up, you know, over the years. Pass on knowledge*

When talking about what he valued about palliative care he said:

> *And nothing is too strict in there. They talk about alternative ways of doing things you know. Not just purely medical. So they'll give you a talk about different things you know. Not just about your...your care but other things. Yeah alternate care, you know like things you can do at home to stay calmer, things like breathing techniques, you know and other things you can't get from your G.P. on the prescription.*

Frank too articulated his need for an improvement of quality of life. A very sick, frail, wasted man, confined to his bed; he tired easily during our conversation, and I concluded the interview as soon as I felt he had said all he wanted.

> (Researcher) What do you hope that (the hospice) will be able to do for you as time goes on, in the future?
>
> *(Frank) Well it's there to help you,*
>
> (Researcher) to help you relax, to improve your quality of life?
>
> *(Frank) Well that's what **I hope** it can do, you know, because I haven't got much quality of life left now.*
>
> (Researcher) You feel that that's not... it's not good at the moment?
>
> *(Frank) Oh, it's not really. No, no, .but they say that anyway so. Um.. if they can make the last bit more comfortable then it would good, you know.*

Brian attempted a measure of problem solving with the technical aspects of his catheter equipment:

> *I've had this catheter now for six months and I suppose basically you can say it's been annoying- you can't always get it right without it rubbing on your penis- something like that I've found nowadays the tapes you use to hold the bags on. I've bought two more of those- its much more comfortable.*

Brian also carefully set himself a series of goals or targets by which he measured his progress.

> *(Brian)...okay that's a target I've set myself which is something I've done all the way along the line. ... and (wife) has helped me greatly, haven't you love with the various targets that we want to achieve.*
>
> (Researcher) Is that how you kind of keep the year planner going by, ...going by setting dates through the year that you know you're going to achieve at a certain time?
>
> *(Brian) Well, that I'm going to aim to achieve. It's the same when I came out from my first op when I had a colostomy......I set myself targets......and one I didn't achieve but I achieved it within a fortnight of my expected date...*

Helen, the youngest of those I interviewed, and who died within two weeks of the interview, talked of a long and difficult diagnosis period, after which she was given only a short prognosis. This prognosis in fact was incorrect and Helen went on to live for far longer than she and health professionals expected. This in itself brought great difficulty. Helen was a professional woman, and had been raising two children on her own for some time. She was articulate and even at the stage I spoke with her, was a dynamic forceful woman. Helen expressed the conflict of keeping personal control, but establishing a way to seek help for her sons who would outlive her:

> *...because initially I um October I was given three months to live at the end of October and so there were a lot of decisions that related to three months... We had to sort of evolve a management plan if you like, that allowed the boys to have a life of their own, you know , their lives don't change just because I'm sick. I was concerned for my children. I wanted some body there...a grief counsellor, which she is*

> *among things. I wanted someone to be there that they knew before I died, um, so that if the need arose after I'm gone there would be somebody professional for them to turn to. And Anne has been that and I must say that she has been absolutely marvellous because the boys were really suspicious and quite hostile to her presence. They didn't understand my reasons for doing it, and um, she broke down those barriers and in fact, was very helpful. She suggested that they visit my doctor and have questions and ask because she realised that they didn't feel comfortable talking about me in my* presence.

Helen with great fortitude and presence of mind recognised she needed companionship when discharged home, and having been disappointed by a local health assistant agency, sought with continuing difficulty to find a suitable long term helper. From the conversation below she has been able to identify the strengths and weaknesses of each 'companion', and how they maintained her ability to stay in her home.

> *I employed somebody myself on Mondays to Wednesdays to come into the house and, my reason for doing so was primarily to get me out of the house so that um, yeah, I'm not confined and therefore, because I already said I have a need to get out and see people and change my environment, and um, so I mean it doesn't matter what we're doing um, but um, just even going shopping or something like that, but I can see now... anyway that um, that was a friend of Judith's, a nice little girl- Jane. I mean it was nice and um, so it was good to have her to come in. It was a familiar face and I think that was what made the difference, but when Suzanne's mother came out and she was available, that made the world of difference, it was somebody familiar to come in and um, and that was, that was good, you know, and she came in and then originally it had been decided that she would take me in her car on Thursdays, but in actual fact her car packed up and she could not afford to have it repaired. So we didn't go out in her car and that*

> *became basically staying in all day when she came and did things and that's why I think it irked me and that she would sit around for considerable periods just reading and everything and stuff was, um. . You know, she wasn't sort of able to fulfil what the original job description would have been yeah and then after I found another girl who was absolutely fantastic and honest- Alice. She's just gone, and this last person I've got, I think... no I think now Alice was was right for her time, and we went out and did all sorts of exciting things, went out and had lunch and coffee and art galleries... We could, you know, I was still quite limited in what I can do but it was great. I enjoyed it and then um, ..but I think I'm getting beyond that now. I mean ... that this (new) lady has a car and is willing to take me but I suspect that I'm not going to be well enough to go out very often but she's a very motherly person so that um, and I think she's right at this stage of my illness.*

Carol similarly tried to retain an interest that sustained her emotionally:

> *(Carol) You can amuse yourself and I play the piano and they've got a piano...And they've got an organ. And um, oh, I can keep myself amused there as long as I like.*
>
> (Researcher) You enjoy that side of being able to...
>
> *(Carol) Yes I do. Even though I'm 84, I can still play. Oh yes, music's been my life really.*
>
> (Researcher) Has it?
>
> *(Carol) Yes, I was a singer all my life. So you know, that ah, has given me a great incentive really- music.*

Vance had thought carefully about how he might retain control till death, recognising that he would have to rely on assistance of someone to care for him:

> (researcher) And what do you hope they will provide ultimately for you? What's the greatest wish that you will have of their care for you?
>
> *(Vance) Die with dignity.*

Chosen isolation:

From the dialogue emerged the idea that some people chose to find personal space and not to interact with others when they are within the hospice. Interacting with other patients and relatives was not appealing, and was actively resisted by Vance:

> *but this other thing ah talking to people I very quickly became because of my condition I'm always ah earlier I became very tired, very quickly, talking to people, and even listening to people. I didn't talk to people easily I sort of sat and smiled and say Hello. In fact because I quickly became aware that a lot of people didn't want- couldn't be bothered in conversations.*

Other people although not actively resisting the company of others, found their own thoughts to be enough, and were quite pleased to be on their own. Frank, who seemed a very quiet person, obviously enjoyed the staff's company, but needed his own space:

> *No I didn't (share a room) Just on the last day I was just... I was packing to leave and somebody was coming in ... I would prefer to be on my own."*

Even if there was someone else in the room, the quality of silence and lack of interaction, was appreciated. Carol said:

> *And I was in a ward where there was just one other lady, she was a very sick lady with cancer, so she didn't bother me. No, No, She didn't, she didn't annoy me at all. She was very quiet. And I'm fortunate I don't have any pain you see so I don't have to annoy anybody.*

Helen although not expressing displeasure at having to share a room when distressing events were occurring; described them in such away that suggested the degree of impact that they had on her:

> *I mean it was just so sad to see her having to suffer in that way really, you know, and it was the one form of - you know to lose her dignity like that - it was just so terrible, but they were so gentle. I didn't have the patience that they had either. I used to despair at this lady, but they were very good. You know this last incidence with the..the whining lady in the bed next to me, and no matter how difficult and demanding and unfair she was to them it still didn't make any difference - though she got treated with the utmost care and devotion and fairness, you know, regardless of how difficult she was.*

Vance was the only person to go even further on this theme, and say how it affected him being in close company with others who were in their dying stages, or with people whose behaviour he found unpleasant:

> *There was one visitor who came in obviously the daughter of a patient, and and, and she drove me mad with her baby talk, and she probably drove him mad too,- treated him a man older than myself, and I'm old enough... ah, but um, baby talk to an old man made me cross. You know, when people... when they're ill like that, dignity becomes bloody*

> *important.*

Vance went on to say:

> *...when I first went in I went into a single ward, because they wanted to have a look at me and, and then they found someone who was obviously very ill- he was obviously pretty ill, so I was moved out and put into another ward and from a purely social point of view, ah it didn't matter at all. There were three chaps who were obviously pretty ill . I quickly became more mobile and it was it was difficult and it was pretty depressing. I was in the dark end of the ward- the curtains around them- it wasn't bad but the others had to cope with them and the lights out., so the light was out, it was dull but I mean that that's a tiny criticism and uh, and of course, and they always snored at a different rate. It would affect some people. I'm sure I'm quite sure. It really was depressing, that the people couldn't talk really, I was on my own.. fortunate I was so fortunate um, and I was getting up and about and able to wander around and all that sort of thing. And of course, the exercise did me a great deal of good, and in a sense it drove me out of the ward, and mobilised me. But that could, I agree for some people it could have been depressing.*

Being Safe

The element of being safe seemed linked with the ability to trust in both the staff and the effect of the environment It was expressed implicitly and explicitly. It related implicitly in people's stories about how the environment affected them, and explicitly in ways that they were kept safe in the hospice, as well as giving relatives a change from full-time home care. Rose talked about the inner turmoil she felt in coming to understand her illness, and her mortality. In coming to a place of safety, she was about to respond to that turmoil in a positive way:

> *I was in the hospital.. (a public) Hospital for seven weeks.*
> *Now I.. I really.. I've no complaints about them.*
> *I must say everyone was kind and they were good but when you get into a hospice it's entirely different background.*
> *As I said before, when you get in there, there's, that sort of, peace about the place. There's not the bustle and activity that's at the general hospital. When you get in there, there's, that sort of, peace about the place. You know what I mean - there's that peace and they've also got that little chapel and whenever you feel like it , you can always walk down there, and sit, you know, a get that tranquillity, which when you've got a terminal illness, you need...you need that, because your mind gets in a turmoil sometimes.*

For Helen the hospice providing a physical place of safety when her family who although they didn't live with her yet kept a close eye on her, had gone on holiday:

> *As I say the one time I did go in was when they were all away with having a nice family time and John my elder son, who couldn't come over from Australia, and um, so everyone was here, but of course after he'd gone there was only one more week left of the statutory holidays, and there was sort of nobody here for that week and um, the day therapy unit was closed at the hospice because it was Christmas and New Year you know what I'm saying- yes I needed intermittent care then.*

Another critical component of a place of safety was how it affected the home caregivers of these people. It was very obvious from our conversations, that these individuals understood what stress it placed on the (mainly) relatives in caring for them constantly. Frank was delighted to be part of a regular respite programme. On this programme he spent one week every six weeks in the hospice. When speaking of the goal of his programme said: *"...hopefully its going to give some relief to me and also to her my caregiver my flatmate you know."*

Carol appreciated the effect the respite programme could have, not only having her symptoms regularly reviewed but also respite for her family with whom she lived:

> *I go in again on the sixth of May for another week, and then it gives these people home here a bit of a rest, you know from me , because they are I have attention all the time Jane gives me showers and so it's good that they can have a rest.* (Carol was referred to the hospice, by the home oncology nurse in order to allow the daughter a regular break) *They need a rest from me here at home. If Jane wanted a rest you know, she might want to have a nice rest from me sometime, well they'll always take me there.*

As well as giving Brian a chance to relax he too saw the value for his wife: *"I would honestly feel now but these future visits are going to work because its going to give her that break again".* This was the same reason for Vance as well, who knew at this stage in his illness, that it was critical that his wife be able to have a rest, and be given support, as well as himself: *"... but the correct thing is the consideration of* (my wife) *and the real help, and the contacts."*

Rose, despite being very frail, lived on her own in a little flat; her daughter lived fairly close. There was daily contact between them; as well as many supportive neighbourhood contacts. Three people dropped in while the interview was in progress:

> *and I'm booked to go back to the hospice on the 5th of July , for another week they assess my medication and check everything. I know everything's under control. I'm booked in 5th of July to the 25th. She's (daughter) delighted about it.*

Rose also appreciated the effect that the environment had on her, creating an internal safety:

> (Researcher) What does it feel like? What do you feel you're in there for?
>
> *(Rose) Well its very difficult to explain, you just feel at peace, with the world in general...*

Relinquishment and relaxation

Inextricably tied in with being safe was the sense of relaxation, and being able to temporarily relinquish; the voluntary 'letting go' of the ongoing responsibility for caring for oneself (either totally or in conjunction with family\friend caregivers). After you felt the sense of being safe, there came the ability to relax. This seemed to also be related to feeling that you didn't have to keep going by yourself, or with your partner. The responsibility for keeping a watchful eye on yourself and making decisions about your state of health, could be left to the staff.

Brian found being able to relax was a great benefit to hospice care:

> *(Brian) I'm independent, and they just know that and they just watch and see if I'm relaxing and things like that. As far as problems go, there haven't been any problems down there. Um, they've been really good.*

> (Researcher) Does that make you able to relax more, or
>
> (Brian)... *It's the general atmosphere and informality that's right through the whole place. There's no problem with being there, .and I find that it gives you a chance to catch up on things that I haven't caught up on. Like I'm now starting to read books. Whereas before, 15 minutes and I'd have to put the book down, I couldn't read any more.*
>
> (Researcher) Why was that?
>
> *(Brian) Couldn't concentrate. I was so tired, and bit of pain and I just couldn't concentrate but now, um, it's so much better, um...I went to the library two days ago and I've finished one of the books already. I'm halfway through that one. So that's the difference that's come about. And I think it's come about by being able to relax in the hospice and sort of just do what you want to do when you want to do it. Yeah, yeah. Relaxation is, um relaxing in there has been excellent. And you can't help but relax anyway.*

Brian also related being safe to not having to focus his life on ongoing targets, to relinquish this motivation for a period of time: For Brian this target setting presented his way of getting on with life, of monitoring and measuring the way forward:

> *..... in the back of my mind I say I'm going to achieve that target but by going to* (the hospice) *I'm having a break where I say to myself, I have no target at present.*

Defining what relaxation was proved very difficult:

> (Researcher) What does it feel like? What do you feel you're in there for?

> *(Rose) Well its very difficult to explain, you just feel at peace, with the world in general Let's put it that... that's the only way I can put it. Very difficult- you cannot put your finger on it.*

Frank too, found it difficult to express the meaning:

> (Researcher) You like to be able to relax freely?
>
> *(Frank) Yeah.*
>
> (Researcher) Is that easier in there or is it the same as at home?
>
> *(Frank) No, it's a lot easier there. For some reason it's........*
>
> (Researcher) Yeah. Can you put a finger on that?
>
> *(Frank) In there, yes.*
>
> (Researcher) Is it quieter, is it, or..?
>
> *(Frank)It's just the way people move around - they don't bash and crash around the place, you know, whereas they do in a general hospital. It's the way they work*

Vance talked about the outcomes of his being in the hospice. For him there was a measurable difference in having palliative care:

> *Oh yes it was really quite remarkable but I've come back.. I'm not doing very much but I feel I can do a few things extra things better. I'm feeling much better. You probably know when one is very limited in terms of energy, puff, and all that sort of thing, having a bath is a major*

> *exercise.. and ah, I'm doing these sorts of things as a matter of routine, whereas before I was sort of, I'm a slow starter, but the thing is the other night we just sort of said, well shall we have a game of Scrabble, doing it like we've done in the past, we've sat here from eight o'clock in the evening until three o'clock in the morning, just playing solid Scrabble. I was so glad that I could do a little bit more and just by being a bit more cheerful, it all helps.*

Frank spoke further about relaxation, and found it was linked to the effect the environment had on him; that was the ability to relax. Frank described being able to relax, as related to the noise-free environment and the way the staff interacted with him: *"Even the way they treat you and talk to you, you know it's good".* .

Mortality awareness

Those interviewed, talked spontaneously of their impending mortality and their wishes for death. There was no hesitation in their conversation on this matter. It was a very natural component of their whole experience of care. There is a sense of completion in some conversations. The moment of death was coming close, the decisions had been made. All those interviewed have subsequently died. Rose, Helen and Brian's hope being to die within the hospice. Rose expressed this choice:

> *you don't feel as if you're in there to die. And I hope to die there But as I say, as far as the hospice is concerned, they've done all they can do for me, dear. They can't possibly do anymore. And in the environment at the hospice, what a better way to die, I don't know dear. I hope to be there when it happens.*

Rose had begun to ensure that she could die without the intensive treatment given in the past by the acute care public hospital. Rose also spoke of the need that she felt, that her beloved daughter 'allow' her to die. She had spent time talking to her daughter about her wishes for her death.

> *(Rose) If I take another heart attack - don't do all that heavy medication and price and all that - don't use it. Use it on somebody that it will do some good, .because it's only an extension of time, as far as I'm concerned, and I don't want them to do it.*
>
> (Researcher) No.
>
> *(Rose) So I said well, I says, I'll sign, no I don't need tell my family so I told her (daughter) - No...No fuss- any thing, cos they said how did they do, did they do everything which is only natural. I'm all she's got, but I've got to go sometime, as soon as she realises she's very lucky, very lucky girl ..... I was 80 on Monday. I made my 80th birthday- I lost my mother when I was 21, you know what I mean.*
>
> (Researcher) She's had you for a long time.
>
> *(Rose) She's had me for a long time and I said that you must realise you can't live forever, and I said you've been very fortunate you know now, you've got your own family and they're all grown up and that. I said so you've got to learn to let me go, when the time comes.*

Helen had had several unpleasant experiences being cared for at home, and appeared anxious about the thought of dying there. In our conversation she explored the anxiety of being alone at the moment of death:

> *I want to die in the hospice... don't want to die at home. I think this*

> *results from the unfortunate incidents' I had when the services fell over for me I think that we're all frightened of pain. I think the best provider of pain would actually be in the hospice where they can constantly monitor my condition. I think that I would be best looked.. you know, my final hours and days would best served for myself if I spend them in the hospice. Yes they're trying to persuade people to spend that time at home and die at home but I would really like to go and end my days at the hospice.*
>
> *My boys are quite young. It's a major thing to um, ask them to deal with it. I think that I'm better in the hands of professionals who will not only care, take care of me, but will help them too, you know.*

Vance had had a life time of illness with a heart problem, and had only very recently been diagnosed with advanced cancer of the lung. He was undecided about where he would die. Initially he said he wanted to die at home; however later in the conversation Vance expressed anxiety about how his wife would manage. From this point in the conversation he started to discuss the possibility of dying in the hospice. This seemed to be in response to the sense Vance had that his beloved wife would be cared for and supported, at the moment of, and after his death. He said that all he wanted was to *"die with dignity.. it doesn't worry me actually oh, oh, oh, but I care for her, that's my worry".* Vance was also concerned with how his wife would cope with pragmatic matters after his death, and was beginning to assist her in undertaking the roles he did at home.

> *(Vance) and... and ah, there's so much help and ah, you know, with the... tax and money matters - we haven't got much money but we've got... we found a very, very good accountant, .who looks after things and she rang him the other day and you know, he said, all right my dear, all things... you know, we'll deal with these sorts of things.*
>
> (Researcher) Sort it out.

> *(Vance) but I.. I didn't, .I didn't make her do it but I suggested she did it, rather than me do. You know, I think it's all part of the (palliative care)... sort of philosophy you know..*
>
> (Researcher) Do you think that this is part of it - that's it's sort of encouraged you to set about these things?
>
> *(Will) Well I think in the sense of preparation - for something it is unpleasant, inevitable, but unpleasant*

Frank found his symptoms; his shortness of breath very limiting and frustrating. He viewed the hospice's function as well as support as being to enhance his quality of life.

