THE PERCEIVED NEEDS OF

THE TERMINALLY ILL

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ABSTRACT

While there is considerable international interest in the development of hospice and palliative care programs, as an alternative form of care for the terminally ill, there is minimal empirical research undertaken on the needs of recipients of these programs. Using a Q-sort, developed by the author, this research examined the relationship between individual patient's ranking of their needs, and the nurse's perception of the needs identified by individual patients in their care.

A basic assumption of the study was that patients' needs could be categorised in four groups, namely spiritual, physical, emotional, and social. Consequently, the study also examined whether patients and nurses identified, as most important, needs from one group, more frequently than the other groups.

The limited size of the sample placed severe restrictions on the analysis of results derived from this research. However, while no definite conclusions could be drawn from data obtained from the small sample, tentative analysis identified trends that may have proved significant had they continued in a larger sample.
PREFACE

Embarking on a project of this nature affects the lives of many people; some extensively, others only slightly. There are many people, friends and relatives alike, who have endured my constant preoccupation with this research project, that I thank for their perseverance and understanding during the life of this study.

I thank the Director of Nursing/Community, ACT Community and Health Service, for supporting the project by giving her permission to approach nurses to participate in the research. Also I thank, not only the palliative care and community nurses who participated in the research, but also those who shouldered the additional work load to enable individual nurses to participate.

I owe a deep debt of gratitude to my supervisor Dr Jim Clough for his searching questions that inspired me to clarify my own thinking, search for my own answers and stopped me from following interesting but fruitless tangents; his constant encouragement and support when difficulties arose; his patience with my self-doubts; his ready availability for consultations that were significant in allaying my anxiety throughout the study; and his sense of humour that contributed immensely to the maintenance of
my sanity during fieldwork, analysis of data, and writing of the thesis.

I cannot find the appropriate words to express my thanks to the individuals who took part in the research, particularly those individuals, who were living with their terminal illness, and their families. There is much that I learnt from these people, of a personal nature, that is not included in the results or discussion of this study. I feel very privileged to have been welcomed into the homes of these families and honoured that they shared so honestly, their thoughts and feelings, during this difficult part of their life.

I thank Hilary Parkinson for her untiring willingness to be a sounding board, proof reader, close friend, and honest critic throughout the study.

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CHAPTER 1

Introduction

Patterns of death and dying in Australia have changed considerably since the turn of the present century. While death was commonly experienced as part of family life during the late nineteenth, and early twentieth, century, several factors have lessened familiarity with dying and death for Australians of the 1980s. These experiences of the community generally, and health care professionals specifically, have influenced the way in which dying and death are managed in Australia.

Although the development of death education, and the Hospice movement, arose from the emerging humanitarianism surrounding the problems inherent in all types of illnesses, infirmities, and disabilities, and the general disenchantment with traditional health care for the individual with a terminal illness, empirical research has failed to adequately address the needs of individuals with a terminal illness. Previous research has focused on an examination of the needs of family members of critically, or terminally, ill individuals or expectations of nursing behaviour. The rare studies that addressed the needs of
the individual with a terminal illness did so by requesting principal carers to identify the patient's needs.

This study involved clients of the Home Based Palliative Care Program operated by the Community Services Division of the Australian Capital Territory (A.C.T.) Community and Health Service and was conducted during the period November 1988 to May 1989. Using a Q-sort, developed by the author, this research examined the relationship between individual patient's ranking of their needs and the nurses' perception of the needs identified by individual patients in their care.

Background

The Home Based Palliative Care Program provides 24 hour, on call, nursing services within the client's home and is run in conjunction with the A.C.T. Hospice Society's Volunteer program. Both programs were established simultaneously in April 1985. At the time of the study the program was limited to a maximum of 20 patients at any one time and had specific eligibility criteria (See Appendix 1). Once patients were accepted into the program nursing care was normally shared between palliative care nurses and the patient's local community nurse, who may have been involved
with the family from the commencement of the patient's cancer treatment, months or years earlier.

Due to the increasing reluctance of palliative care nurses to participate, the research was stopped after only eight patients, four palliative care, and four community nurses had completed the Q-sort. Consequently, the limited sample size placed severe restrictions on the analysis of results. While no definite conclusions could be drawn from such a small sample, tentative analysis identified some trends that may have proved significant had they continued in a larger sample. Although there was a significant relationship between the overall Q-sort of individual patients and the attending nurses, the accuracy with which nurses perceived patients' needs was small. However, both palliative care, and community, nurses were able to perceive the physical needs of their patients with a relatively high degree of accuracy. Neither group of nurses were generally able to perceive the spiritual, social or emotional needs of patients with any degree of accuracy. Both palliative care, and community, nurses tended to rank social needs as most important more frequently than did patients.

As well as tentatively identifying these possible trends, the research raised a number of interesting questions.
CHAPTER 2

Literature Review

Despite the rapid social and technological changes that have occurred over the past 100 years, contemporary Australian society is still not particularly proficient in the management of dying and death. The effect of these changes has been to distance modern Australians from the personal experience of death and consequently, they have had a great influence on current attitudes toward dying and death at the individual, professional and social level. The result of this personal and social distancing is reflected in the current manner in which dying and death are presented to the community; the way individuals learn about death; the lack of clearly defined attitudes and beliefs of professionals to whom death is a more familiar phenomenon (Warren & Chopra 1979); how the community educates its health care professionals; and, ultimately, the provision of health care services for the terminally ill (Radford 1979). It will be argued that the prevailing attitudes toward dying and death lead to deficiencies in the way dying and death are commonly managed in modern Australian society.

To understand prevailing attitudes toward dying and death and the consequences for health care for the terminally ill, it is useful to compare the common death-related
experiences of Australians at the end of the nineteenth century with those currently experienced by Australians in the 1980s. Examining the past can provide clues about how and why present attitudes evolved (De Spelder & Strickland 1983). Since attitudes have cognitive, emotional and behavioural components (Oppenheim 1968), it is crucial to consider the way Australians in the late nineteenth century believed, felt, and behaved about death. It is also important to examine the factors that, over the years, have influenced our attitudes toward dying and death.

**Early Australian patterns of dying and death.**

Throughout most of Australia's early history of white settlement, and well into the twentieth century, the home was the centre for the multitude of activities and events associated with a death (Griffin & Tobin 1982). At the turn of the twentieth century most people died at home with all family members present, including the youngest children. In this situation each person learned about death firsthand. Children, along with adults, were often involved with caring for the dying family member, kept vigil beside the open coffin, and, as a result of limited availability of living space, sometimes slept in the same room as the corpse. Thus dying and death were an accepted
part of the every day reality of the Australian family at the turn of the twentieth century.

Death was also very much within the realm of the family. Not only did the person die at home but the family also washed and prepared the body for burial. Embalming, if necessary, and placing the body within the coffin, was all completed within the family home. Not only was the coffin kept at home prior to the arrival of the hearse, but also the lid remained off to enable friends and acquaintances from the community, and other relatives, to come to the family's home to view the body of the deceased and to share in the ritual of mourning. Even in the height of an Australian summer, the difficulties associated with odour were overcome by a variety of simple homespun remedies (Griffin & Tobin 1982). The custom of funeral services being held in the home prior to the funeral procession and burial was so entrenched well into the twentieth century that advertising blanks used by undertakers for their announcements in the daily Press had the words "the funeral will leave ... residence" already printed on them (Griffin & Tobin 1982, p 4).