> *Well its there to help you.. to help you to relax, to improve the quality of life. Well that's what I hope it can do, you know because I haven't got much quality of life now.......if they can make the last bit more comfortable then it would be good.*

The component of existential hope was discussed by Rose. She was very conscious of the fine balance of choice, either to retain her existence here on earth and go on living, or to make the decision to die and go to a place where her husband had already gone. She articulated the balance between wanting to die and wanting to live; they can almost occur simultaneously.

> (Researcher) ...when you went in the pain was bad..
>
> *(Rose) Oh it was very bad....was very bad,.....I wouldn't have cared.. in fact I wanted to. I hoped they'd give me a good injection, and finish it.*
>
> (Researcher) Did you still feel that sense of calm even though you were still in pain?

(Rose) No I didn't...until they controlled the pain, No, I went in when I was so ill, dear......I didna feel anything......it was only when you realise it- it was the Sunday. It was only a couple of days afterwards when I was sort of straightened out as you probably put it...Then, I was straightened out then I realised God I've got no more pain. ..I feel more different. I feel I could get up and do something...You know, I felt that good but to say that immediately, no dear, I was too ill. All I wanted was to die when I went in there... just thought they'd give me the one good injection and forget it...That wasn't so... but the reason is you see I felt it immediately and that would not be true.....but when I came round, you know, now things were settled and I had this and that, -I realised how good I felt.....and I've got no pain - I just couldn't believe it.
No, honest, I could not believe it...and that's when I felt good. I felt oh, you know, I felt I wanted to live...to be honest...I felt then- you could go on. I was there for some purpose whatever it was but I felt quite good about it. I felt I didn't mind here. I didn't mind everything you know. I felt quite good about it.....because of that. So that was actually when I started to feel good...and that's when I sort of got the atmosphere of the hospice.

The Staff: The final three components relate to actions and characteristics of those who gave care in the hospice, the staff. There are descriptions of aspects of care, and also of the staff themselves.

From the stories that the patients told about the staff it appears that they were viewed in a generic way as 'hospice staff', with little formal recognition given to their professional roles. This appeared to be consistent with emphasis within palliative care philosophy on the importance of interdisciplinary palliative care roles.

Being Watched

'Being watched' was care and protection being given in a careful considered manner; protecting autonomy and privacy, yet being human and available. A sense of trust and safety was involved within the idea of 'being watched'.

Brian described this as:

> *I don't need them sort of bathing me and things like that. I can do all those things- I'm independent, they just know that and they just watch and see if I'm relaxing and things like that. And I think its come about by being able to relax in the hospice and sort of just do what you want to do when you want to do it. Relaxing in there has been excellent. Just a case of watching and seeing how I was and how I was feeling.*

Brian's conversation was threaded through with the key idea of hospice allowing him to 'relax'; an idea which he was unable to elaborate further on, yet was the key to his satisfaction with the care he received.

Helen went on further to say: *"...they're people trained to look and see* *what needs to be done.* This notion was central to Helen's description of her care, over a long period of time. There had been many crises for Helen: some physical, some psychological, some spiritual, and some relational. Helen described a situation in the previous year were she felt that she couldn't go on; this being about the time when she realised the original time frame for her dying was incorrect, and that she was still in the process of living:

> *There's been family conferences and they've been called on in their time. Because I was difficult, I must say that, in the middle of last year. I did not want to come home. I got to the point where I'd lost my confidence. I didn't think I could cope at home. I happened to have three very unfortunate incidents there - the system fell down and left me in dire straits. I was at home yes and um, that preyed very heavily on my mind. I was very reluctant to come home again. But I must say since I've been home this time, nothings happened untoward like that at all. You know, moral, mental, emotional, physical support that I've been given - I mean you couldn't fault it.*

She talked of a sense of timeliness and of authentic relationship, that was part of this *"...being trained to see what needs to be done*"; and explained this in an anecdote she expressed about the long standing relationship she had developed with one of the spiritual care team:

> *You know, she went to all sorts of trouble, you know, she spent time, she let me ask questions, and she found books and, gave me a series of exercises to work through, um, nothing too onerous - suggested I do some writing.*

Later in this piece of conversation she went on to talk of a subsequent relationship she developed with a religious minister whom she had known several years before, which was fostered by this hospice spiritual care team worker, Helen said of this fostering that the worker: ...*"very gently and without any thought of herself guided me into his hands."*

The notion of the "...watching eye" and being "...trained to look and see what needs to be done" gave both these people a sense of safety which Frank too spoke of:

> *No its (relaxation) a lot easier here For some reason its..... the noise is not as bad..... Its just the way that people move about- they don't bash and crash around the place, you know whereas they do in a general hospital...its the way they work. Even the way they treat you or talk to you , you know its good. It's (the hospice) there to help you, to help you relax, to improve the quality of your life*

Caring Qualities:

Although this research was not focused at those who give the care; there were many consistent comments made by those who spoke with me. Some comments were made about health professionals from specific disciplines, but many were general; reflecting perhaps the intentional hospice process of interdisciplinary team work including those not characteristically viewed as providing therapeutic care. (cleaners and volunteers). These comments spoke not of professional\technical skill; but of an attitude, and approach. Because there was an emphasis on the qualities exhibited by the carers, it seemed that it became an important component of the experience of care. In this relationship, caring grows as those interacting begin to understand the inherent 'nature' of the other:

> *(Rose) They're all quite cheery and.. and I tell you what, it's not my nature because I was born and reared in Wales and where we're colder as cold is our nature, but they're hugging and always making a fuss of*

> *you...and you know, it's strange to me because it's not my nature, you know, what I mean. But you accept it and I realise that they're showing me how much they cared for me.*
>
> (Researcher) How do they make a fuss of you? What do they do?
>
> *(Rose) Well they come in and say how are you- you know and come over and I say - we're going to throw you out, and they'll throw their arms around you, we've had enough of you- we'll have no more of this, there're will be no more of this cheek- and that sort of talk, and maybe they'll come in and say something and I'll say something and they'll say what does that mean I don't know what you're saying? (Rose had a pronounced accent) and then of course, I've got to unravel it for them. What it means and all about it, you know. And some of them tried to mimic me, why you've never heard anything as funny in your life. Its no more like me than fly in the air. But they do that - that's the sort of attitude- they sort of try to brighten your day, you know what I mean but they always asking you one minute do you want anything...do you need anything..*

Carol said:

> *I enjoyed the nurses They're all so free and easy They're not stuffy people, and I enjoy their company. In fact one of them comes in and does the fandango dance. and I enjoy that. Yeah they're all very kind. And I enter into the spirit of informality with them. The nurses are very good. They never leave you for very long. They never leave you to find out something for yourself. They'll always help you.*

Brian who had had several previous public hospital experiences said of those admissions:

> *They were terrific but they didn't have the time to talk to you or anything like that whereas in the hospice if one of the nurses had s bit of spare time they'll come and sit down and talk and things like that.*
> *But the whole atmosphere. I suppose what makes it good are two things: one is the informality where you haven't got uniformed staff, and the other is the um the great rapport between the volunteers and the permanent staff. they certainly go out of their way to help without giving the impression that they're labouring to do it.*

Rose felt the qualities of the staff affected the way they did their work: ...*"people with a cause".*

> *I found the people that work there dear, were not just the ordinary brand of nursing people- I'd call it a vision, after that its the attitude of the staff, everybody from the cleaner on, they're all caring. Everybody's caring and you only have to make a request and it's there. I think its the people that work in the hospice that make it so, because they're all dedicated people they're not just nurses, they're not just domestics, they're not.. and look at the helpers that come in with the meals and do everything, voluntary workers, all that, people that give their time. But you see, they all make it as though the pleasure is theirs serving you...that's the difference (from the public hospital). They are a people with a cause.*

Frank described the effect of staff attitude too; the sense of being consistent, treating all with concern and kindness. He also described the experience of the staff member who planned to stay a short time; ending up staying much longer:

> *So they're very good you know.. very special kind of people I think. Not everyone could do it Yeah not everyone could do it. They do it because they want to, and that's all there is to it you know. One said she'd been*

> *there for... she'd gone there for three months and then she was there for seven years.. Everybody's so helpful, you know. The volunteers they're terrific. Even with them, nothings too much effort. It didn't matter who you were you know they still did their best for you know. They didn't have to know you to do their best.*

Vance talked of this interior motivation for people working within palliative care, which gave them an ability to relate to people in an honest way:

> *They're all mature sort of people. There's no sort of, you know.. well you feel that they're there because they want to be, and they're interested in other people.*

He went on to express: *"...and of course* the *wonderful thing was .. you start realising that they weren't just treating me - they were treating us."* The care that the staff gave to Vance's wife seemed to be viewed by Vance as far more important than his own care. His concern for his wife was visible, and parts of the interview involved Vance telling his wife of his love and care for her.

Although many of the caring actions were viewed as generic interdisciplinary work; occasionally staff were referred to by their professional status:

> *(Helen) I was introduced to Sister Robin, the Chaplain, and she was wonderful because I was a bit lost actually...*
>
> *(Brian) I suppose what makes it so good are two things. One is the informality, where you haven't got uniformed staff and the other one is the, um, the great rapport between the volunteers and the permanent staff.. And the permanent staff know that they're relying upon these other people*

(Rose) you're not just a patient, you're ***someone****, and everyone of them cared for you even the cleaner dusting around the walls, talks to you, you know, so you feel instinctively that they're all caring for you and they're all interested in you,*

(Helen) You know the arts and crafts and it's run by a very efficient and caring team of occupational therapists and that's my thing anyway. I like arty crafty things, and Joan, who's now the, in charge of the day-care therapy unit and an occupational therapist came out and examined my (home) facilities... And the services offered in the day care therapy is that you arrive at ten or shortly after and there's volunteers there that wait on you so that your coffee is brought to you ... they'll wait on you so that you're not having to ask.

(Brian) I saw a couple of the doctors, because of one or two problems I was having but they've changed medication now - it's so much different. It's just a case of ... something that your G.P. can't do but you, he hasn't got the time to do that kind of thing, .whereas the doctors are in the hospice, they're on duty all the time and they can follow-up anything that starts.

(researcher) Did they see you at different times of the day

(Brian) at different times, sometimes first thing in the morning, other times they didn't even worry about coming.

(Helen) The nurses are wonderful. Nothing is too much bother. And um, extremely patient... yeah I think that's what impresses me the most - is their patience. Patience. ... yes, and you know this last incident with

> *the.. this whining lady in the bed next to me and no matter how difficult and demanding and unfair she was to them it still didn't make any difference - she got treated with the utmost care and devotion and fairness, you know, regardless of how difficult she was. And she was a difficult lady - no doubt about that.*

> *(Helen)I wanted there to be somebody there.. a good counsellor, which she is amongst other things. ... I wanted there to be somebody there that they knew before I had died, um, so that if the need arose after I've gone there would be somebody professional for them to turn to... And so* (Jane) *has been and I must say that she has been absolutely marvellous...*

The Humour

It became obvious as soon as I started each interview that humour would be an essential element. Our conversations were interspersed by laughter, jokes, warmth, and times of sadness and tears. These individuals despite the severity of their illnesses were full of life; with humour being very much part of it. Humour was expressed as: the smiles, the laughter, the jokes the "...serious fun", the 'professional yet fun' staff.

Vance detailed an incident where he had dropped his glass on the floor in the middle of the night, and sought help in fixing it up. The staff member then offered a cup of tea, and then subsequently she dropped it:

> *she got so cross she was throwing tea at me- its there somehow a light-hearted sort of thing. it's a funny place. It really is a funny place, its quite extraordinary.*

Brian who had had several admissions, and felt he knew the staff well, put it this way:

> *..they are serious people and yet the way they act is not serious. They- There's a certain amount of hilarity and frivolity in it, but at the same time it's very professional...that mix of frivolity and seriousness- fun and serious work.*

Carol who in a previous piece of quoted narrative talked of how one of the nurses did "*...the fandango dance*" with her, loved the spontaneous informality of the place.

What also was expressed as important was a sense of loving warmth when things were not going well or were embarrassing. Rose with her advanced bowel cancer had increasing episodes of diarrhoea. This was distressing to her and she found it extremely difficult to accept. She described the gentle care and attention given after each episode; and then the cheering up process which took place. Rose found this 'cheering up' component as important as the physical care.

> *..and they'll do anything like that but you see part of my trouble of course with the cancer going to the bowels, you know, I've had a few troubles and when I don't make it you know. I get very upset. I get very, very upset...I really do - I get very upset.....and eh, they say, now look don't worry about it and they take me and shower me, wash me down, and they hug me and carry on, and don't cry... you know, we canna help it...I feel that terrible about it, you know.....so against my nature and I get down to it and they hug me and say its all right its all over and finished with you're all right smelling squeaky clean and all this. This sort of talk brightens you up and they always put you back in bed and give you a hot water bottles or anything that you want.*

Vance was surprised by humour:

> *but as I say there's obviously a lot of deaths -it could be a very sad place... Yes, it's... it's a funny place It really is a funny place. It's quite extraordinary.*

The philosophy of palliative care

Although the questions that I asked focused solely on the experience of care; the interviewees consistently told me what they believed the philosophy of the hospice was. It seemed an important component in their understanding of the process of palliative care to understand the philosophical beliefs behind it. It was not apparent to me how this information was communicated to them. Was it because they were now integrally involved within the service, and that they wanted to know and understand more?

Providing a firm and mostly unspoken base for the palliative care philosophy was *best practice quality palliative care*. This term encompasses the unseen combination of quality management practices and effective symptom management: the watch word of palliative care.

Brian who lived out of the urban area had followed the development of the new rural palliative care service, but also knew how the urban service functioned:

> *Here at* (the*) Hospice have changed their philosophy now, and you don't go in there for long term stays now, that's a very good philosophy really because it's caring for those who really need the care. But the philosophy now I think is ... its like a lot of these health services, get them home, get them out into the community, and if you can live in the community, I think it's a good thing to move them out, and then that*

> *leaves care in the hospice that can go to somebody who needs short term care, and I think that's the way they appeared to work or to me they appeared to be working that way, and as far as I'm concerned, well I can say from my point of view, it's working damn well*

Helen discussed this from a personal angle; expressing how she saw the palliative care philosophy in relation to the place of death, but then expressing her own personal preference

> *Yes they're trying to persuade people to spend that time at home and die at home but I would really like to go and end my days at the hospice. So I guess just more of the same (care), really that's what I see. I would like to happen in the hospice in the future, you know, to continued access to their services.*

Vance talked of how the hospice philosophy had impacted on and influenced his preparation for death.

> *I'm not worrying about everything, but there's a few things I, I, I think are important, and I want to make sure she understands what has to be done... that she's aware of these things. We found a very good accountant who looks after things. and* (she) *rang him the other day, and you know, he said, all right my dear...\\ we'll deal with these sorts of things. \\ I didn't make her do it, but I suggested she did it. You know, I think it's all part of the* (hospice) *sort of philosophy you know. Well I think in the sense of preparation- for something.. it is unpleasant, inevitable and unpleasant.*

Frank talked (as several others did) of another unique component of hospice care: the place of volunteers within the service. Frank understood that volunteers were an important part of the palliative care philosophy. He also expressed the underlying aim of the palliative care service; to improve the person's quality of life- however that might be.

> *Everybody's helpful you know. The volunteers are terrific. You know the to help you relax, to improve the quality of your life.*

Both Helen and Frank in my field notes expressed the unseen dynamic of the hospice experience; Frank when he said: *"Hospice is a magic word, when you say it, results happen"*. Helen expressed it on our initial meeting at the hospice by saying: "*...maybe it is the hospice that has made the difference".*

Although Helen had experienced difficulties with the interface between hospice and community care which at the time of interview was provided by the Crown Health Enterprise, she expressed how intent the hospice had been on alleviating the difficulties that had occurred as her disease progressed:

> *And then um, you know I think what started was that the district nurse or the oncology.. I had a lovely oncology nurse, who contacted the hospice and set up the original link and Joan, who's now the..in charge of the day-care therapy unit and an occupational therapist came out and examined my facilities and so that was something I wasn't aware would happen but she looked into....*

Helen went onto explain all the physical changes which had happened.

> *And then um,.. transport is provided.*
> *They arrange transport with the hospice van which travels around and picks up people. Because I've got a very painful back which is rather tender I can't sit in the back of the van in comfort so I sit in the front of the van.*
> *And then at another point, this is fairly recently, prior to Christmas my benefit. \\.. my benefit had reached its 12 months and I was to forward*

> *them more information and update the file. Now I had a considerable hassle with the Social Welfare Department the first time round \\ so I have kind of this mental block about Social Welfare Department in the first place because I've had such a rum deal \\ I couldn't remember what information had gone forward to the Social Welfare Department first time round so I was procrastinated.. it just got left and finally I got a second letter to say that well it had expired \\. And so I was telling (the hospice accountant) a bit about this so there's another lady at the hospice and she's sort of a welfare officer I suppose \\ and she was able to get from them all the information that had been forwarded the first time and she just went through it and she dealt with the matter like in about half an hour flat and less probably in my presence. She might have spent a lot more time behind the scenes - I'm not sure. But yeah, so my benefit has been reinstated and backdated to the date at which it expired, thanks to her.*

Although a number of these people who spoke to me, had severe physical symptoms either expressed or obvious to me; there was little focus on this in their conversation, and little expression of how the relief of these problems impacted on them. Symptom control seemed a 'taken-for-granted' or 'always-there' aspect of palliative care. Something that is now viewed as an essential component of the service. However Rose talked about this at length explaining that for her, unless her severe pain (which caused her admission) was relieved she would not have been able to take part in the experience of care which the hospice offered:

> *All I wanted was to die when I went in there. \\ When I came around, you know, now things were settled and I had this and that, - I realised how good I felt, and I've got no pain, - I just couldn't believe it, and I've got no pain - I just couldn't believe it No honest, I could not believe it, and that's when I felt good. I felt I wanted to live, to be honest, I felt then - you could go on. I was there for a purpose what ever it was but I*

> *felt quite good about it. So that was actually when I started to feel good.. and that's when I sort of got the atmosphere of the hospice.*

The environment

The inexplicable link between the caring process and the environment was illustrated by the difficulty with which people described what was going on, yet referred to it constantly. Brian when he was attempting to name what aspects of the environment made him relax: *"I still can't put my finger on it"*. However it was an essential component of what was perceived as the caring process, and was integrally linked with a sense of peace, relaxation and safety.