Griffin and Tobin suggest that one of the major reasons for this centrality of the home was the lack of alternatives. They produce evidence to substantiate the claim that "where one had a choice the wise course was to stay out of
hospital when ill" (p 6), as during the nineteenth century the average Australian considered that hospital was the certain precursor to the cemetery. Whatever the reason people chose to die at home, it still remains evident that by remaining closely involved with the many activities associated with a family death, Australians at the turn of the century were more accepting of death as a natural part of life. Although the death of a close family member was an emotional experience for the surviving family members, it appears that the expression of grief and mourning were acceptable within the community. With death such a common companion to these early Australians, it appears that this familiarity produced either acceptance, or resignation, to the inevitability of death. Dying and death were not relegated to specialised institutions, but remained very much part of community living.

Current Australian patterns of dying and death.

The situation is vastly different in the 1980s. Although statistics are not kept on place of death [Australian Bureau of Statistics (ABS) personal communication] it is generally regarded now that deaths rarely occur in the home. Instead, most people are dying in specialised institutions such as hospitals, nursing homes, etc.
where rules and regulations regarding treatment procedures and resuscitation techniques often govern the manner in which individuals die, as well as the timing of their death.

In these institutions, care traditionally undertaken by family members has been replaced by the professional care provided by medical practitioners, nursing and allied health care staff. Responsibility for the patient's well-being is relinquished by family members and taken over by health care professionals who are highly trained to perform technical services in combating disease and death (Coombs & Powers 1975). All available medical technology is utilised in prolonging life as long as possible. Resuscitation techniques are often routinely undertaken, despite the underlying illness or overall prognosis, until the patient is either revived or does not respond and ultimately life is pronounced "extinct".

Once the patient is pronounced dead, relatives may choose to view the body briefly in these institutions before handing over responsibility to a funeral director to make all necessary arrangements for preparation of the body, and its final disposal. Although there is no legal impediment to retaining the body in the home until the funeral, there is now a reluctance, widely felt throughout the community.
about sharing the house with a dead body (Griffin & Tobin 1982). The majority of people the author has come into contact with as a grief counsellor express the belief that the body must be taken from the home as soon as possible after death. They also believe that, along with a medical practitioner, one of the first people they are required by law to contact is the funeral director. Funeral directors have developed a 24 hour service to cater for this community "need", thus perpetuating the myth. Modern refrigeration techniques allow the body to be kept at the premises of the funeral director, perhaps until the widely scattered members of the family can assemble for the funeral service, now held either in a church or funeral "chapel", and the ensuing burial or cremation.

Although Australian attitudes have not yet reached the general community denial of death outlined in Mitford's classic, The American Way of Death (Mitford 1963), there is still a reluctance to openly talk about dying and death in the Australian community. Personal experience as a grief counsellor leads the author to believe that people generally assume that death, like car accidents, will occur to someone else rather than themselves or their family members. The modern Australian individual is less familiar with dying and death and therefore more anxious about its eventual occurrence. The question naturally arises, What has produced this change? It is crucial to examine how
these changes have influenced the community's response to the provision of care for the individual with a terminal illness.

Factors lessening familiarity with dying and death.

The changes in how Australians have dealt with dying and death over the past 100 years result from a combination of social and technological factors. These factors are not limited to the Australian context but are common throughout the western world. The accepted result of this "progress" is that personal experience with dying and death continues to be limited in everyday life. The following factors have been significant in influencing this change.

1. Life expectancy and mortality rates.

In 1901 the infant mortality rate was 103.6 per thousand and, at birth during 1891-1900, life expectancy for males was 51.1 years and 54.8 years for females (ABS 1988). With 34.8% of the 273,120 deaths during the period 1901-06 occurring before the age of 20 and 50.0% of deaths occurring prior to 40 years of age (Commonwealth Bureau of Census and Statistics 1908), death was a common family
experience. Most people experienced the death of brothers or sisters during the early years of childhood. It was also a probability that one or both parents would die before their children had grown to adolescence. Therefore, young and old experienced death as a natural and inevitable part of the human condition.