Rose who had been in extreme pain on her previous admission, and had wanted to "*...be given a big injection of Morphine*" spoke of the way the sense of the environment affected her:

> *...as I said before, when you get in there, there's, that sort of, peace about the place. There's not the bustle and activity that's at a general hospital. You know what I mean - there's that peace and they've also got that little chapel and whenever you feel like it , you can always walk down there, and sit, you know, and get that tranquillity, which when you've got a terminal illness, you need... you need it... because your mind gets in a turmoil sometimes, you know, only human and that's all you think, why me you know - wonder how this happened, you know. When you've been suddenly healthy all your life, you know. Why suddenly you get something like this, and I found that was one of the differences. As soon as you get into the hospice, and you're settled in, everybody is so quiet in their manner too. Very quiet and there's no - any loud noises.. and yet they're all cheery - they're no long faces.*

Rose's husband had also sensed the safety of the hospice environment, and chose to die there despite Rose wanting him at home:

> *(Rose) I'd always hoped that if anything that he would die when he was at home....you know,.....it wasn't meant to be. ..but, mind you, he'd go back now, see all the people there and doctor - like the last time I said, I'm sorry dear, you have to go back. He was only home one day, took him back the next day. He was that ill. I said I'm sorry dear but I'm getting the ambulance to take you back. And you know what he said, he said Rose its the only place for me now.*
> *He knew it. Because he knew it. And that was what he said, he says and I told Anna- oh your father said and I says I told him, I'd get an ambulance- so she wasn't there at the time and she went to collect her friend to come and see him you know, when he was at home and when she came in oh she was shocked because she came the same time as the ambulance you know. And she thought her farther had died and I know she took a turn and I said your father has gone back to the hospice...but I said, she said oh Mum and I said your father said- it's the only place for me. So it shows you the atmosphere had got to him too. He felt safe there. .... He felt safe. He felt safe.*
> *So I would say all that is the background to the atmosphere of the hospice against the background in the hospital.*

Vance with his multiple previous acute care hospital stays found the hospice environment unexpected:

> *...the atmosphere, the whole thing at* (hospice name). *I have I've had in my lifetime various friends in hospital, in and out and ah, long spells too, but oh, but I am enormously impressed. As I say there's obviously a lot of deaths- it could be a very sad place- but it isn't. They create a as happy as can be situation, ah, and the compassion is clear*

> *and evident all the time.*

For Frank the environment allowed him to relax. He talked of trust in the actions of the staff, that he knew what they did, and would do would: *"...be good, you know, I couldn't get over the amount of care they give, you know. Not just physical care too."*

Brian in expressing the effects of the environment saw it as a number of interactions:

> *The big thing I like is that they're not fussing over you, they leave you to your own devices but if you need them you got the call button and that's it. But the whole atmosphere. I suppose what makes it so good are two things. One is the informality, the other one is the, um, the great rapport between volunteers and the permanent staff. And the permanent staff know they are relying upon these people. There is the feeling of co-operativeness- you don't get the impression that they're ...fighting to get that co-operation... fighting to do things, to make certain they co-operate.*

Rose had had several long admissions to the local public hospitals. She had no complaints about the care she had received within these institutions. She stated she was well cared for; however the 'care' was different at the hospice, with a sense of peace and safety:

> *.but that's the one thing about the hospice - as I said, you can't put your finger on it, but it seems to surround you like a cloud, that sort of serenity.*

Carol sensed the beauty of the building: *"Oh, I think it's a lovely building. And there's a lovely lounge you can go and sit in".*

For Vance it was in the actions of the staff, and the building:

> (Vance) *Create a as happy as can be situation, ah, and the compassion is clear and evident all the time".*
>
> (Researcher) Do you think it's by both action and what is said?
>
> *(Vance) Yes, I think that's the whole thing. You know, the- the place itself*

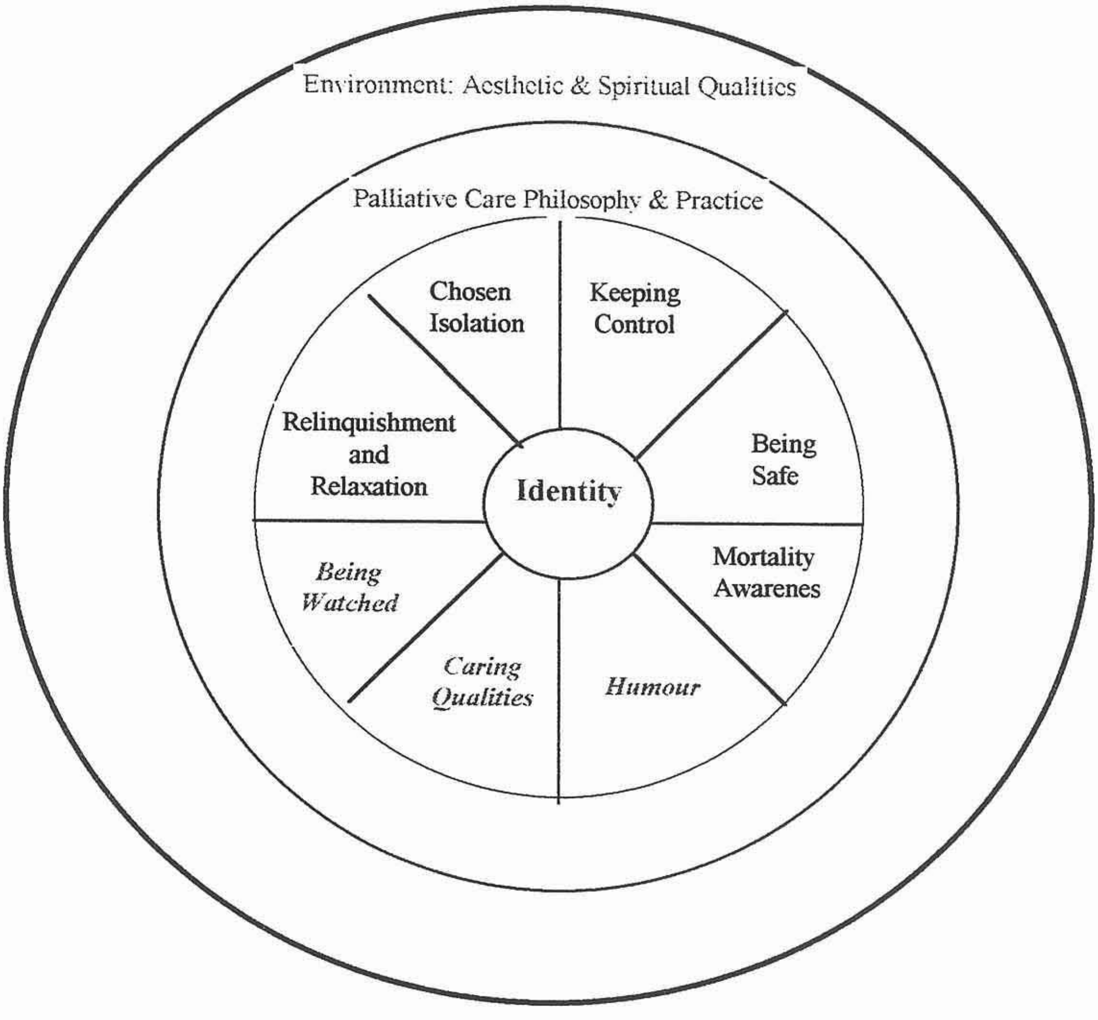
Review and summary

This chapter presents the experience of six people undergoing palliative care. This experience formed a number of interconnected themes. I have described these themes and have used the narrative to illustrate and inform these themes. In doing this I was attempting to give "...portraits... of human experience" (Sandelowski; 1993, 1).

In the following chapter I wish to discuss the meaning of the themes, utilising other descriptive literature which I have collected, and describe how the themes form the configuration or representation of 'The circle of care'.

Figure One

The circle of care



Chapter Seven

The Discussion: The representation, 'the circle of care'.

Introduction

The purpose of this chapter is to present the interpretations of this study, and to discuss the meaning of the six participants' life-world of receiving palliative care, indicating the areas for further study and elucidation.

In presenting the background material, literature review, and the results of the research, I believe the complexity of the subject of how palliative care is experienced is highlighted. It becomes increasingly apparent to me that there is a unique life-world of those receiving palliative care. This life-world encompasses both the experience of 'living while dying', and also being involved in a care experience which could possibly be quite different from what has happened previously.

I did not start this research with any hypothesis, in fact I deliberately developed a process of attempting to become explicit about my own biases or assumptions. I was well versed in the dominant ideology of palliative care, but also functioned in a mode of critique, symbolic of my background of quality improvement theory; particularly I was questioning of the gaps in knowledge regarding patients' experience.

The 'patient' although well described in palliative care literature in terms of requirements for symptom control and holistic care; was comparatively unknown in reporting what they valued themselves about the care received.

There are many unique and genuine ethical questions relating to research with those who are dying. It is because of these concerns that I believe attempts have been made to determine patients' experience through other means, rather than by asking them directly. Both these issues are fully expanded in chapter three, Palliative care: 'the patients experience' and chapter five, 'the methodology'.

This chapter contains first a section on the storytelling processes by which these narratives were conveyed to me, and then through means of phenomenological reflection the resulting interpretation of the stories.

A process of telling: the story-tellers.

> Language is a symbolic representation of the human experience. Human language is replete with metaphors and symbols which offer creative pathways to understand lived experiences of health. \\ One picture is worth a thousand words!
>
> (Banonis cited in Parse; 1995, 87).

> It is through an examination of the language we use to describe our experiences that we uncover the discourses constitutive of the frames of reference which we use to make our lives meaningful to ourselves and others. Placing our language under scrutiny facilitates an analysis of the words which we choose to use and the ways in which we construct our dialogue. It enables us to tell our stories \\ from a number of different perspectives...
>
> (Street; 1991, 10).

It is my belief that as well as there being a pattern or representation which has emerged from the stories, there was also a 'way of telling' that the story-tellers used to convey the stories of care experience (Frank 1995). This was very clearly demonstrated in four of the narratives, (Brian, Vance, Rose & Helen) where the participants stated that they had used the intervening time between the initial meeting and the eventual 'interview' to think about and 'construct' the story. I had no sense of having to question to receive answers, but that I was there to be the 'holder and bearer' of the story.

With three of these four 'prepared' story-tellers the conversation on my part was very sparse, other than the initial questions. I noted that their conversations did not always coincide with my questions. They had a way that they wanted to tell this story (Sandelowski, 1991; Frank 1995), and my questions were not going to distract them. Tappan (1989 in Astrom et al 1993, 184) describes this phenomenon of the need to "...compose a narrative... in some sort of temporal sequence".

> (researcher) Now I think what I'd start off with was ask you what services you've been involved with at (the hospice) because I know you've been before?
>
> *(Rose) Started off.....*
> *Well I started off with my husband.*
> *My husband had bone cancer and he was in and out of (a previous hospice).Now at that time that was housed in at (name of a building)- they hadn't built the new premises, they were being built at the time and my husband died on the 20th of July, about 7 years this July.*
> *So that's how I first came in contact - was my husband. They looked after him and the attention, and I mean he had the bone cancer which was the most painful cancer you can get, and I mean He was a big tall farming man, you know, -see the photos- a big tall man and it was sad to see him wasting away like he did..*

The narrative goes on to detail the husband experience of care, following on through Rose's next years until she became ill.

There was an urgency for some to tell the story (balancing the awareness of how ill these people were and also the other demands that seemed to take up their time). Even when I suggested that two of the participants defer from the research because they sounded so weak and tired on the phone, there appeared a need for them to fulfil this obligation. This was often stated as a way of paying back the hospice for their care, coupled together with an anger at the present political system which the participants were aware did not fully support hospice care financially. "Service can take many forms, but for the person who is seriously ill, a primary possibility for service is storytelling as an act of witness" (Frank; 1995, 41).

> *(Rose) ...and that's why if there's anything that I can do to help the (name of organisation) "Society" I'm only too pleased to do it, dear. Anything. Just ask me anything, and I can't say anything but the highest praise....for them because both my husband and I have been both patients....and as I say my husband died there. And I hope to die there. ... The disease will run it's course. They can't stop it. But what they can do and what they do is.. I'm as comfortable as it's possible for anybody to be....and that's due to the hospice....being there. If we didn't have a hospice, I'd have been in the hospital. Well that's what makes me so cross, that they don't give them more help. I don't want them to take them over because it would spoil it because they'd take over the (name of hospice) and they don't need anyone to run them they're doing very well on their own. But I do think that they should be relieving them of the financial burden......with all this fund-raising. I mean they've got to have Daffodil Days, they've got to have this day, that day and I'm sure the bairns must be tired fund-raising.*

There was a sense that this way of telling a particular version or interpretation of a story was a 'type' or a metaphor of an experience that the participants wanted to convey.

> Thinking with stories means joining with them; allowing one's own thoughts to adopt the story's immanent logic of causality, its temporality, and its narrative tensions. ... The other's self story does not become my own, but I develop sufficient resonance with that story so that I can feel its nuances and anticipate changes in plot
>
> (Frank; 1995, 158).

> Metaphors and symbols can shed light on the meaning of complex human experiences. ... Making connections between images and lived experiences is a creative process which serves to express the wholeness of meaning in a situation as uniquely lived by the person
>
> (Banonis cited in Parse; 1995, 88-89).

Although I had anticipated the story-tellers wanting to detail difficulties they had found in the system of palliative care (as I had been used to receiving within quality improvement interviews), they chose not to make these aspects the main focus or as Banonis (1995) says above the 'wholeness' of the story. It's true they were there, but were conveyed in a way which minimised their importance in the overall scheme.

> *(Vance) I spoke to the visitors in the smoke room, which you may remember...I mean, if I have one complaint it was about that, but they've got to provide a facility for people like myself I'm virtually an addict ah, it doesn't matter now if you like ......and,... but how stupid it is to have a very loud fan in a place like that...the fan... the moment you go in it automatically comes on....blasts away...and the heaters there.. and a television provided...the fan makes so much perishing noise, that you can't hear the television...*

Interpretation of the data analysis

As the analysis of the data occurred, a representation evolved which visually described the experience of the six individuals interviewed, 'The circle of care'. It was my intent from the start to faithfully report the aspects of care of which these individuals talked. However what in reality occurred was the conveying of a process of 'being', as well as an experience of palliative care. They talked of who and how they were, and those whom they loved and cared for; a life-world of existence (Tappan cited in Astrom et al, 1993).

I could no longer just extract what was said about care; I needed to examine and reflect on what the whole narrative meant, why they chose to tell me, an unknown person, of this precious and meaningful living world. This process of reflection encompassed using words; the writing and re-writing process to hone, clarify and refine the explication of their words to convey an authentic and true report of this life-world of the experience of palliative care.

> Writing fixes thought on paper. It externalises what in some sense is internal (or inter-subjective); it distances us from our immediate lived involvement's with the things of our world. ... Thus writing creates a reflective cognitive stance. ... The object of human science research is essentially a linguistic project: to make some sense of our lived world, of our lived experience, reflectively understandable and intelligible.
>
> (Van Manen; 1984, 27).

In this process of writing I could not remain unmoved or stand apart from these people. Although encountered briefly, these special people left lasting visual and sensory images. And too, how precious to be invited into a person's home, to see how they live, the aesthetic surroundings, coupled with noting the number of steps up to the house, how cold the room was, the pile of medications on the bedside table, and the hiss of the oxygen concentrator.

Van Manen (1995, 7) describes the process of using the themes believed to be the essences of the phenomenon in undertaking data analysis.

> Now that you have the themes, the abstractions, you have elevated yourself from this experience, but these are abstractions these themes. They become the keys to open up the text itself, the experience....
> ..grasping and formulating a thematic understanding is not a rule-bound process but a free act of 'seeing' meaning
>
> Van Manen (1990, 79).

Van Manen (1984, 20) uses the metaphor of a spider's web in describing the role which themes play in interconnected lived experience:

> ...themes are more like knots in the webs of our experiences, around which certain lived experiences are spun and thus are experienced as meaningful wholes.

Within the discussion I have chosen to illustrate the stories with 'like-metaphors' from literature by those who are dying, or about dying. I have particularly framed these 'like metaphors' around "The death of Ivan Ilyitch" by Leo Tolstoy published in 1886. I first read this book in the year prior to beginning this research and was struck by a reality that the process of dying remains the same across time (1886-1998); although it is hoped that the ability to alleviate symptoms is now more widely available. The book poignantly captures the dying of a middle aged man in Russia. It is written from his perspective and describes his feelings about his disease, his care, and others reactions to him. When I re-read this book more recently, I was struck by the similarity of the themes expressed by the people I had just finished interviewing, and the elements of experience described within the book. It was then that I decided in order to elaborate the interpretation of the themes, I would use quoted narrative from this book within the discussion of each theme. As an introduction to each theme, I have inserted selected portions of this text. As well, I have extensively quoted from Doug Smith's (1994) 'The Tao of Dying'. Its poetic text expresses a picture representing the essence of palliative care.

Within this discussion chapter, there is a tension between the descriptive and interpretive component of the methodological approach. I often refer to extracts of the conversation, (often being quite substantial), which will be identified by page number of the results chapter (Chapter Six), thus allowing the reader to follow the decision trail of my data analysis (Sandelowski, 1986). As I stated previously I feel honoured and duty bound to 'hold' and recount the anecdotes of the storytellers as this is what I believe they desired. As well I attempt to look further than the words that the participants used:

> Phenomenology does not simply iterate what is already given and understood in lived experience in the way that it is given and understood. It seeks a transcending theoretical understanding that goes beyond lived experience to situate it, to judge it, to comprehend it, endowing lived experience with new meaning. Without this transcendence, phenomenology would be superfluous.
>
> (Burch; 1989, 192)

Within the experience of these six people receiving palliative care, there are themes which are interconnected, lie in relation to, and inform each other. They form a pattern of lived existence, which is complete in itself.

What is the significance of these themes, and the pattern that they create? What does it mean to those administrators attempting to lobby politically for the continuation and extension of such a service? What does it mean to people who work in that setting, both as the carers who give what is needed to patients and those who attempt to evaluate and measure the quality and effectiveness of this care? From this window of experience which is entirely contextual and situational, is it possible to make statements which advance the art, craft, science, and politics of palliative care?

The mystery of beginnings and endings
is beyond description.
Foolish people limit the mystery through words
and concepts.
We must merely allow for the mystery.

There is mystery in birth.
There is mystery in death.
Every individual is a mystery.
The whole world is a mystery.

We must allow for mystery.
We must accept the mystery.
We must be part of the mystery.
We must be encompassed by the mystery.

What is not mystery?
(Smith; 1994, 51)

Generating meaning: The components of 'the circle of care'.

As the reading, listening, writing process evolved, a pattern with inner layers, and segments of meaning became apparent. These separate components were explicit within themselves as aspects of care. As well, they formed a dynamic with the other components, thus becoming inextricably linked; creating a synergy of effect.

The notion of 'identity' is the central component of 'the circle of care'. Around identity are five other components which are factors which the participants generated themselves: 'keeping control', 'chosen isolation', 'being safe', 'relinquishment and relaxation', 'mortality awareness'; and three components generated by the actions of staff: 'being watched', 'caring qualities', and 'humour'. Palliative care philosophy created the next border of care finally encompassed by the aesthetic\spiritual\physical environment.

Identity

The central component of The Circle of Care around which the other aspects encircle is identity. Identity manifested itself as:
unique identity
positioning my present existence
how I am now -normalcy
you must understand 'me'- empathy
valuing my difference: I am important
being in relationship
taking down the barriers: being normal and ordinary when you relate to me

> The previous history of Ivan Ilyitch was the simplest, the most ordinary,

> and the most awful. Ivan Ilyitch died at the age of forty-five, a member of the Judicial Council. He was the son of an official, whose career in Petersburg through various ministries and departments had been such as leads people into that position in which, though it is distinctly obvious that they are unfit to perform any kind of real duty, they yet cannot, owing to their long past service and their official rank be dismissed; and they therefore receive a specially created fictitious post \\ He had three sons. Ivan Ilyitch was the second son. \\ And Ivan Ilyitch got married \\ Children were born to him. His wife became steadily more querulous and ill-tempered. \\ They moved, money was short, and his wife didn't like the place they had moved to. Such was Ivan Ilyitch's life for seventeen years after his marriage \\ He went with the friend who had a friend a doctor. And with him to the doctor's. Reviewing the anatomical and physiological details of what, according to the doctor's view , was taking place within him, he understood it all. It was just one thing- a little thing wrong with the intestinal appendix. It might all come right. At the bottom of his heart Ivan Ilyitch knew that he was dying; but so far from growing used to this idea, he simply did not grasp it-.......
>
> (Tolstoy 1886; 17, 24, 27, 29, 55, 59, 60).

Identity clearly took the centre of 'the circle of care', because of its repeated form within the storytelling. I understood that this universal story telling form had a meaning; all experience that the patient attempted to relate, was relayed because of their own lived experience. It is living from their perspective. In order for the patient to inform the researcher about context, important information about them must be revealed, so the patient could be located in the frame of reference'.

Perhaps this is why the notion of identity is so threatened when someone faces death; the loss of personal existence, past and future, as well as friends, loved ones, and place in the world. "Human contacts affirm who we have been, and contact with our own body and mind affirms our own being-self" (Mansell Pattison; 1977, 53).

Academic literature has tended to come at the perspective of identity from the health professional's point of view, and labelled it as 'empathy' (Raudonis, 1993; Zderad, 1969; Olsen & Hatchett, 1997), and 'hope' (Flemming 1997). However it appears that in this study the participants initiated articulating the process of the valuing of their identity as a unique person. Arblaster et al (1990, 38) study affirms this idea:

> From the patients' perspective nurses are called upon to respond to them as people, not as terminally ill patients... Nurses should find ways to respond by listening to patients and identifying nursing behaviours designed to meet needs as patients discerned them.

Raudonis (1993, 308) in her study on empathy states:

> The findings of this study suggest that acknowledgement as an individual, as a person of value, was the basic meaning of an empathetic relationship for hospice patients.

Although there is some evidence to assist recognition of a therapeutic empathetic relationship from the health professional's perspective, Raudonis (1993) says that: "...the patient's perspective of empathy in nursing has not been fully explored" (pg. 305). Tyner (1985) agrees that, for an empathetic relationship to occur, there must be a recognition by patients that nurses have genuinely attempted to understand their past and present experience. Zderad (1969) describes empathy as: "...intuitive" and as having: "...a flashlike intuitive quality and penetrates to the real feelings hidden behind the other's defences" (pg. 657).

Flemming (1997, 16) concluded from her interviews of patients, that one of the most potent effects of emphasising the identity of people was the maintenance of hope.

Brown (1986) in her study of the experience of care, recognises identity as a prime theme, and views it from a health professionals' gaze. The theme, "*...recognition of individual qualities and needs*" (pg. 58), was characterised by perceptions of the nurse modifying the usual way of doing things to fit the unique needs of the individual. However this idea coincides more closely with the emerging concept of 'knowing the patient' (Radwin, 1996). This review of the concept included the notions of nurses being able to make forward decisions on behalf of the patient because of their knowledge of patient's previous responses to his/her illness, but also attempting to suggest there may be a far wider context from which staff need to attempt to know and understand the patient:

> ...striving to understand events as they have meaning in the life of the other. (Swanson cited in Radwin; 1996, 1143) and

> ...grasped the meaning of a situation for the patient.
> (Tanner in Radwin; 1996, 1143).

These latter ideas seem more consistent with a type of 'positioning', identifying who they were, who they now are, what their physical capabilities were and are now The participants were trying to identify what was important to them.

That which is not disturbed
cannot be defiled
That which is not attacked
cannot be violated.

> Allowing people to be who they are
> allows them to be who they want to be.
> (Smith 1994:121)

This type of positioning contributes to a feeling of 'normalcy' whereby the patient attempts to regain or retain the ability to engage in normal everyday tasks (Arblaster et al 1990, Bottorf, Gogag & Engelberg-Lotzkar; 1995, Frank 1995). This attempt at regaining normal living was explained by both Vance in his attempts to maintain previously enjoyed Scrabble games with his wife, (pg. 118) and Brian in his need to go back to playing bowls (pg. 100). 'Normalcy' or 'Normalisation' allows one to follow the well trod path of living, routine matters taking over the disruption of dealing with illness and dying. Arblaster et al (1990, 39) described this as the terminally ill person wanting to chose a nurse "...who would provide them with emotional support that enabled the status quo to be maintained; that is a state of normalcy within the family unit".

This need to maintain as much of life's normal pattern appears to continue until the patient enters the dying phases, and is physically unable to continue, although some will continue to act as organiser or manager from the 'sick bed' (Davis, Cowley & Ryland 1996).

Although there is an overall recognition of how 'knowing the patient' contributes to process and outcome measures, Radwin (1996) suggests that inadequate work has been completed on how to undertake this process. In one study it is liked to a "...process of 'bonding" where the patient" comes to be known (Lamb & Stempel 1994 cited in Radwin 1996, 1145). Within this discourse is the consideration of how the patient's identity emerges. It seems imperative that this information is volunteered within the developing relationship and communication with staff. van der Riet (1997, 96) aptly described this when she says:

> Patients are coerced or encouraged and expected to confess their inner secrets to doctors and nurses and other health professionals. They are often dis-empowered by their circumstances and, in many instances, are unaware of their rights to protect themselves and their privacy. The nursing history is testimony to patients being expected to conform to levels of personal exposure- all for the sake of a 'good' medical or comprehensive history, which allegedly enables health professionals to feel as though they are giving 'good professional care'!

This is a salient reminder for me, as someone who has devised 'comprehensive' patient history formats for palliative care patients, with the motivation of ensuring quality care. There must be a balance between obtaining vast amounts of information about patients as part of the admission process, and in the careful development of a relationship where such information will be volunteered if the patient desires. James (1986 cited in Field 1989) in her study of hospice nursing attempts to provide this balance:

> Care requires time, involvement, and a good atmosphere, but this is part of getting information about an individual patient which may then be remembered for future use, or acted upon by all nurses to improve an ill-person's care (pg. 134).

A study of the needs of people with cancer within Wellington, New Zealand (Litchfield, Clark, Edwards, Richardson, Tansley, & Woodman 1995) revealed there were needs associated with 'being'. Such 'being' related to "...the networks of relationships that gave the person a place in family and society" (pg. 31). The report concluded that close intimate relationships did not always allow for this to occur; and as well, relationships with health professionals did not always encompass the areas of "...everyday living, emotional subjects or concerns, and questions about the future" (Litchfield et al; 1995, 31).

Staff being 'informal and ordinary' seem to promote the notion of identity by the sharing of being human together. This concept is articulated by Taylor (1992 & 1994b). She says: "...ordinariness of human commonality connects all people" (1992, 33). Within this concept is the building of mutual human to human relationships where the gradual sharing of detail and intimacy occurs. Hunt's (1991) study on 'being friendly and informal' as described by terminally ill patients and families debates whether in fact there is a conflict of motivation between the goal of informality; the breaking down of "...traditional, authoritarian, professional-client barriers" (pg. 936), and the creating of "...equitable encounters and partnership" (pg. 936). Hunt asserts that although these are admirable motivations, there are times when one must be authoritative; there may need to be boundaries established within the friendship between patient and nurse (pg. 936). For professional and non professional carers there will always be vigorous debate on professional boundaries which is outside the scope of this research. The participants recognised ordinariness and informality as important. Brian (pg. 115, 116) in attempting to explain what it was within the atmosphere causing him to relax, identified a contributing factors as 'informality'.

Ramsden (1988) in a model for negotiated and equal partnership, proposed a way where nurses could incorporate bicultural values in their care. This model explicates the philosophy and implications of the Treaty of Waitangi (1840); the original bicultural agreement between Maori and the Crown. The Treaty of Waitangi as a model represents a method of negotiating a partnership between any party, particularly between health professionals' and their patients. Inherent within this model is the recognition of power differentials and the importance of attempting to create a dialogue of equity. Personal identity is central in this notion, and is a cultural norm within Maori tradition; stating your origins, land and whanau are preliminary to any conversation. Maybe consideration of this as a universal mode of communication should be considered but especially so in palliative care.

Arblaster et al (1990, 41) also consider *partnership* a key issue. They said partnership: "...indicated the need for a sensitive approach to the sharing of care between nurse, patient and family with emphasis on 'working with' rather than 'doing to'.

The components which encircle the centre of identity are:
keeping control
chosen isolation
being safe
relinquishment and relaxation
mortality awareness
being watched
caring qualities
humour

The first five components were generated by the patients themselves, the final three being the patients' interpretation of actions of the staff

Keeping Control

'Keeping control' manifested itself in the often detailed and elaborate descriptions people gave of their ways of maintaining the balance of control over parts of their life. It consisted of:
resistance to the exposure of one's life to the 'health bureaucracy
I understand what is best for me
problem solving- I can sort out **some** things for myself.
choice
keeping control sometimes means giving away
empowerment
doing till dying
having targets

hope for life actualising events

> But just from this most unpleasant side of his illness there came a comfort to Ivan Ilyitch. There always came into his room on these occasions to clear up for him the peasant who waited on table, Gerasim. ... Ivan Ilyitch, asked him to carry him to the sofa. Gerasim, without effort, carefully not squeezing him, led him, almost carrying him, to the sofa, and settled him there. ... Gerasim smiled again, and would have gone away. But Ivan Ilyitch felt his presence such a comfort that he was reluctant to let him go. “Oh move that chair near me, please. No, that one, under my legs. I feel easier when my legs are higher ... it seemed to Ivan Ilyitch that he was easier at the moment when Gerasim lifted his legs higher (Tolstoy; 1886, 67).

“A sense of being in control means believing that one has choices or can exert an effect on the outcome of events” (Fryback 1993, 151). Control is a phenomenon well described in nursing literature as a means of maintaining order in a situation where there is potential disorder. Ways in which people may attempt to recreate order in their lives after the diagnosis of a life challenging disorder are: adoption of a strict regime of diet, exercise and meditation, use of so called alternative therapies, seeking spiritual enlightenment, and learning as much as they can about their disease. Liossi & Mystakidou (1997, 33) define this as: “...the need to be self-directing and freely engaged with the directions of a greater whole”.

The ideal of being ‘self-directing’ should be attainable throughout a period of illness and even into the dying phase if maintained as a philosophical goal and enacted in practice. Arblaster et al (1990, 39) called this *empowerment:* “...this facilitated by consultation and discussion in an atmosphere where the patient’s role was not perceived as subordinate”.

For the person in the final phase of the dying trajectory, there can be an anxiety that there will be a:

> loss of control over body and mind, with a diminished sense of consciousness, (which) may then create anxiety and fear about the integrity of ourselves. One is placed in a position of dependency and inadequacy so that in a sense the ego is no longer master of its fate nor captain of the self.
>
> (Mansell Pattison; 1977, 53).

I sensed that Vance had anticipated this phase when he talked about wanting to die with dignity (pg. 120). Prior to this comment he explained several ways in which he and his wife had retained and maintained control throughout his illness including keeping control over the medications he took and discontinuing some, because he believed that was best for him (pg. 104, 105).

Vance and his wife set up strategies to enable him to be admitted intermittently to a medical ward for his heart problems, instead of being assessed through accident and emergency. They also avoided referral to the palliative care services until they were desperate, because they didn't want to be involved with yet another service (pg. 104). This perhaps speaks of the level of invasion that health care institutions have on people's lives, the personal information that they require, and the control over everyday living.

For Helen staying in control meant she had to trust that another would do what she would have wanted herself in the provision of support for her young adult sons. Helen herself organised this, thus undertaking the choice of who might provide it (pg. 107, 108). Balancing the need to meet her own self actualised needs as a providing mother, with the concern that she may alienate her sons by making them consult someone (the bereavement counsellor) they did not chose too, was a difficult choice. However this ultimately resulted in great benefit for all. Being a dying person does not exempt people from difficult decisions.

"Patients suffer to stay in control, or to have a feeling of being in control" (Flaming; 1995, 1122). It is quite possible that some of the examples described: avoiding referral to palliative care service, discontinuing medication, and other not so obvious aspects such as the with-holding of patient history or personal information (see Identity) may have caused suffering; however balanced by the need for people to maintain control of their destiny. It is possible that the palliative care team will at times be forced to stand and wait while the patient retains control and dignity at the expense of what they perceive a quality or best practice palliative care. This balance between control and needless suffering is recognised by Davis, Cowley and Ryland (1996) in their study of terminal illness on patients and carers. They describe the reporting of a high degree of unrelieved symptoms as a reflection of:

> ...their preferred state of affairs, and illustrates a high degree of lay competence in coping with illness. In some cases though, patients and carers were struggling needlessly with difficulties which could have been eased quite readily...(Pg. 517).

This difficulty in maintaining balance which I have already identified in the section on 'Identity' with regard to information collection, reflects the great sensitivity in decision making utilised by palliative care staff. It is wise to consider the issues of policy, access and equity in decision making discussions regarding provision of quality symptom control or support mechanisms. Informed and consistent patient control is the paramount goal. There is also careful consideration to be made of the health professional discourse on patient control. Health professionals often state that they are moving to allow patients to have increased control; yet I believe this control can only be exerted in minor ways.

Staying in control has links to the concept of hope. Although hope is not static, and changes according to the treatment goals; for many there is hope of further life actualising events. Flemming (1997) identifies factors which patients say maintain hope. The participants in her study agreed that: "...loss of control over any one of the areas (self) identified as maintaining hope would cause them to lose hope" (pg. 17). This emphasises the fragility of hope, and the investment of both staff and patient in maintaining it at all cost as a factor which enhances the quality of remaining time and life. Such hope was articulated by Frank in his admission that his current quality of life was very poor, and that all he wished for was some improvement (pg. 106).

'Doing till dying', both Carol and Helen described by the way they pursued their interests. Carol loved her music (pg. 109), and Helen the ability to just 'get out', enjoy company and to visit favourite spaces and places (pg. 108, 109). Having targets or goals was a mechanism which Brian employed to avoid being overwhelmed or out of control (Holden 1990).

It was partly the intensity of their desire to do what they loved (in Helen's life with continued difficulty), and the ambivalence about having to leave their world that Dylan Thomas speaks of in selected verses of:

> 'Do not go gentle into that good night'
>
> Do not go gentle into that good night,
> Old age should burn and rave at close of day;
> Rage, rage against the dying of the light.
>
> Though wise men at their end know dark is right,
> Because their words had forked no lightning they
> Do not go gentle into that good night.

Grave men, near death, who see with blinding sigh
Blind eyes could blaze like meteors and be gay,
Rage, rage against the dying of the light.

And you, my father, there on the sad height,
Curse, bless, me now with your fierce tears, I pray.
Do not go gentle into that good night.
Rage, rage against the dying of the light.

Dylan Thomas (1972, 159)

Holden (1990, 72) described the patient who always needed to "...follow a diagram or a set of plans", but due to his illness he couldn't determine any course of action. Targets were a mechanism which allowed Brian (pg. 107) to gauge his progress, set goals, and create a sense of meaning for his year. I wondered if not being able to meet those goals would affect Brian if his disease progressed. I sensed a great need for him to keep assessing his disease; such close monitoring of the body is inevitable when dying becomes an all consuming concern. Brian also retained a measure of innovative control by the self management of his indwelling catheter, which was causing him pain and discomfort, and which either the staff hadn't been able to address; or maybe it was that he chose to sort it out himself (pg. 106).

In this concluding section of 'keeping control' I wish to discuss the understated subtext in two of the patients' stories, which may represent considerations for those providing palliative care.

The complexity of the phenomenon of patient control is well illustrated in the many descriptions of these participants. It is a stated and un-stated component of palliative care philosophy and appears to have been actualised within policy and practice for these particular patients. There is however another question to be addressed; one which has been articulated by critics of the post health reform palliative care admission ideology. There may exist access and equity issues for an silent group of patients and carers (Street 1998).

There was a subtext within several of these conversations which created a sense of disquiet for me. These conversations were not included within the results because the patients did not appear to sense that it was within the realm and responsibility of the palliative care service involved The issue identified may be part of a wider palliative care philosophical and ideological debate or it may relate just to this particular service which at the time of these interviews utilised a public hospital service to provide community support. Although never posed as a direct criticism of the service, Frank and Helen identified their own difficulties with aspects of home support, including the ability to retain control over the quality of their care at home. Helen identified a breakdown in the care she received when she could not contact somebody within the community care service to assess her pain, whilst she was under the palliative care service.

> *(Helen) Because I was difficult, I must say that, in the middle of last year I did not want to come home. I got to the point where I'd lost my confidence...I didn't think I could cope at home on my own.*
> *I was doubting of the services available in the community and in fact I still do believe that they're not always going to meet everyone's needs, you know, but that's not the nurses fault. I mean they are the same wonderful caring people that have- the community service but, you know they're battling against unfair odds also you know not enough money, diminishing resources, more people.*
>
> (researcher) That's right.

> *(Helen) But I happen to have three very unfortunate incidents there - the system fell down and left me in dire straits.*
>
> (researcher) When you were here?
>
> *(Helen) No, I was at home, yes and um, that preyed very heavily on my mind.*
> *I was very reluctant to come home again, and maybe find myself again in a situation where I was left with in some cases, very severe pain for several hours was because they were- the paging system broke down and I couldn't contact anybody and things like that, you know. It was, because here on your own, you know, frightening oh, frightening.*

In my field notes I described a conversation Frank had with me after the audiotape was turned off. He relayed that since he was now a patient under a palliative care service, the home care service organised by his local Medical Centre and primary health care team had been reduced by half. Frank was bedridden, and relied on the devoted attention of his flatmate who as well worked full time, and needed the support of a home helper during day time hours. We discussed what measures he had been able to take to address this difficulty. It appears that because there was a fragmented service, with one aspect being undertaken by the palliative care service and the other by the primary health team, plus a geographical difficulty where there was a dividing line between two Crown Health Enterprise areas; Frank's holistic care was being compromised. My only suggestion was that at his next admission for respite care in three weeks time he would discuss it with his palliative care social worker.

For both these people there are similarities in the difficulties identified. Keeping people at home and thus in control of their personal circumstances, is a strong component of the palliative care philosophy. When the complete care of the patient is divided between services, these divisions need detailed description, accountability and monetary allocation. This will addressed further in the recommendations (pg. 211).

Chosen Isolation

The ability to still make choices in social interaction was manifested in many conversations. For many this was to be able to be in 'chosen isolation' from others, especially other patients and their visitors. For me this was a partly unanticipated aspect of our dialogue. This was expressed in the narrative as:
my personal space
non-interaction
avoiding distressing events
personal company
spending time apart

> It was morning. All that made it morning for Ivan Ilyitch was that Gerasim had gone away, and Pyotr the footman had come in; he had put out the candles, opened one of the curtains, and begun surreptitiously to put the room to rights. ... "Will you have tea sir?"
> "He wants things done in their regular order" ... he thought, and only said- "No". "Would you care to move to the sofa?"
> "He wants to make the room tidy, and I'm in his way. I'm uncleanness, disorder," he thought, and only said- "No, leave me alone"
> (Tolstoy 1886; 71, 72).

I have been aware for some time of the dislike which patients had, of being in close company or watching others where were in the final trajectory of dying (McDonnell, 1989; McKinlay, 1994; Stroh, 1995). However, I had not noted that in general terms for some patients, even having social discourse with other patients and relatives\friends, was distressing.