By 1985 the situation had been changed dramatically. The infant mortality rate had been reduced to 10.0 per thousand, life expectancy at birth was dramatically increased to 72.3 years for males and 78.8 years for females; only 5.03% of the 118,808 deaths occurring in 1985 were of individuals below 24 years of age, and the vast majority of deaths (71.0%) were of people 65 years of age and over. Whereas at the turn of the century the greater proportion of deaths occurred to the younger members of the community, by 1985 the majority of deaths occurred to older community members. Gordon (1976) suggests that improvement in mortality is a transference of death from the young to the old rather than life-saving in the literal sense. Therefore, it was likely that individuals within the community would reach adulthood without experiencing the death of a close family member.
2. Geographic mobility.

In the early part of the twentieth century relationships were closely tied to place and to kinship, while today's relationships are characterised more by present function than a lifetime of shared experiences (De Spelder & Strickland 1983). Children, now reaching late adolescence or young adulthood rarely live in the same house as their parents, or even less likely, with other siblings in an extended family (Edgar 1988). Family and friends become separated from one another by large distances as changes in lifestyle, undertaking tertiary education and seeking employment often necessitate moving to another city or state. School and university friendships are now less likely to continue through marriage, the child-rearing years and into retirement. In this highly mobile pattern of living, death is unlikely to occur among family and friends.

3. Life-extending technologies.

Advances in medical technology have changed the experience of dying and death for the modern Australian (Gordon 1976). The invention of the kidney machine in 1954 became the first in an ever increasing number of sophisticated technologies designed to aid in prolonging life. A multitude of choices in health care are now available to
the modern Australian as a result of the introduction of these new biomedical technologies. Skilled surgical techniques that take advantage of companion technologies, such as those used in open heart and transplant surgery, can now repair previously lethal biological malfunctions. The replacement or repair of dysfunctional organs is an accepted, even expected, part of current medical practice. The development of sophisticated mechanical monitors allows the "high-tech" physician or surgeon to instantaneously obtain information on various biological functions, including brainwave activity, heart rate, body temperature, respiration, blood pressure, pulse, blood chemistry, and a host of others. Such apparatus, with the ability to signal minute changes in body function by light, sound and computer printout, often become the crucial factor in medical situations of life and death.

Other sophisticated diagnostic machinery has been developed to aid the physician. Innovative imaging systems such as the CAT (computerised axial tomographic) scanner which provides images of plane sections of the patient's body, along with ultrasound systems such as NMR (nuclear magnetic resonance) augment the familiar X-ray machine in assisting the physician to make accurate, and earlier, diagnosis of a potentially life threatening illness. When coupled with modern advances in pharmacology, these technological
achievements can often significantly reduce the risk factor in a previously life-threatening, or fatal, illness.


Changing causes of death represent another major reason why experience of death today is so different from turn of the century experiences. Then death was typically rapid and sudden, often caused by accidents (Gordon 1976) or infectious diseases, principally respiratory conditions such as pneumonia and influenza along with gastric infections, tuberculosis, typhoid and diphtheria (Najman 1988). Now the typical death is a slow, progressive process resulting from diseases such as heart disease and cancer.

Not only have improvements to community health care and advances in medical science and technology been responsible for the decline in the death rate, but also they have been responsible for changes in the causes of death. Although a series of comprehensive health acts were passed towards the end of the nineteenth century and efforts were made to improve infant nutrition (ABS 1988), it was the improvements to hospital care and antiseptic surgery, the discovery of antibiotics and the development of immunisation programs that changed the causes of death.
(Better Health Commission 1986). Many of the infectious and diarrhoeal diseases, maternal mortality, pneumonia and tuberculosis were brought under control by the 1950s with consequent reductions in mortality rates from these causes. Whereas in 1905 6.3% of deaths resulted from cancer and other malignant tumours and 3.3% of deaths were the result of organic diseases of the heart (ABS 1908) these figures had risen to 23.5% and 48.4% of deaths, respectively, in 1985 (ABS 1988).