There has been a developing movement in the care of those with cancer and other life challenging illnesses to encourage group support and synergy. This is the principle that palliative care occupational day therapy works under. These groups have some history now and appear to work well.

However perhaps there is a point in the dying trajectory at which social interaction is not helpful. Certainly there is a recognised period where people disengage, and no longer are interested in maintaining human contact, but this is usually only days to hours before the moment of death. What is described here is a longer period, perhaps some months before death. This could be a unique occurrence, although a number of people within this group directly addressed it: Vance (pg. 110) and Frank (pg. 111), and Carol (pg. 111) alluded to it.

There has been a persuasive argument within the palliative care movement, that as part of re-normalising the notion of dying and death, that dying and death be brought more into the community. Thus the palliative care movement receives significant exposure from the media especially when fund-raising, often using personal stories of those who are dying or their loved ones. Such 'normalising' ideology, (which may not be so apparent now in new palliative care services), included the use of shared rooms, not removing the person as they were dying to a single room, and not covering the face of the deceased person or placing them in a specific container before removal from the room to the mortuary; in other words not attempting to hide the process of dying and death.

Vance, whom I would describe as a warm and engaging person actively went out of his way to avoid conversation with other patient and their relatives (pg. 112). Although he did not explain why this was, his other conversation regarding his distress at seeing others who were dying, and seeing an example of demeaning lack of dignity, suggested that interacting with others who were dying or family of those dying, was too difficult and might cause him to wonder what was ahead for him.

The more common aspect of chosen isolation for the participants was the desire to be by themselves in a room. Vance (pg. 112), Carol (pg. 111), and Frank (pg. 111) talked of this.

> That which is not disturbed
> cannot be defiled.
> That which is not attacked
> cannot be violated.
>
> Allowing people to be who they are
> allows them to be who they want to be.
> (Smith 1994, 121)

Vance described in depth how he felt being transferred from a single to an occupied four person bedroom, what he saw in the room, how it distressed him and caused him to feel ill at ease in what should have been a personal private space for him (pg. 112). Despite this experience Vance was effusive in his praise for the overall care he received. It is quite probable he didn't feel he could 'complain' or make comment about his distress, as he would have felt it might compromise other's opinions of him, or perhaps he felt he was not having a 'normal' response to such a situation.

McDonnell (1989) in her study of patients' perceptions of care identified that a few: "...spoke of being upset in the environment of other very sick and dying patients" (pg. 49).

Rose is unique in that she did not mention her room or room mates or any other people other than the staff in the hospice, her whole conversation focused on her past experience with her husband's dying, and her present story of care. Rose focused on the spirit of the people who gave the care and the 'environment' (the aesthetics) of the care. She talked about the tranquillity and serenity of the place; for me this implied her preference for her personal space (Pg. 113).

'Chosen isolation' as described by these participants did not include wanting to be isolated from the staff. Isolation in itself is described by writers as a self identified difficulty of those who are terminally ill, and dying (Flaming, 1995; Saunders & Baines 1983; Hinton 1984). This 'isolation' relates to a separation from previous strong relationships which the patient has had.

However from my clinical experience in both oncologic and palliative care nursing, relationships between patients and clinical staff became so strong that the patient preferred these associations to those of previous 'old friends' and even family. Deep relationships often form quickly with someone who is dying (see 'special relationships, pg. 187), to the point where the staff member can feel embarrassed at the intensity of preference that the patient has for them rather than their own family.

However some of my storytellers were not at that imminent point of death and Vance certainly spoke of many close and engaged social contacts, although perhaps his illness was an unspoken topic. Maybe that is why he and Frank, Rose, and Carol (but not to the same degree) chose to remain in their own personal space, apart from all but the staff, from whom they derived a sense of great care and attention.

Being Safe

'Being safe' related to the sense of being watched, yet also involved the intangible effect of being within a safe healing environment. It was expressed as:

ease of turmoil
tranquillity of environment
physical place of safety
relief for other (home) carers
professional assessment
a place of suspended time
immediate action if necessary

> From that time forward Ivan Ilyitch would sometimes call Gerasim, and get him to hold his legs on his shoulders, and he liked talking with him. Gerasim did this easily, readily, simply, and with a good-nature that touched Ivan Ilyitch. Health, strength, and heartiness in all other people were offensive to Ivan Ilyitch; but the strength, and heartiness of Gerasim did not mortify him, but soothed him (Tolstoy; 1886, 68).

> Most patients with terminal illness say they are more concerned about the process of dying than death itself.
>
> (Herbst, Lynn, Mermann & Rhymes; 1995, 30)

'Being safe' is an existential phenomenon. All people require places of safety within their lives, both physical and spiritual to reflect, rejuvenate, replenish, suspend time, contemplate, regain passion and sense their inherent spirituality. These story tellers appear to be describing a physical place of retreat, where both they and their home-carers could regain their 'centre', and a spiritual or existential safe space to recreate peace and hope. Only those experiencing the world of dying can know what assault it creates, and what vulnerability and fear it creates:

'Being safe' as an aspect of valued care in the palliative care setting is perhaps what characterises it as a clinical specialty. Apart from Larson (1984, 47) who defined 'feeling cared for' as : "...the sensation of well-being and safety that is a result of enacted behaviours of another"; I could find no other reference of 'being safe' in papers which studied patient defined instrumental and expressive aspects of care. When a patient is in a curative setting it appears that the care qualities valued, relate to the instrumental activities which staff undertake such as technical, and information giving rather than the creation of an environment or an existential place; a safe place.

Rose intuitively understood this link and spoke of the sense of internal peace that was created for her when in this palliative care area (pg. 113). She differentiated it from the feeling of 'good care' which she received in her general hospital experience; this was something more than hands on caring activity.

For many of the participants 'being safe' related to being cared for in an environment which was not their home but which had similar characteristics, and served the purpose of allowing their home-carer to have a rest, knowing that they were safe having care and professional assessment. This statement implies the degree of responsibility and vigilance which home-carers assume, and how necessary it is for them to be able to temporarily lay down that responsibility.

In two interviews, the wives of the participants were present and took part. Although I had made provision to allow a support person to be present, I did not expect that this would happen, nor that the support person would want to take part. Such participation was an unanticipated aspect of the research and I acknowledge that this will have altered the conversations in many ways. I did not have permission to use their narrative, but it was easily apparent that they lived with a great deal of stress, were both at times physically and emotionally unwell, and found it extremely difficult to leave their ill husbands at home to undertake shopping and household management tasks. They were delighted that at least every six weeks there was a break from this routine, as it provided them a chance to have personal space, know their husbands were 'safe', being watched and assessed; and allow them to catch-up and be ready for their return. Both expressed that they wanted their husbands at home for as long as was possible, one very adamant that her husband should die at home if at all possible.

"They (the dying person) are fearful of pain, abandonment and loneliness" (Herbst et al; 1995, 30). Being in an environment where one feels safe, and trusts the staff, meets the criteria for alleviating some of the fear which is said to be common to those who are dying. Fear is almost an opposite of being safe. Bunston & Mings (1995, 67) similarly identify: "...fear of the unknown" as one of the dominant themes in their study of the psycho-social needs of people with cancer.

Relinquishment and relaxation

'Relinquishment and relaxation' were bound together and were often expressed in the feeling of relaxation. Although similar to 'keeping control' the theme of 'relinquishment and relaxation' distinguished itself by always being expressed in conversations as 'relinquishment' followed by 'relaxation'. People wanted to keep control over some aspects of their lives; yet they also equally wanted from time to time to temporarily relinquish this control, to allow themselves to be 'watched' over by another, to be able to relax. Aspects expressed in relation to this were:
to allow another to take over
another can make the decisions
suspend goals and targets
temporarily remove responsibility from home caregivers
relaxation is healing

> He saw that no one felt for him, because no-one would even grasp his position. Gerasim was the only person who recognised the position, and felt sorry for him. And that was why Ivan Ilyitch was only at ease

> with Gerasim. He felt comforted when Gerasim sometimes supported his legs for whole nights at a stretch, and would not go to bed, saying, "don't you worry yourself, Ivan Ilyitch, I'll get sleep enough yet"... (Tolstoy; 1886, 69).

Although being 'in control' was perceived as valued and essential palliative care, the storytellers also talked of the importance of being able to temporarily allow another to take over. This is an example of what could be seen by some as being an inconsistent theme, or as Frank (1995, 58) would describe as part of the: "...interrupted story". O'Berle and Davies (1992) in their exploration of support and caring have constructed a model which incorporates the concept of 'doing for'. 'Doing for' seems to represent the mirror of relinquishment and relaxation, and is seen as the caregiver's role, and is defined as:

> Engaging in specific comfort activities, co-ordinating care, doing things, helping, providing physical care and monitoring and directing action doing for, and taking on (pg. 766).

Henson (1997) writes on the concept of mutuality which appears to have some of the components contained in relinquishment; these being the relationship between carer and patient is comfortable and contained mutual involvement, however there may be asymmetry in connection depending on the illness. Overall there is:

> ...understanding, shared common goals and satisfaction for both parties even when one is giving very little... Each believes the other can contribute worthily to decision making (pg. 79).

Arblaster et al (1990,41) considered it important that the individual and family context be carefully assessed prior to offering support, so that "...independence and control are not jeopardised". When relinquishment by the patient is voluntary, giving control to the nurse, or the patient deteriorates and loses "...the sense the ego is no longer master of its fate" (Mansell Pattison; 1977, 53) the result for the patient is relaxation, yet with the retention of what Henson (1997, 79) calls "situational control". Relaxation was not easily described by the storytellers, even when invitation to expand on this was given. Rose (pg. 117) in her narrative was unable to establish any definite factors which contributed towards it.

In considering the outcomes of the concept, 'relaxation' appeared to have a healing, trusting and restful quality; the absence of worry and anxiety. I can only relate this to my own past hospitalisation experience, where I was constantly on edge and vigilantly aware of what might be going to be done to me without my input or consideration.

Osterman & Schwartz-Barcott's (1996) study of presence identifies 'transcendent presence' as a way of being there for patients. It is:

> ...felt as peaceful, comforting, and harmonious. An outcome is a positive change in the affective state, such as when anxiety is diminished, and there is a feeling of being connected to another, of not being alone (pg. 28).

Brian (pg. 116), Rose (pg. 117) and Frank (pg. 117) articulate similar experiences; the end result a healing experience.

The concept of 'relinquishment and relaxation' were inter-linked and woven together. Where a storyteller was attempting to describe relaxation and how it felt, s\he was also attempting to describe an alternating pattern of temporary relinquishment, yet also because the story was being told outside the hospice; retaining the 'in control' mode of being. One appeared not to happen without the other. It would be of interest whether staff sensed when this relinquishment occurred and whether it made a difference to their practice, and whether they recognised it was temporary and integrally linked to staying 'in control'. In attempting to assist people to relax in a palliative care situation, it would be important to address the issue of control, assessing whether there be more assistance and time needed to gain the trust of the patient.

> People say that it is absurd to allow the dying to
> have control.
> People say that such an idea is impractical.
>
> Look inside yourself.
>
> Would you feel comfort around the person
> who gives choices or the person who takes
> choices away from you?
> Would you respect the person who trusts your decisions or the person
> who does not allow you to make decisions?
>
> Would you cheat a marathon runner out of his last mile?
> Would you take the brush away from an artist
> before he makes his signature?
>
> The caregiver has an attitude of allowing.
> That is the greatest wisdom.
> That is being very practical.
> (Smith 1994, 135)

Mortality Awareness

Despite the conversation always beginning about care, in almost all dialogues there was a time usually later in the discussion when participants began to talk about their dying. I called this 'mortality awareness', because it encapsulates the inherent bravery of these people in both having considered their dying, and also being able to talk to me about it. The aspects of mortality awareness were:

the place of death
fear of being alone
fear of being in a place were others cannot support them
the effect of their death on loved ones
the 'dying'
wanting to die at the hospice
being safe
choosing a time to die
existential hope

> Ivan Ilyitch's great misery was due to the deception that for some reason or other everyone kept up with him- that he was simply ill, and not dying, and that he need only keep quiet and follow doctor's orders, and then some great change for the better would be the result. He knew that what ever they might do, there would be no result except more agonising sufferings and death (Tolstoy; 1886, 68).

Kellehear (1990) in his study of those dying reported that sixty percent of his participants had talked significantly with others about their mortality. Such conversations included topics of funeral arrangements, type of potential life changes for significant others, including child-care, remarriage, and death anxiety. Kellehear (1990) quotes a similar study by Kalish (1977) who found sixty six percent of subjects talked about mortality. In contrast Arblaster et al (1990, 36) found the least preferred 'nurse behaviour' as defined by people who were terminally ill was: "I would like the nurse to talk to me about death and dying". It could be that patients may not like this type of conversation to be formally contrived by health care staff, but are relaxed when it happens spontaneously or when they initiate it themselves.

Parker (1992) discusses the roles patients are required to assume according to the different approaches (curative to palliative) of cancer treatment they receive. Such patients who are told that there can be no more medical treatment are required to "...switch from an attitude of trust, to one of understanding (pg. 58).

Morse (1997) identified three responses of those who are very ill, to their illness one of which was "...enduring to die" (pg. 23). This implied a reaction which contained understanding of the terminal event, yet a hope to create endurance to that end.

It is quite possible that patients who do not, or refuse to talk about their eventual or impending death, are seen as having difficulty in adjusting, to the palliative care staff.

> ..non-acceptance of death in the hospice setting is problematized by the interdisciplinary team of nurses, doctors, ancillary health professionals and pastoral care workers who see it as their role to facilitate acceptance and eventual surrender to death
>
> (McNamara, Waddell, & Colvin 1994, 1505).

Mortality awareness was directly addressed by five of the six participants. It was as if this issue was integrally woven with palliative care. Discussion related to the pragmatics of death: where they wanted to die, their need to have professional input from staff to help them to die well, and the settling of monetary matters. Helen (pg. 120) expressed her desire to die in the hospice, both for herself, because of her anxiety about pain, and for the need for support for her sons. Helen died in the hospice not long after this interview.

There was discussion of quality of life in how it related to death; dying with dignity. Vance (pg. 120) used this phrase. Vance also conveyed his great care and anxiety about his wife which subsumed his own concerns. It was my feeling that up until this moment Vance had not been able to talk to his wife about dying; he as Kellehear described was one of the 40 % who were unable to articulate with loved ones their deep distress at leaving. As stated previously I had not fully anticipated the impact of spouses being present at the interviews; however it was a great privilege to be used as an intermediary in such a conversation, which was carried out naturally and in an uncontrived way, and hopefully opened doors for further healing communication between loved ones.

Rose (pg. 119) and Vance (pg. 120, 121) talked of their concern for loved ones after death, how they would cope, how much they worried about them, and the inability of loved ones to let them go. Rose (pg. 121, 122) talked of existential matters; the maintenance of hope whilst dying. Greisinger et al (1997) identify existential hope as the major concern for terminally ill patients. They say that when treatment is unsuccessful: "...patients find other sources of hope" (pg. 149). These include relationships with family, friend's and health professionals; comfort and strength in beliefs and faith; having symptoms controlled; maintaining dignity; finding inner peace; enjoying humour and reviewing meaningful parts of their lives (pg. 149). Flemming (1997, 18) describes this as: "... maintaining a positive state within the future for themselves, and for those meaningful to them". Brown (1994, 169) defines five facets of hope including: "...an inner force for survival in face of threat; a future orientation that permits the individual to transcend the immediate situation; and relationship(s) with an important other(s)".

Other existential matters included the reflective and reasoned choice that this was the right time to die as Rose did (pg. 119), letting go deliberately, and informing family members that this was so (pg. 119).

From what these people told me, one can expect most of those receiving palliative care to spontaneously talk about the matters of death. The media has publicised the role of palliative care organisations in attending to these matters of dying and death, and many patients are aware of this. Vance (pg. 120, 121) understood that settling his financial affairs was something the hospice would have espoused and he set about teaching and encouraging his wife to be able to manage her own affairs, thus preparing her for an aspect of their shared life for which he had always been in control. Whether he would have done so before his hospice admission is unknown. Maybe the environment around him, which had distressed him, caused a realisation of unfinished business.

Staff see managing mortality issues as their role and are attuned to make responses which are affirming and encouraging (Mount, 1980; Doyle, 1994). Those who choose not to talk of their mortality, or actively deny it, also require affirmation, gentle openness, encouragement, and above all acceptance. There may be a moment right up to the time of death where they may chose to share these things, but equally there may not be. There must be open acceptance of this as the way these people chose to live. It may be as Parker (1992) discusses, a reflection of previous roles lived out in their past; it should not be made into a palliative care problem.

> Dying can be very painful.
> Do not waver in your attitude of allowing.
>
> Death can be very exhausting.
> Do not waver in your attitude of allowing.
>
> Death can be very ugly.
> Do not waver in your attitude of allowing.
>
> Childbirth can be very painful, exhausting, and
> ugly.
> Yet a beautiful child can still be born.
> So it is with dying.

Do not judge the death by the dying!
Do not judge the dying!
Do not judge the death!
Do not judge!

Be prepared for anything.
Allow for anything.
Accept anything.

There is no other way.
(Smith 1994, 106, 107)

Being Watched

'Being watched' was a term used by one person several times during our dialogue but echoed often by others. It was used to describe caring behaviours such as:

Measured protection
Other people are watching how I am doing
I can do for myself, if I want too- or I can allow others to do for me: autonomy vs chosen dependence
professional help being available
monitoring and surveillance
nothing will escape their attention- trust and safety
professional knowledge- they have seen this before
staff know how to anticipate need

> Late at night his wife came back. She came in on tiptoe, but he heard her, opened his eyes, and made haste to close them again. She wanted to send away Gerasim and sit up with him herself instead. He

> opened his eyes and said, “No, go away.” ... And all of a sudden he slipped and fell and woke up. Gerasim, still the same, is sitting at the foot of the bed half-dozing peacefully, patient. (Tolstoy; 1886, 82).

Brown (1986) identified surveillance as one of the major themes identified by patients within their experience of non-life threatening medical surgical conditions. Surveillance was described as: “...interactions in which the nursing activities were experienced by the patient as keeping him or her under watch. The emphasis of the watch was always the physical condition and safety of the patient...” (pg. 60). Larson (1984) similarly identified: “...checks on patient frequently” as one of the key factors noted by cancer patients in an assessment of care (pg. 49). Aranda (1993) in her study of the relationship between palliative care philosophy and care given at the City Mission Hospice in Melbourne identified under the component of care titled ‘Emotional Support’, that there was a: “...role of the hospice staff in monitoring the client and ensuring against mistakes or problems” (pg. 23).

Osterman & Schwartz-Barcott (1996) describe the phenomenon of ‘presence as having four components: ‘presence’, ‘partial presence’, ‘full presence’, and ‘transcendent presence’. One of the attributes of the component presence is being “...quietly watchful” (pg. 26) This phrase creates a sense of non-invasive professional assessment. Brian (pg. 123) felt this watching was as essential to him in achieving his much needed relaxation, as an assisted bed sponge.

The participants took note of the careful observation and assessment of their capabilities, and were reassured that if anything untoward was too happen that the staff would notice and take action. It was as if they had an anticipation or a fear that something potentially catastrophic was likely to happen. Four of the participants had experienced medical emergencies at home. These events had sensitised them to their vulnerability: having to wait until medical attention was able to be arranged; the anxiety of their loved ones who had to act as their assessor and advocate; or for Frank, being alone when this happened and trying to obtain assistance.

There was a sense of professional judgement that the participants attributed to 'being watched'. As well as this including the ability for staff to be able to judge the patient's situation and know when something might be or was going wrong; but also the ability to judge when the patient was able to act for him\herself; Frank (pg. 125) who was unable to do very much for himself found this aspect of anticipation very helpful. Astrom, Norberg, Hallberg, & Jansson (1993) describe this form of caring as: 'Deliberate distanced interaction and intervention with the patient'. This manifestation of caring is characterised by:

> The nurses noticed cues from the patients that made them stop near them for further observation. They made no contact with the patients nor did they tell them about their intentions in order not to intrude. They took only discreet actions (pg. 186).

Helen noted this as "being trained to see" (pg. 124); using expert judgement by observation, holding back or intervening as the case may be.

> The best things can be communicated without the
> use of words.
> All the commotion runs its course.
> Disruptions come to their own conclusion.
> So, keep quiet!
> Words mean so much less than actions.
> and the best action is no action at all.
>
> (Smith; 1994, 47)

This method of professional reasoned assessment, and discreet action where necessary reflects an example of Benner's (1984) 'expert nurse' category.

Such expert care is critical in palliative care where staff need to be able to elicit verbally or visually identify any difficulties which may be contributing to the patient's quality of life and which the patient may not be able to identify themselves, because of the belief that the difficulties or physical symptoms are all "...part of the illness" (Davis, Cowley and Ryland; 1996, 517). Such a degree of expertise is not developed immediately, as a variety of complex situations need to be observed before recognition of similarity occurs. Helen recognised that this assessment had occurred when the chaplain handed on her spiritual care to an old trusted acquaintance (pg. 124, 125). There is too, a sixth sense which clinically and humanly adept (trained and informally trained) staff develop which allows them to 'sense' intuitively about a patient.

Caring Qualities

'Caring Qualities'; My initial questions focused on the person's experience of the hospice, and then narrowed in on what they valued and did not value about the care given. I made no attempt to direct the conversation to the caregivers themselves. However this very clearly emerged as an aspect that people wanted to discuss. Those giving care were described as:
people with a cause
can never do too much
human contact- loving care
interdisciplinary care (Including non-professional staff)
the role of the volunteers
maintain dignity

> Ivan Ilyitch made Gerasim sit and hold his legs, and began to talk to him. And strange to say, he fancied he felt better while Gerasim had hold of his legs. ... Gerasim alone did not lie; everything showed clearly that he alone understood what it meant, and saw no necessity to disguise it, and simply felt sorry for his sick, wasting master. He even

> said this once straight out, when Ivan Ilyitch was sending him away. "We shall all die. So what's a little trouble?" he said, meaning by this to express that he did not complain of the trouble just because he was taking this trouble for a dying man, and he hoped that for him too some one would be willing to take the same trouble when his time came (Tolstoy; 1886, 70).

It would understate and undervalue the nature of the 'caring quality' to attempt to fully review the health literature that describes and analyses how this role is perceived. Because nursing as a professional group, and certain nurse theorists (e.g. Watson (1985), Leininger (1984), Paterson & Zderad (1976) identify 'caring' as one of its key roles, (although this is not without keen dispute), there continues to be a burgeoning amount of literature focusing on the notion of 'care'. In attempting to explore this component, I confine the discussion to literature which relates mainly to the elements of 'palliative caring' described within the model in an attempt to capture the essence of what I believe is a unique form of care.

Although I am a nurse and believe in and value the essential and leading contribution that nursing makes in the care of those who are terminally ill, I recognise that in the stories related here, there is very little that speaks of nursing as a profession. That is why when discussing the interpretation health professionals could take from these stories, I have tended to use the generic word 'staff' rather than nurses. This should not be viewed by palliative care nurses as a negative thing. Interdisciplinary care itself seems to provide an equation where the end result is greater than the sum of the individual health professionals.

Skobel, Cullom & Showalter (1997, 202) say:

> The greatest contribution Hospice makes to the end of a person's life is its comprehensive utilisation of trained professionals in dealing with

issues of death and dying.

The 'stories' entrusted to me illustrate this and reinforce the worth of the model of interdisciplinary care in this setting where cure is not the aim, but enhancement of life. Working in a team doesn't just happen; volunteers and non-health professionals require careful selection, and skilled education in the nature and manner of communication required with those who are vulnerable and have specific needs. Looking at the stories conveyed and their positive outcomes, it is apparent to me that there is a method of practice that underlies the interactions; this method is not apparent to the storytellers and is therefore not articulated. Rose described the consistency in which everyone in the team, health professional and non-health professional, approached her (pg. 127). However we need to remember that the invisibility of policy and method in creating interdisciplinary teams, does not belie the fact that such a model is easy to achieve.

The modern palliative care movement since the time Cecily Saunders established St Christopher's hospice in London espoused the ideal of the multidisciplinary (now interdisciplinary) team for giving care (see Chapter Two, The history of the hospice movement). This ideal has become so well integrated within this (and many other) palliative care service, that patients do not make the same distinctions between the different health professionals as within general hospital services. Having said this, they did as Brian described (pg. 129), still note an awareness of medical doctors, however without attributing a certain power laden role to them.

Within the stories were references to the caring being carried out by the unspecified 'they': 'they' did this or 'they' did that. However there was mention on occasion of a specific services: the day therapy, the volunteers, the cleaners, the nurses, the chaplain, the bereavement service, the administration staff; and all appeared to be attributed with the same manner of caring (pg. 128, 129, 130).

Raudonis, (1993); Larsen, (1992); Bottorff, Gogag & Engleberg-Lotzkar, (1995); Parker, (1992); Davies & O'Berle, (1990); Arblaster et al, (1990); Heaven & Maguire, (1996); Tyner, (1985); and Artinian, (1995), have written on different aspects of palliative caring.

Davies & O'Berle (1990) through a descriptive study utilising in-depth interviews with a clinically expert nurse self-identifying and discussing paradigm cases, defined six aspects of care unique to palliative care nursing. These aspects of care are: *valuing,* recognising the worth of the individual; *preserving own integrity*, the nurse recognising inherent and therapeutic skills of self; *connecting,* bonding with a patient (and family\significant others); *empowering*, encouraging the patient to have personal strength; *finding meaning,* attempting to help patients and family\friends come to some understanding of what is happening, and *doing for,* relates to direct clinical care.

Although this study focuses on nurses' interpretation of what constitutes 'care'; the components identified are similar to the components in the model described by patients within this research study. Arblaster et al (1990) study on patient specified 'helpful nurse behaviours' identified several caring behaviours which were similar to those described by patients in this study: *normalcy, empowerment, autonomy, support, partnership.*

Tyner (1985) writing on empathy identifies the need to understand the identity of the patient; their past, present, and future aspirations. She refers to Buber's 'I -Thou' relationship as a model to follow, and details the roles that patients may undertake when receiving palliative care. Raudonis' (1993) study on empathy demonstrates an improvement in patients quality of life.

Larsen (1992) warns that although the development and use of empathy is the nurses' most useful and therapeutic skill in palliative care; there must be recognised awareness that such a skill can lead to emotional depletion. It must be balanced by adequate individual support through colleagues or structures set in place such as clinical supervision (Vachon; 1987, 1995).

> The relationships empowered the patients to cope and reconcile their needs and other issues experienced during this phase in their lives... Patients were able to maintain their personhood and individuality (Raudonis 1993, 308).

A factor in establishing empathetic relationships between staff and patients seemed to be the pervasive air of informality or ordinariness (Taylor 1994a, 1994b), which many participants noted. Hunt (1991) focuses her study on being friendly and informal. She states:

> The impetus for promoting 'informality' and 'friendliness' in nurse-patient relationships seems motivated by desires to break down traditional, authoritarian, professional-client barriers, thus creating more equitable encounters and partnerships (pg. 936).

In the conclusion, Hunt doubts whether this can be successfully achieved, citing difficulties with professional boundaries and dealing with 'difficult' situations whilst remaining informal. Within the six stories analysed, there was evidence of satisfaction by the participants with the informal atmosphere that was created. Carol said the atmosphere was "...free and easy" (pg. 126) and contributed towards the 'informality'. This was an aspect where a favourable comparison was made with the public hospital. Whilst no-one complained about the care they had received within general hospital settings, they noted that it was different once admitted to the hospice; one aspect seemed to be informality, including lack of uniformed staff, and use of Christian names.

Parker (1992) analyses roles (and their effectiveness) that patients may assume when on the 'Cancer Passage'. Parker's study encompasses the acute and terminal phases of illness, and the roles that relate overall to both. It would be helpful if work similar to Parker's be undertaken with those on the terminal trajectory. Pollack Latham (1996, 561) agrees and suggests: "...that further research of personal characteristics of patients may enhance our understandings of their perceptions of caring by nurses, use of coping strategies, and resultant outcomes. Whilst staff working in palliative care are used to making assessment about the level of acceptance a person has of their dying, and the manner in which the family and friends are coping; there has not been a comprehensive model devised to describe the totality of the roles adopted by those who are dying. It would be superficial to postulate the different roles that the participants were adopting, but it is certain they were using different ways of managing their illness and dying, and their view of their illness and dying was unique and personal.

Although none of the participants identified a particular person who had played a special role in their care, I had not asked them to do so. However their conversation led me to think that there could be such special relationships. Helen (pg. 124, 125) and Rose (pg. 131) talked of the ways that members of staff brought love, physical caring, and humour into their lives and how much they valued that.

Artinian's (1995) study on 'special relationships' developed between nurses and people with cancer describe the activities used to foster involvement with certain patients: 'minute observation'- the nurse's observation skills became heightened, 'special consideration'- the nurses actions went beyond what was usual, 'modification of personal schedules'- the nurses own personal time was altered to take account of the patient, 'participation in death'- the nurse chose to come back to work to be with the patient at death (pg. 299). The initiation of such 'special relationships' are a spontaneous event unanticipated by both parties and often start because they share some similarity.

Artinian (1995) discusses the positive effects of such a special relationship, and also the consequences if the nurse did not understand the level of grief associated with the loss of the relationship. Palliative care staff, particularly nurses because of their protracted contact with patients will recognise Artinian's characteristics of a 'special relationship', and if they have been working for some time in that area will have experienced several, and will be able to well judge the consequences (positive and negative) of their involvement.

Artinian (1995) makes no judgement of 'special relationships', except to point out the difficulties in novice nurses experiencing their first relationship, and nurses who do not learn how to manage their own feelings and grief. From Artinian's perspective if the 'special relationship' is handled well the patient can only experience positive benefit "because the nurses acted in a concerned manner" (pg. 303).

'Special relationships' are a facet of palliative care to be fostered, because of the positive effect that they have on those cared for. However there should be detailed attention given to staff selection and support mechanisms such as ongoing education, mentorship, role modelling\preceptorship, clinical supervision, debriefing, counselling, monitoring by clinical leadership, peer support, and time off to attend funerals.

Bottorff et al (1995) describe the notion of comfort in respect to caring for those with cancer. Many of the characteristics of comfort are recognised by the participants as elements of valued palliative care:

> ...gentle humour, physical comfort measures, emotionally supportive statements, and comforting and connecting touch. In addition they increased physical proximity, provided patients with information, supported patients' active participation in decisions regarding their care, and offered opportunities for patients to engage in social exchange (pg. 1077).

The discrimination used by staff determine what strategy to use with patients is not easily learnt. Heaven & Maguire (1996) in their study about the type of training required to teach nurses to communicate more effectively with the dying showed that usual educative approaches were not effective in improving such skills, and other factors needed to be considered. Astrom et al (1993) describe three different approaches to care which nurses utilise to 'make a difference' to the patient. The nurses said when asked how they determined which quite different stance was applied: "...how I act depends on the situation" (pg. 183). Carper (1978) would describe this as 'personal knowing': "...the knowing, encountering and actualising of the concrete individual self" (pg. 18). Personal knowing utilised in nursing practice requires:

> the acceptance of others in their freedom to create themselves and the recognition that each person is not a fixed entity, but constantly engaged in the notion of becoming (Carper; 1978, 19).

Katims (1993) similarly believes this discrimination of caring action comes from nurses' ability to:

> relate their interpretation of a client's particular situation, their knowledge of theoretical principle of the human sciences, and practical knowledge gained from years of practice that predisposes them to participate in a client's lived experience in a certain manner, while the client struggles to become well, to face loss, and death (pg. 270-271).

The level of skill required by all involved in palliative care is very high, requires advanced ongoing education, research, multi-focused support, and constant evaluation. Like any discipline, palliative care is ongoing, and changing; retaining the essence of the philosophy, however changing the outworking, as skills and knowledge improve. We understand that the patient recognises the caring qualities of the staff as an essential component of valued care.

The caregiver does not invade anothers space.
The caregiver does not exercise control.
The caregiver does not label.

The caregiver allows for the dying person's anger.
The caregiver allows for the dying person's
depression.
The caregiver allows for the dying person's denial.

Styles of dying:
there are not good or bad ones.

In judging others,
the caregiver has judged himself
not worthy of giving care.
In not judging others,
the caregiver has judged himself
most worthy of giving care.
(Smith 1994, 61)

Humour

Our conversations were interspersed with humour. We laughed at ourselves and together at each other, and at the some of the experiences the participants had had. As well, the participants talked explicitly of the value of humour:
the smiles
the jokes
"dancing the fandango"
"serious fun"
professional yet fun

> Gerasim was a clean, fresh, young peasant, who had grown stout and hearty on the good fare in town. Always cheerful and bright. ... Wearing a clean hempen apron, and a clean cotton shirt, with his sleeves tucked up on his strong, bare young arms, without looking at Ivan Ilyitch, obviously trying to check the radiant happiness in his face so as not to hurt the sick man, he went up to the night-stool. ...
> "Gerasim," said Ivan Ilyitch faintly. ... "I'm afraid this is very disagreeable for you. You must excuse me. I can't help it."
> "Why upon my word, sir!" And Gerasim's eyes beamed, and he showed his white teeth in a smile. "What's a little trouble? It's a case of illness with you, sir (Tolstoy 1886, 65,66).

"... humour serves three major functions: a communication function, a social function, and a psychological function..." (Robinson cited in Tennant 1986, 246). Dean (1997, 34) adds a "spiritual benefit".

Astedt-Kurki & Liukkonen (1994) in reviewing previous research on the use of humour and laughter (not the same and not always synonymous) as a nursing intervention, suggest multiple benefits: a coping strategy, enhancing of the nurse patient relationship, to help people relax, alleviate tension, release energy, facilitate perspective, problem solve, benefit the climate of care, and a teaching and learning strategy. Parse (1993) and Malinski (1991) through their research elaborated on the effects of humour on personal and interpersonal relationships, fostering the feelings of: warmth, closeness, positiveness, and the ability to envision the past and become buoyant about the future. Herth (1990 quoted in Dean 1997), studied the effect of humour on those people who are dying and found it supported hope, pleasure, relaxation, created a sense of connection, and also of perspective. Arblaster et al (1990) found patients preferred nurses who: "Help me to keep my spirits up", and "Maintain a sense of humour" (39).

It is recognised that humour reduces anxiety by allowing people to distance from the current problem and not become paralysed by helplessness (Tennant 1986). The physical benefits of humour have also been acknowledged for some time: "...exercises the heart and lungs, stimulates the circulatory system, and decreases blood pressure; in addition, it ultimately produces a state of deep relaxation of the muscles and thus promotes physical and emotional well-being" (Peter & Dana 1982 quoted in Tennant 1986, 246). Most writers on the effect of humour quote Cousin's (1976) who having a painful condition, experienced endorphine release and consequent analgesia, after 10 minutes of uproarious laughter. The participants in this study although not specifying the process of benefit afforded by humour, recognised the end result of enjoyment. Vance commented he hadn't expected to find humour where people died, as if humour is inconsistent with dying (pg. 132).

In recognising the beneficial effects for patients, families, friends and staff, there should be an awareness that humour be engaged in only after an assessment for receptivity, with great sensitivity, and at appropriate timing. All parties must feel similarly engaged in the process; ridicule, or parody have no place (Dean 1997). Humour should be recognised as a therapeutic intervention which patients may see as helpful, special, and unexpected.

> ...sharing our humanity includes, for many, a gentle, spontaneous sharing of humour. ... Natural moments of shared laughter and wit may occur during the last phase of life just as in other phases (Dean; 1997, 34).

Brian explained the 'almost' ambiguity in the manner in which humour was exhibited; he recognised in the 'serious fun' an intent to alleviate the anxiety of those for whom the dying phase is fraught with anxiety (pg. 131).

How unnaturally we usually treat the dying!
We treat them as already dead.
We put them in sterile environments.
We give them no attention.
We provide them no touch.
We show them no laughter.

However, if we allow people to live until they die:
their environment is a living environment,
they can give and receive attention,

they can touch and be touched.

And never never forget to share the laughter!
(Smith 1994, 93)

Staff can be encouraged to value humour and to appropriately model humorists already in the organisation giving care. Light-hearted conversation can assist the discussing of delicate or sensitive issues; this can often be the case where very ill people suffer great embarrassment when their bodies mis-function as Rose felt when she had uncontrollable diarrhoea (pg. 131).

The philosophy of palliative care:

The participants voluntarily discussed how they viewed the philosophy of palliative care. This happened spontaneously, and often in relation to aspects of their care. They were informed consumers. How did this happen? Was it because once they became a long term consumer of the service, they purposefully, or passively absorbed aspects of information about the service (especially as it might relate to them)? Did it relate to the initial selection of participants by the staff; those who as well as fitting the inclusion criteria were also considered to be more amenable to talk to a researcher, and were perhaps more articulate, or more willing? Why this happened cannot be determined. The participants described aspects of the philosophy that related to:

selection criteria for admission
the place of death
home care
dying
long term vs respite care
death preparation
holistic care
volunteers
the importance of symptom control

> How it came to pass during the third month of Ivan Ilyitch's illness, it would be impossible to say, for it happened little by little, imperceptibly, but it had come to pass that his wife and his daughter and his son and their servants and acquaintances, and the doctors, and most of all, he himself- all were aware that all interest in him for other people consisted now in the question how soon he would leave his place empty, free the living from the constraint of his presence, and be set free himself from his sufferings.
>
> He slept less and less; they gave him opium, and began to inject morphine. But this did not relieve him. The dull pain he experienced in the half sleep condition at first only relieved him as a change, but then it became as bad, or even more agonising, than the open pain. He had special things to eat prepared for him according to the doctor's prescriptions; but these dishes became more and more distasteful, more and more revolting to him. ...
>
> His moral sufferings were due to the fact that during the night, as he

> looked at the sleepy, good-natured, broad-cheeked face of Gerasim, the thought had suddenly come into his head, "What if in reality all my life, my conscious life, has not been the right thing?
> (Tolstoy; 1886, 64,65,90).

As well as aspects identified by the participants, there was an almost non-verbal layer of meaning; a response to the relief of distressing symptoms; an integral component of palliative care philosophy.

Although described in great depth and taking up considerable amounts of space within palliative care texts, symptom control was only fleetingly mentioned by these participants. It was difficult to elicit the participants' experience about this within the interviews, and even when I asked deliberate probe questions, these were not specifically responded too.