5. Reduced contact among generations.

Changing causes of death, geographical mobility, a declining percentage of deaths occurring among the young, the rise of the nuclear family and the increasing proportion of elderly people in the community combine to create a situation where few people are present when close family members die. Consequently, the first experience with death for the modern Australian is likely to be associated with a grandparent who was not living with the family at the time of death. It is also highly likely that this grandparent had been living alone, in a retirement village or a nursing home and had reduced contact with extended family members. This is another reason why few people in today's Australian society are likely to directly experience an actual death.
6. The displacement of death from the home.

Not only is death less prevalent than it once was, it is certainly less visible. So too with dying. The technological society has almost succeeded in removing death, and those who are about to die, from the home and family (Radford 1979). As outlined earlier, dying and death have become institutionalised and responsibility given over to professional carers in the health care professions. Even in these specialised institutions death may be kept a secret from the person who is dying (Bowling 1983, Cramond 1970), or the institution may go to elaborate lengths to hide the fact of death from other patients (Sudnow 1967).

7. Changes in the practice of medicine.

These technological changes have also affected the practice of medicine. As medicine has increasingly become a highly sophisticated science, intricately involved with a multitude of scientific principles that concentrate on cure, or the prolongation of life, so the cost of receiving such medical treatment has rapidly increased. To facilitate cost effectiveness these new medical technologies have been concentrated in the larger hospitals situated in the bigger cities.
Medical science has expanded to the degree that it is now commonly accepted that no single medical practitioner can possibly keep abreast of all the new developments across the broad areas of medicine. Consequently, specialisation has evolved where doctors have developed detailed knowledge of specific parts of medicine, e.g. Ear, Nose and Throat, heart, and oncology. The information explosion that has occurred since the 1960s has made even keeping abreast of specialist areas a difficult task. This has meant a changing role in the practice of family medicine.

In the past the general practitioner was often the family friend as well as medical adviser. As such it was common for this individual to have been involved in the birth of several members of the family, attended many of the childhood ailments and accidents and most, if not all, the medical requirements of the family. Now if a patient is to receive the benefits of high technology medicine, the general practitioner must refer the patient to a specialist who has acquired this detailed knowledge. This practice increases the number of people involved in health care and increases the risk of poor communication between medical practitioner, specialist and patient. Many patients spoken to in the course of the author's work as a loss and grief counsellor complained of the inadequate communication between the medical profession and themselves. A frequent
comment from these patients was that the medical staff, with a few exceptions, were interested in the disease, and its progress, that was occurring to the patient rather than the patient as an individual who had a particular disease.

Another significant change related to medical technology is the developing expectation that medical research will continue its breakthroughs against disease. Since medical science has won so many previous battles with death-causing diseases, it is becoming a widely held belief that it must be simply a matter of time before death is completely defeated (Kastenbaum & Aisenberg 1972). Recent developments in cryogenics, with its belief that future medical techniques will be able to successfully thaw the body, treat the death-causing disease and reinstate the individual to former health and life, show that many people support this belief.

Experiences of the Community.

These social and technological changes have far reaching effects on all members of the community. Since fewer deaths are occurring within the family environment, fewer members of the community are having personal experiences of death before they reach middle adulthood. Consequently, individuals are not given the opportunity to become
familiar with, or even experience, the death of a close relative in the familiar surroundings of their home environment. Increasingly death is becoming a stranger to the younger members of the community.

Experience of Health Care Professionals.