For a while I thought that perhaps these people weren't troubled by difficult symptoms. However when I reviewed the content of the stories, there were such instances relayed to me: Brian having had a severe gastrointestinal haemorrhage at home; Vance experiencing severe dyspnoea, and being admitted to a public hospital at midnight; Helen's story of being unable to summon help at home in her time of terrible pain; and the visual impact of watching Frank with his emaciated form and continuous oxygen, somebody who was on the brink of death. It did became apparent that there was discussion about the alleviation of symptoms hidden within the narrative, particularly in a long conversation with one patient (Rose pg. 135);.

When the conversation about palliative care philosophy as a whole was considered and reflected on, it appeared to encircle and became an encompassing aspect to the central components of care. It is my belief that within this particular organisation, palliative care professionals appear to have advanced and stream-lined their 'symptom' assessment, intervention, and treatment skills to a degree where this process is invisible to patients, except when their symptoms were so prolonged and severe before admission, that they had extinguished the will to live.

Quality management practices in palliative care are a systematic and documented approach to ensure that best clinical practice is applied in all circumstances. It involves the establishing of a common philosophy, the adoption of contemporary methods of ensuring the quality of clinical and management practices, and the establishment of methods to ensure there is customer satisfaction.

After the relief of acute physical symptoms other aspects of care assumed a greater priority, and were more memorable to participants. Rose noted the order in which she remembered her feelings about the hospice; it was not until her excruciating pain was relieved that she 'felt' the hospice atmosphere. Until I asked several probe questions, she didn't 'remember' this relief of pain in the initial admission experience; it seemed that it had been subsumed by other memories (pg. 135). Cronin & Harrison (cited in Kyle 1995) reflect on this similarly and liken it to the meeting of the minimum physical requirements in Maslow's hierarchy of needs before other more qualitatively expressed aspects of care can be articulated.

I believe that these participants had a high level of information about hospices and palliative care; Brian (pg. 132) able to discuss post health reform changes in palliative care policy; and Helen talked of her understanding of the core palliative care philosophy of dying at home (pg. 133).

The role of volunteers was well articulated by both Frank (pg. 133, 134) and Brian (pg. 128). Volunteers although integral to palliative care service functioning, are virtually unknown in the public hospital service. Their function is diverse and sometimes incorporates a monitored amount of patient assistance. It is clear from the descriptions that the participants understood the constraints of the role. Patients know and understand complexities about systems of management purely through observation; health professionals should take cognisance of this.

The aesthetic and spiritual dimensions of the environment

The outer circle of the model enveloping the inner core was composed of an aesthetic and spiritual dimension. The effect of the physical and non-physical aspects of the 'environment' was identified by all. This was related within the context of a healing presence. It assumed a great importance to some, and was expressed as:

peace
relaxation
serenity
tranquillity
lack of hustle and bustle
lack of noise
manner of staff
compassion
happy environment
staff interaction
rapport

> Another fortnight had passed. Ivan Ilyitch could not now get up from the sofa. He did not like lying in bed, and lay on the sofa. And lying almost all the time facing the wall, in loneliness he suffered all the inexplicable agonies... -of late in this fearful loneliness Ivan Ilyitch had lived only in the imagination in the past. One by one the pictures of his past rose up before him. It always began from what was nearest in time and went back to the most remote, to childhood, and rested there. If Ivan Ilyitch thought of the stewed prunes that had been offered him for dinner that

> day, his mind went back to the damp wrinkled French plum of his childhood, of its peculiar taste and flow of saliva when the stone was sucked; and along with this memory of a taste there rose up a whole series of memories of that period- his nurse, his brother, his playthings. "I mustn't.,.. it's too painful," Ivan Ilyitch said to himself, and he brought himself back to the present (Tolstoy; 1886, 85,86,87).

> Man is a multidimensional being, interconnected with the environment and the fields. Beauty, particularly nature, activates our awareness of our connection to the whole. It takes us outside of ourselves lifting us
>
> up and out. We can see more
>
> Anon. in Sheppard 1994, 106.

> *(Rose) The atmosphere - as soon as you get in the hospice, dear, it seems as soon as you cross the door, get into bed, the atmosphere - as though as you breathe it in - it's different. It's a serenity. That's the only word I can... I know (*they*) use it a lot for alcoholics but I can understand the meaning of the word, there's that peacefulness, seems to settle on you like a cloud...*

> The effect in sickness of beautiful objects, of variety of objects, and especially of brilliancy of colour is hardly at all appreciated (Nightingale; 1974, 33).

Literature on aesthetics in health care seems to have focused on: the art of nursing practice, the use of the self as therapeutic (Appleton 1994, Katims 1993), and the larger global environmental connection (Kleffel 1994).

Architecture writers note the effect of an 'experience of place' (Hiss 1990). There is writing on the therapeutic effect that the prepared environments of health spas, and psychiatric hospitals, where matching the needs of the client base for both peace and planned interaction, with the shape and design of the building spaces, and interaction with the outdoors, positively affected the outcomes of the therapy (Mehrabian, 1976; Leboyer-Levy 1982; Hiss 1990).

Tochs (cited in Hiss 1990, 185) describes "...the enabling environment" (pg. 185) which is: "...the unbreakable connection between the condition of the environment in the area and the well-being of the people who live there" (pg. 183). Canter cited in Leboyer-Levy (1982) notes that whilst the environment influences behaviour, there is always the influence of behaviour on the building (pg. 157). Ideally there is synergy in these interactions rather than the building inhibiting the actions of the staff, or patients. Similarly there is the Feng Shui philosophy of:

> ... harmony between the person and their immediate environment; harmony between the immediate environment and its broader surroundings; and harmony among all energetic forces that converge on a person, all emphasise the direct effect of the aesthetic, positional and spiritual effect of building and environment on an individual
> (Master Lam Kam Chuen 1996, 64).

From the participants' narratives, it appears that the hospice environment was enabling; that it allowed space to isolate, peace to calm, and a way for staff to be able to interact therapeutically with all. However provision of intimate space was not always ideal; the four person bed rooms did not always provide the personal distance from others that was needed, as described by Vance (pg. 112).

What the storytellers were attempting to convey was a spiritual, and aesthetic sense which affected them throughout their stay, and no doubt interconnected with the other dimensions of the circle of care. It could be said that they were talking about the communication and interactional qualities exhibited by staff.

> Perhaps the wisdom lies not in the constant struggle to bring the sacred into daily life but in the recognition that there may be no daily life, that life is committed and whole and, despite appearances, we are always on sacred ground.
>
> (Remen 1996, 266)

However an aesthetic\spiritual sense seems more than that; having a quality which set it apart from humanity. For Carol (pg. 138) and Vance (pg. 138, 139) it was the beauty of the building itself. For Frank it was something to do with the care, but more than the human aspects of caring (pg. 138), whereas Brian described it as "...the whole atmosphere" (pg. 138).

Rose focused on this aspect of her story in great depth giving several examples in language which attempted to capture a sense which was invisible or spiritual (pg. 136, 137).

> Who is the one who rests in the eye of a storm?
> Who is the one who can find refreshing streams in the middle of a desert?
> Who is the one who can see clearly at the darkest hour?
>
> Is there anything greater and more powerful than peace and contentment?
>
> (Smith; 1994, 157)

Hospice as a philosophical ideal encompasses the effect of a beautiful environment (Saunders & Baines 1981). McDonnell (1989) similarly noted in her study of perceived palliative care that patients: "...expressed surprise at the relaxed atmosphere, and feeling more free than in a general hospital" (pg. 49).

Rose who experienced palliative care as a caregiver of a dying loved one, and then as one with a terminal illness herself, made no distinction between the quality of the two experiences even though they happened in different hospice buildings (pg. 137). There seemed a universality about the effect of the environment. Rose's use of the word serenity is telling. Roberts & Whall (1996, 359) describe serenity as: "...an emotional experience of inner peace that is sustained regardless of life events". At its most basic level Roberts & Whall believe it evolves from: "...the safe self" (pg. 360), which could connect with the component of 'being safe' in the circle of care. The 'safe self' is found within a quiet and tranquil mind; "...where the world can be viewed with detachment and a sense of safety" (Roberts & Whall; 1996, 361).

I believe we need to be open to the old truths which Nightingale recognised: "...that caring means being open to other realities. Healing takes place in the invisible realms" (cited in Sheppard; 1994, 108). Such realities complement and augment the human dimension of care, and combine to allow universal connectedness. Staff become aware that patients' care is affected by quietness, tranquillity and reflection; there is healing in allowing the intrinsic presence and beauty of a building to engage with people.

It is therapeutic to allow space, peace and silence. To attempt to constantly connect with patients denies this opportunity to experience the spirit of palliative care. Staff can:

> unleash this healing power in other patients by inspiring them to seek serenity and supporting them in their efforts to find and maintain the nurturing inner tranquillity.
>
> (Roberts & Whall; 1996, 363)

Review and summary

This chapter summarises and discusses the findings presented in Chapter Six. The discussion attempts to explain and interpret in one way, the meaning of six patients' experience of palliative care, and the components which were most useful to them.

I believe the phenomenological methodology has allowed the authentic experience of the patients' experience to prevail. For me, the results and discussion provide a challenge to the existing knowledge of the value of palliative care.

As discussed, modern palliative care knowledge although originating from the patient's expressed need (Saunders & Baines 1981), has progressed through a problem orientated (symptom control based) model, coupled and balanced by a strong holistic all-encompassing individual\significant other paradigm view.

The 'circle of care' complements and augments the existing view. It presents the gaze of the recipient of care, the re-interpretation of the mirror image of existing knowledge.

Chapter Eight

Conclusion

Introduction

This final chapter concludes and summarises the process of the study, including how this process affected me personally; a brief discussion about how the outcome of the research, the representation of 'the circle of care', fits with existing concepts of care; a statement about the limitations of the research; and finally some recommendations for future research.

It was my initial quest to explore several persons' lived experience of receiving palliative care. It was my hope that some aspects of this care would be shown to be considered valuable from the patient's perspective; signaling to palliative care staff that these are important. These aspects could be used as the basis for further study about quality indicators for palliative care.

Accompanying this quest was the desire to be allowed to explore an aspect of lived experience in a safe manner with those who were terminally ill; to be able to hear their own voices articulate experience. The process of eliciting opinion from those who are terminally ill has not always been believed to be ethically sound. Instead, proxy opinion such as that of family members has been sought as a 'thought to be valid' replacement.

The methodology used was qualitative descriptive informed by phenomenology. Van Manen's (1990) method of interpretive phenomenology was utilised to inform the researcher about a way of viewing lived experience. This method seemed to fit well with the aim of allowing the participant to story or provide anecdote about the experience of 'care'. I believed that if allowed, the participants would speak of what was most meaningful to them, rather than being guided by closed questions. I also hoped that the interview experience would be helpful, even therapeutic for those who spoke, by allowing them to verbalise real feelings.

Both the goals of allowing the participants to speak of their concerns, and the conversation being of value to them as people, appeared to be realised. There was a feeling of shared warmth, intimacy and compassion between us, including laughter, touch, tears, and the sharing of cups of tea. Most of the participants offered thanks for being part of the interview as it had allowed them a chance to think through and speak out unthought or unarticulated feelings. The process of my 'just listening' appeared to provide affirmation and support to their expression of feeling. I felt this was especially so for the for people who had pre-thought out the story, and had it ready to express to me.

> Telling stories can be healing. We all have within us access to a greater wisdom, and we may not even know that until we speak out loud. Listening to stories can also be healing. A deep trust of life often emerges when you listen to other people's stories. You realise you're not alone; you're travelling in wonderful company. Ordinary people living ordinary lives often are heroes.
>
> (Ornish in Remen; 1996, xvii)

Through previous experience, I was aware that talking about issues that touched on mortality could arouse sadness, and unresolved feelings about potential loss. For Vance there was overt sadness, expressed through interaction between him and his wife, and through discussing his experience with me; and for Rose there was grief in the recollection of her husband's death; for others there may have been unexpressed feelings. I had devised a system of confidential referral for the participants to a counselling service, if I thought this would be helpful. When I mentioned this to Vance, he said that the hospice had already offered this help to him and his wife.

Overall the descriptive-phenomenological method allowed both the ability to describe the experience as expressed to me, and also to to view what was said in a new light, using past clinical, theoretical experience and creative envisioning.

Research with people who are terminally ill : personal issues

The anecdotes and stories revealed the lived experience of palliative care for six different people. It showed that some people who are terminally ill want to talk to others about their experience of care.

As well, it clearly illustrated the difficulties for them in doing so; the balance between the initial negotiation and the actual undertaking of an interview when obvious ill health exists, the pressure of obligation people feel to continue with the process once they have agreed to be interviewed, the 'consent to interview' being sought within the hospice may have made the potential participants pressured to accept. The type of participant chosen for me to seek consent from, may have been unconsciously manipulated through the good intention of staff wanting to find me somebody 'good' to talk to. It is impossible to answer these questions although they created a tension for me to struggle with.

Maybe this is how it should be; researching the lived experience of people who are dying should be approached with trepidation, and questions. There must be an arguable reason to undertake this.

An issue which I had not initially considered, was my own personal feeling of a need for continued connection with each patient. The method I had established stated that I would meet each patient within the hospice to introduce myself, discuss the study, and obtain consent; with one subsequent interview in the patient's home after discharge. However, after this one interview I found that I would have like to have maintained ongoing contact with each patient; because of the sense that a relationship had been created. Although I thought that the participants would have been happy for me to return, this may not in reality have been so; maybe it was a reflection of my own personal need.

I also felt a need to facilitate 'closure', which was more than the ringing up, and letter sending, after the interview. In the past, I had always facilitated closure in palliative care clinical practice, by following the patients' progress either through cotinued caring for them or visiting them, seeking information from colleagues, attending funerals and sending condolences.

In undertaking this study as a researcher not employed within the organisation, and because the participants were to remain anonymous, (even though the staff knew with whom I had made initial approaches); I felt it would be unethical to contact the staff and seek information as to the well-being of the participants. Although I looked in the 'death notices', I could not be sure of accurately noting all the deaths, as these are not always publicly announced. When I did see death notices, I responded only by sending an anonymous written sympathy to the family.

There is a process which occurs when a researcher undertakes an intense process; being involved deeply with the stories of living people. Although our meeting was brief, I felt moved with gratitude for their expression of sharing, and their time.

This aspect of closure should be considered by future researchers.

Within 'the circle of care'

The narrative revealed a representation of describing a personal world of caring. This world of care is unique to people who are terminally ill, and receiving palliative care, although there are many similarities with the concepts expressed within writing on 'care' as a general notion (Kyle, 1995; Brown, 1986; Dyson, 1996; Forrest, 1989; Gendron, 1994; Magilvy, Congdon & Martinez 1994). There is however no disagreement as there is with the claim that 'caring is the essence of nursing'; 'care' is definitely the central object in the specialty of palliative care. The difficulty is, who decides which aspects of care are the important; the staff, or the patient, or perhaps the patient's supporters?

Only people who are living with all that it means to be dying, the symptoms of the illness, the threat to mortality, the anticipated grief and losses, the look in their loved ones eyes, coupled with inevitable fatigue and mental clouding can truly state what is of value to them. It is because of the above factors and many others, that the emphasis on the value of aspects of care is different. Anything which describes facets of care related to curative interventions is irrelevant, yet the care of one's spouse or daughter assumes enormous importance.

The limits of the study

In presenting the results of this study, and the resulting discussion, I have attempted to remain true to the stories of the participants, yet be aware of which aspects I was bringing into the study and identify them as the study progressed. Van Manen (1990) believes that the phenomenological approach encompasses a certain route. First the conveying of the story to the researcher or story- bearer. The story bearer's task is to attempt to articulate into written word, the inherent meaning of the stories. It is the final act by you the reader that makes the story relive; you as reader re-interpret the written word by your own experience.

> Truth always hides. As soon the concept surfaces it hides again ... all you can ever do is constantly explore things, find the meaning, but as soon as it shows it always falls again
>
> (van Manen; 1995, 13).

There are limitations to be considered in terms of the sample; six people being cared for in one organisation with certain physiological conditions, at certain stages of the dying process, and who met inclusion criteria designed to protect the most vulnerable, will not represent the experience of all receiving hospice care. However their stories are an icon of valued care for these people and those who are similar to them. I have discussed this in chapter five, the Research Process.

In order to validate the interpretation of 'the circle of care', it would be essential to return to the participants at least once more. This of course raises pragmatic difficulties in terms of the unpredictability of terminal illness. With two of my participants it would have been impossible to return, with their quite sudden final deterioration and death. I sensed too, that for most, although they were prepared to talk in depth once, that although they would have been happy for me to return to socialise; in depth thought and conversation would have been too exhausting.

Despite the limitations identified here, the process by which the data was obtained, and analysed, is transparently presented within the study. By including portions of the narrative, I have invited the reader to engage with the stories as I did, and attempt to make sense from lived reality, thus creating a decision trail obvious to all (Sandelowski; 1986, 1993).

I believe this study to be context specific; the representation belongs to the environment where the participants where contacted, and perhaps to palliative care environments which replicate the same facilities. There may be elements within' the circle of care' which are common to all people who are terminally ill within New Zealand and perhaps universally. There may be other themes which could be added. This would require further investigation, replication of this study in other environments, particularly looking at people whose care was solely or mainly carried out in their homes. I do believe however, that these stories or anecdotes create a beginning representation of patient perceived 'valued care'. I believe they need to be carefully 'carried' and further reflected on, and used to form the basis of further research.

> More research is needed to evaluate which palliative care interventions, by whom, in what combination, form and amount, for what kinds of patients and families, and with which types of concerns, work best in a particular set of circumstances.
>
> (O'Henley, Curzio & Hunt; 1997, 230)

If the elements identified to be valued aspects of care do prove to be common to those receiving palliative care in other settings, they may occupy different sites of importance within 'the circle of care', depending on their relative perceived importance. When I write this I am thinking of pain and symptom control when this has been inadequately managed. Access to quality symptom control assessment, and interventions is not the same through out New Zealand. This area of care is considered to be of prime importance for study by overseas researchers (Broadfield, 1988; Davis, Cowley, & Ryland, 1996; O'Henley, Curzio, & Hunt, 1997). They are in agreement with the importance of seeking the opinion of the patient in determining this:

> ...patient participation in the process of evaluation is arguably one of the most effective ways of articulating the views of service users and measuring outcomes of care.

(Ingleton & Faulkner; 1995 cited in O'Henley et al, 1997, 230)

My introduction to this study signals my long term interest in determining relevant and measurable quality indicators for best practice palliative care. How has this study advanced this quest? Given that I believe there are factors which make this study situational, it is not possible to conclude specific areas as indicators for quality, although I believe there are components which have arisen which are validated by previous research on patients' and 'health professional's interpretation of 'good' care (McDonnell, 1989; Arblaster et al, 1990; Greisinger et al 1997; Gates, Lackey & White, 1995; Davies & O'Berle 1990).

After undertaking a further replication study, it may be possible to construct the variables which exist between different situational care contexts, philosophies of palliative care, and availability of interdisciplinary team skills. It is after this has been considered, that one may begin identifying how some of the components could possibly be measured perhaps through work place observation, patient opinion, and other audit measures.

Recommendations for further study

As stated within the limitations there are valid reasons why this study may be site specific, and would need to be replicated within different environments within New Zealand.

Although the participants valued all the components within 'the circle of care'; the configuration of the circle is my interpretation and estimation of how the participants, mapped, and attributed value to each component. As in any phenomenological approach, there are a multitude of ways of viewing the story- this way belongs both to my participants and myself, and is open to the reader's revisioning.

I also believe there are components identified which require close scrutiny, in response to addressing the notion of 'care' as valued by these people. These areas have been explored within the results and discussion chapters, and I summarise the concerns as:

> The need to attend to the 'artificial divisions' between providers of care to determine whether completely seamless care is being provided, ideally with one advocate for co-ordination.
>
> Re-appraisal of the notion of privacy and sharing of intimate spaces, particularly bedroom areas; consideration of what roles palliative care patients adopt and how this may influence the outcomes of their care.
>
> Further investigation of the tension between maintaining and relinquishing control which appears to be a process undertaken with some difficulty by both patients and staff.
>
> Look at whether research into the development of a model describing the unique roles which people undergoing palliative care adopt, could have value in identifying individuals' strengths that could be fostered, and weaknesses that could be acknowledged by supportive care.

Other issues not addressed or analysed within this study are differences experienced by male and female in regard to the valuing of care, and cultural need and interpretation in palliative care. Despite having a gender balance in this study, I was unable to determine whether there were gender differences in the experiences of care, although I found it interesting that two of the men specifically requested their wives present at the interview. My study was not framed around looking at these differences, and I believe they merit study.

None of my participants identified as Maori. This is an area wide open to study, particularly accessibility and cultural safety issues when cultural norms regarding care and responsibility for the dying and death are different.

'The circle of care' identified therapeutic skills such as the strength that a carefully moulded interdisciplinary professional and non-professional team has; creating existential 'safety'; therapeutic use of 'humour'; judging and sensing need for intervention - 'being watched'; 'chosen isolation'- the need for personal space; empowerment- 'keeping control'; and 'relinquishment and relaxation', all these skills being difficult to convey educationally to staff.

They constitute a 'personal knowing' about palliative care which requires a new paradigm of teaching. It is in this area that perhaps the most progress has been made in upskilling and professionally sensitising palliative care staff in New Zealand. There is an overall acceptance to provide in and out service opportunities both from skilled educators in palliative care, and within tertiary institutions. Evaluation studies by those providing such educational opportunities would provide a guide for other countries attempting to determine ways of developing a skilled workforce.

Concluding statement

The undertaking of this study is like an end and a beginning. As an end it has justified for me the necessity of "going to the things" (Heidegger, 1927\1977, 74), that is the patients themselves, to find true meaning in their experience. As a beginning it has created a pathway for me to continue examining ways of determining the quality of palliative care.

This pathway will include utilising phenomenological methodology as a way of revealing truths which can only be understood by those experiencing them. As a health professional skilled in palliative care my greatest handicap is in my inability to see a patient's lived world through their eyes.

> The skills and practices we bring to our everyday activity are, for most part, so overpractised and familiar to us, so taken for granted, that we are simply unaware of their existence
>
> (Packer; 1985, 1083).

I believe that the limitations of this study are clearly defined; and there are parts that can only be read for interest in relation to the context of study. However there are areas for all to consider who are concerned with the planning and delivery of quality palliative care, and for educators and researchers in palliative care. It is for health professionals, volunteers (and those within the community) committed to the philosophy of palliative care to act as advocates for the best possible informed care for people who are dying, to push the boundaries of knowledge, to reflect on old truths, and to develop new ways of visioning the future.

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Appendix One

Timeline of the development of New Zealand Hospice\Palliative Care movement. (Parr 1985)

1977\78 St Joseph's Hospice, Auckland (Mater Hospital)

1979 Te Omanga Hospice, Lower Hutt

1979 Mary Potter Hospice, Wellington (Calvery Hospital)

1982 Cranford Hospice, Hastings

1983 South Auckland Hospice, Auckland

1980s (mid) Wanganui Regional Hospice Service

1984 Rotorua Community Hospice Trust

1985 Franklin Hospice Trust, Pukekohe

1986 Community Hospice Service, Whakatane

1986 Whangamata Hospice Support Group

1987 Hospice Home Care, West Auckland

1988 Palliative Care team: Canterbury Health, Ashburton & Community Health Services.

1989 South Canterbury Hospice (Inc.)

1989 West Coast Home Hospice Trust Fund, Greymouth

1990 Waipuna Hospice, Tauranga

1991 Arohanui Hospice, Palmerston North

1993 Twenty Nine hospice groups are registered, ranging from complete interdisciplinary team support to one or two services available.

1997 Thirty Seven hospice groups registered with 'Hospice New Zealand'.

Appendix Two

Information for Participants **January 1997**

Principal Investigator:
Eileen McKinlay: researcher, Department of Nursing and Midwifery, Victoria University.
Home Address: 5 Chudleigh Grove, Churton Park, Wellington. Phone 477-3620.

Supervisor
Joy Bickley: Lecturer, Victoria University: Department of Nursing and Midwifery.
Ph 4721000 ext 8497

Project Title: **The patient's lived experience of palliative (hospice) care.**

Introduction

In early 1997, a researcher will be interviewing a number of people who have been receiving care at the ....Hospice, and have been recently discharged. These interviews will take place in the person's home, or at another mutually convenient location.

Invitation for you to participate

You are invited to take part in this study. If you want to discuss this possibility, the researcher would like to meet with you, together with a family member or close friend if you wish, and talk further, before you are discharged from the hospice The hospice staff will notify her if you would like to consider this while you are still in the hospice. **You are under no obligation either to meet her, or to agree to be a participant in this study**. Once you have met the researcher, you may want to spend some time thinking about whether you want to participate, and discuss this with your family member or friend. **Participation, non-participation or withdrawal from the study will have no impact on your continued care by the .... hospice.**

Project Title: **The patient's experience of hospice care:**

Principal Investigator: Eileen McKinlay, researcher, Department of Nursing and Midwifery, Victoria University: home phone 477-3620

Research Supervisor: Joy Bickley, Lecturer, Victoria University: Department of Nursing and Midwifery.

Ph 4721000 ext 8497

The purpose:

The researcher wishes to understand what the patient experience is, being cared for in the hospice, and seeks to convey this experience to health professionals and other carers. The story of the patient's experience of care will give a new fresh perspective on palliative care.

The participants:

The researcher wishes to talk with four to six patients who have been cared for in the hospice and have gone home again.

Because you are about to be discharged from the hospice, you have been asked whether you would be interested in meeting the researcher, and perhaps join this study.

The interview:

The interview will take place within your home shortly after discharge (3-5 days) and will take between 20 -30 minutes. If you are tired or not feeling well you will be free to shorten or cancel the interview either prior to the researcher coming or when she arrives. You do not have to answer all the questions and you may stop the interview at any time. Unfortunately the researcher cannot pay you anything for taking part in this study. She hopes that the results of this study will benefit many patients who are having palliative care.

Project Title: **The patient's experience of hospice care:**
Principal Investigator: Eileen McKinlay, researcher, Department of Nursing and Midwifery, Victoria University. home phone 477-3620
Research Supervisor: Joy Bickley, Lecturer, Victoria University: Department of Nursing and Midwifery.
Ph 4721000 ext 8497

Risks in taking part: It is important for you to know how you may feel after having been interviewed.

You may feel tired after having taken part in the interview. You may decide to talk to the researcher about aspects of your care, or even your illness, which could upset you. The researcher will be careful to see to see if you need a rest from talking, and will discuss anything that has upset you. With your agreement she will help you to get any assistance you need.

Benefit:

People can find it helpful to talk about their care with someone who has had experience in this area, and who is interested in what you have to say. It is the wish of the researcher that you will feel that have gained something from this experience.

Recording:

If you decide to participate, the interview will be taped to assist the researcher in recalling everything that is said. All information given to her will be kept confidential. You will be offered a copy of the audiotape or the interview once it is transcribed. If a professional word processor is used to transcribe the tape, s\he will not be given identifying details of who you are.

Confidentiality:

The protection of your identity will be ensured by the use of code names, and anything to identify you will be altered. It is possible that the researcher may want to directly quote some of what you said within the report.

Project Title: **The patient's experience of hospice care:**
Principal Investigator: Eileen McKinlay, researcher, Department of Nursing and Midwifery, Victoria University. home phone 477-3620
Research Supervisor: Joy Bickley, Lecturer, Victoria University: Department of Nursing and Midwifery.
Ph 4721000 ext 8497

Again any identifying names or characteristics will be altered to ensure your privacy. No material which could personally identify you will be used in any reports on this study.

The researcher would like your permission to keep the transcript of the audiotape in a secure locked file for five years in case other researchers may want to check or further work on the results.

Withdrawal:

You may decide to participate initially, but then decide to withdraw. This will be accepted totally. **You may withdraw from the study at any point.** The researcher would contact you on your arrival home after discharge to confirm the date and time of the interview,

and again on the morning of the interview to check on your well-being. You will be encouraged to decline the interview if you are tired or unwell. **If you decide to withdraw from the study, this will in no way affect any future care you may have at .... Hospice.**

Results:

The final report will be available for all to read in February 1998. If you would like to know of progress prior to this time you would be welcome to ring the researcher. If you or your family would like a report of the final results, this can be asked for at the time of the interview. It is anticipated that the results will be published as a paper in an international hospice publication, and given as a paper in a national or international hospice conference.

Project Title: **The patient's experience of hospice care:**

Principal Investigator: Eileen McKinlay, researcher, Department of Nursing and Midwifery, Victoria University. home phone 477-3620

Research Supervisor: Joy Bickley, Lecturer, Victoria University: Department of Nursing and Midwifery. Ph 4721000 ext 8497

General:

General Practitioner: If you would like, the researcher will notify your G.P (your family doctor) of your participation in this study.

Interpreter: If you require an interpreter, this will be arranged by the research student.

Further information: If you require further information about this study after the researcher has visited you; please ring either the researcher or her research supervisor Joy Bickley.

Who is the researcher ?:

She is a registered nurse who has worked with people receiving hospice care in the past, but is not currently employed by the hospice. At present she is studying in the Nursing and Midwifery Department at Victoria University and is undertaking this as course work for an M.A. (App) degree.

Questions\Concerns:

You may have any questions or concerns that arise through the interview. The researcher will endeavor to discuss these with you. With your permission she will seek assistance if unable to do this to her or your satisfaction.

Ethical approval:

This research project has the support of the .... Hospice, and has been approved by the Central Regional Health Authority Ethics Committee, Wellington.

Project Title: **The patient's experience of having hospice care:**

Principal Investigator: Eileen McKinlay, researcher, Department of Nursing and Midwifery, Victoria University. home phone 477-3620

Supervisor: Joy Bickley Victoria University, Department of Nursing and Midwifery.

Ph 4721000 ext 8497

If you have any queries regarding this research please contact:

Eileen McKinlay researcher, Department of Nursing and Midwifery, Victoria University. home phone 477-3620.

or: The Chairperson, Central Regional Health Authority Ethics Committee, Wellington, Private Bag 7902, Wellington. ph 385-5999 ext 5185. Fax 385-5840.

Please take time in considering whether you would like to become involved in this study, and share your experience with me. Your time is very precious and it will be understood completely if you do not want to participate.

Appendix Three

Consent form- Patients

1. Project Title: The experience of the patient receiving palliative (hospice) care.

2. **Investigator's details**: Eileen McKinlay Registered Comprehensive Nurse: student, Department of Nursing and Midwifery, Victoria University, Wellington.

3. **Aim of the study**: This study is to hear patients talking about their experience of undergoing palliative care. It is important for those people who assist others (caregivers) in the hospice to understand the patients experience of care.

4. **Participants' Consent**

4.1 I have read and I understand the information sheet dated January 1997 for volunteers taking part in the study designed to hear patients talking about their experience of undergoing hospice care have had the opportunity to discuss this study . I am satisfied with the answers I have been given.

4.2 I understand that taking part in this study is voluntary (my choice) and that I may withdraw from the study at any time and this will in no way affect my future health care.

4.3 I understand that my participation in this study is confidential and that no material which could identify me will be used in any reports on this study.

4.4 I understand that the interview will be stopped if it should appear harmful to me.

4.5 I have had time to consider whether to take part.

4.6 I know who to contact if I have any side effects to the interview.

4.7 I know who to contact if I have any questions about the study.

4.8 I consent to my interview being audio-taped. YES/NO

4.9 I wish to receive a copy of the results. YES/NO

4.10 I consent to my GP being informed of my participation in this study YES/NO

5. **Statement to be signed in the presence of one of the investigators and, where possible to be witnessed:**

* I have read the consent form and have had opportunity for discussion with...

* I know that I may withdraw from the study at any time and I understand that this withdrawal will not adversely affect my further health care.

* I understand that this study has been approved by the Central Regional Health Authority Wellington Ethics Committee and if I have any concerns about the study, I may contact Alison Douglass, Chairperson, Ethics Committee Wellington Hospital Telephone 385-5999 ext 5185

I hereby consent to voluntarily participate in an interview for a research project to be undertaken by Eileen McKinlay; registered nurse and researcher of the Nursing Department: Victoria University, Box 600, Wellington.

Signature..(patient)....................(date)
Signature..(witness)...................(date)
Witness name...(print name)

Statement by investigator:
I have discussed with..(participants name)
the aims and procedures involved in this study.

Signed..(investigator).............................(date)
Full names of Researchers Principal research student: Eileen McKinlay
Ph 477-3620

Research Supervisor: Joy Bickley
Ph 4721000 ext 8497

(Note: A copy of the consent form to be retained by participant and (in the case of patients) a copy to be placed in the medical file.)

Appendix Four

Title of Project: The lived experience of a patient experiencing palliative care:

Supervisor\Transcriber Confidentiality Statement

This is to certify that I, (Name and address & telephone number of transcriber) hereby understand that the information contained in these tapes and transcripts is confidential and that the contents will not be discussed with anyone other than the researcher at any time.

Date.......................of..1997

Signature..

Appendix Five

The lived experience of a patient experiencing palliative care
A research project undertaken through the Victoria University Department of Nursing and Midwifery. 1997

Researcher: Eileen McKinlay
Home phone 477-3620

Information sheet: for ....Hospice staff.

The Aim of the research project:
The aim of the research project is to investigate a small number of 'relatively well' discharged patients' experience of palliative 'care'

While I worked at the hospice in the development of the quality improvement programme (1990-1994), one of the things which nagged me was the inability to understand which aspects of care most contributed to the patients sense of well-being. In quality 'lingo' these are the "Quality Indicators". This project is designed to hear the patients voice about what aspects of 'care' are valued by them.

The process:
At the weekly interdisciplinary meeting, inclusion\exclusion criteria (see below) will be applied to all patients who are anticipated to be discharged within the following week.

Those patients who fit the criteria will be approached by a member of the team (probably the primary nurse), and asked if they would consider meeting a registered nurse undertaking a research project with patients who have received hospice care and are about to be discharged. The interview with the patient will take place in their own home once they are discharged.

If the patient wants to consider this further, an information sheet which fully explains the project will be given by the staff member.

No coercion must be applied to encourage the patient to meet me, however if they do wish to talk about the study and consider participating, please contact me at home 477- 3620 (leave a message on the answer phone if I'm out).

It is important the patient understands that I am not undertaking this research for the hospice, am not employed by the hospice, and will maintain confidentiality.

I will phone the patient at the hospice and arrange a meeting with her\him and a support person (family\friend). After having discussed the project with them, I shall give them time to consider their participation with their support person, and seek written consent.

A copy of the research proposal is available in staff base, and you are welcome to discuss it with me, either when I am at the hospice, or ring me at home. I plan to come and talk with staff prior to the project starting.

Thank you for your support in this research.

Eileen McKinlay.

Inclusion criteria

Using phenomenology as a methodology means that participants are chosen for their experience in and knowledge of a particular setting (purposeful or theoretical sampling), rather than through statistical sampling. In the case of researching with the palliative care patient, this too must be modified in light of the ethical concerns of interviewing very ill or dying people. Thus the inclusion criteria for the study have been identified to protect the overall safety of the patients, however the research student is aware that they may bias the information received

The research student plans to interview 4-6 discharged clients of the in-patient service of a hospice.

*These clients will have experienced more than one service within the hospice, including the in-patient service. The other services could be the symptom control clinic, family support service, or occupational day therapy.

*Clients must be currently under the care of a home care team, so that clinical\family concerns expressed to the interviewer or concerns that the interviewer has herself, could be passed onto the appropriate facility with the patients permission.

*Age: adult clients of any age.

*Clinical status: Clients would be in the palliative care phase of a terminal illness i.e. conscious, able to speak, semi-dependent, lucid, comfortable, and considered to be able to sustain a conversation for 15 minutes by the interdisciplinary team caring for them. The reason these type of clients would have been receiving care was for symptom control, or respite relief for relatives.

Exclusion data

*All patients who are not in the above category.

*Patients whose second language is English and have difficulty in understanding or speaking English.

*Children and adolescents who are receiving palliative care.

*Patients whose mental state either through organic cause or psychologically, would cause them to be unable to participate. This will be determined by the interdisciplinary team caring for them.

*Patients whose physical state would cause them to be unable to participate. This will be determined by the interdisciplinary team caring for them.

Note

If the participant's clinical status deteriorates between the time of agreement to participate, and the planned interview time, the researcher or participant may cancel the interview. The clinical status of the participant will be confirmed by telephone contact between the researcher and the participant or caregiver on the day of the interview, prior to the scheduled interview time.

Appendix Six

The lived experience of a patient experiencing palliative care:. A research project undertaken through the Victoria University Department of Nursing and Midwifery.

Researcher: Eileen McKinlay
March - May 1997

Information sheet: for .... Hospice Family Support Team.

I enclose this information sheet with a general information sheet on the research project I will be undertaking.

As part of my preparation to establish safety for those participating in this study, I would like to have available the facility to be able to refer participants and \ or their support person, (with their permission) to the Family Support team. It is not my intent in undertaking this study to cause distress, however through past experience in working with those who are terminally ill, discussion about 'care' can elicit unresolved issues.

You will not know who is a participant in the study, however I may contact you with the name of a patient or family member\friend, and ask you to make contact, or prepare you for a possible contact from a participant or family member\friend.

I hope that this does not cause a great deal of extra work for the team as I know you are busy already. If you have any concerns either about the research project, or your role in it, please contact me at home PH 477-3620.

Thank you for your support in this research.

Eileen McKinlay.

Appendix Seven

Header page for patient's information pack. I attached a photo at the top of the page.

The experience of the person receiving Hospice Care

Information Summary: detailed information attached below.

- My name is Eileen McKinlay and I would like meet you and discuss the possibility of taking part in a study looking at the experience of being in a hospice.
- I am a registered nurse who has worked at Mary Potter Hospice in the past and have a continued interest in the work of New Zealand hospices. I am now studying for an M.A. in nursing at Victoria University. This study will be written up as my thesis.
- I am very interested in meeting with people, after they have been discharged, in their own home, and talk briefly about hospice care.
- If you feel you would like to discuss this possibility while you are still in the hospice, could you please let your nurse know and she will contact me.
- This research project has been examined by the Central Regional Health Authority Ethics Committee, and is conducted with the knowledge and support of Mary Potter Hospice.
- All information given to me will be kept confidential.