These community changes also have a significant effect on those individuals entering the medical profession. Not only do these trainees have to cope with a profession that emphasises its curative aspect, but also few trainee nurses, for example, have had to face death as a significant part of their personal life experience (Lewis 1979). This lack of significant experience with dying or death has ramifications for trainees interacting with dying patients. Confronted with death, perhaps for the first time in their life, trainee nurses are likely to experience strong emotions within themselves. Without the benefit of prior experience, the individual is likely to discount the patient's or family member's feelings (McKissock 1978), physically withdraw (Bowers, Jackson, Knight & Le Shan 1964, Caty, Downe-Wamboldt & Tamlyn 1982, Kubler-Ross 1970, Schulz & Aderman 1976) or engage in medical heroics, (Coombs & Powers 1975, Maguire 1985) to enable them to function as an "efficient" member of the medical team. An
example of medical heroics is the resuscitation of a patient experiencing myocardial infarction despite an underlying terminal illness that is likely to cause the patient's death within a matter of days or weeks.

What the student in any of the medical professions learns about the care of the dying patient also reflects the basic values of the nursing and medical culture where a high priority is attached to life. Frequently, emphasis given to the life saving technological aspects of medical science during the training, and subsequent practice, of the medical profession is at the expense of the emotional well-being of the patient, family, and ultimately the medical professional staff. Redding (1980) suggests that in medical training:

death has become the enemy: and in losing a patient, doctors often feel that they have failed medically, or worse still, made some terrible mistake (p. 372)

Edwardson (1985) reports evidence to support this position particularly when "the overriding focus of the therapist is cure or control of disease" (p 84). Frequently, for the medical profession, this idea that the death of a patient represented a failure was not verbalised but subtly perpetuated and rarely was dying or the events surrounding death viewed as a potentially appropriate part of life (Barton 1972). This attitude has serious implications for
the way in which the medical profession provides a service to those members of the community who have a terminal illness. Without the knowledge and skills to deal with their own emotional conflicts around death, the medical profession is unable to provide adequate support for, or even understand the nonmedical needs of, the dying individual or his/her family.

In our society the medical profession has been placed in an elevated and revered position in the community. From a sociological perspective the role of the physician is that of a specialist whose superiority to his/her fellows is confined to the specific sphere of his/her technical training and experience. Despite the fact that a physician is not, by virtue of his/her modern social role, a generalised "wise man" or sage, there is considerable folklore to that effect (Parsons 1951). Consequently, a belief commonly held by members of the community, particularly in relation to health matters, is that the doctor, and the medical profession in general, knows what is best for the patient. In turn, this belief leads to individuals handing over control of their illness, including related emotions, to the medical profession. As the pivotal figure in our society's death system, the medical practitioner exerts much influence over the general climate of thought and feeling, and also over other members in the system, including the patient and his/her family.
(Kastenbaum & Aisenberg 1972) as well as other health care professionals (Caty, Downe-Wamboldt & Tamlyn 1982). Thus, patients take their cue from members of the medical profession in discussing aspects of their illness. When patients perceive members of the medical profession are unable to openly deal with emotional issues relating to their illness, and in particular dying or death (Kubler-Ross 1970), the patient takes the signal from the medico and does not discuss emotional problems (Coombs & Powers 1975, Hinton 1980, Maguire 1985).

This situation is understandable when consideration is given to the development of modern medicine with its profusion of sophisticated medical technology, a general community attitude that attaches a high priority to life and cure, the development of areas of specialisation, and the broad area incorporated into the psychosocial process of dying.

**Psychosocial process of dying**

The dying trajectory from primary recognition of disease to incipient death is highly idiosyncratic, and it is only from a distance that human behaviour seems subject to laws and to prediction (Weisman 1972). Nevertheless, it is possible to recognise and describe general phases of fatal
illness without imposing sterility or an artificial stereotyped version of threatening events. Weisman (1972) provides a useful framework for examining the psychosocial process of dying by distinguishing between longitudinal organic changes, or the course of the disease, and psychosocial stages of fatal illness. According to Weisman organic changes depend upon the biology of disease, its invasiveness, rate of development, sensitivity to treatment, site of involvement, and potential for recurrence. While organic changes create many personal and social changes in the life-space and style of the patient, psychosocial stages follow a sequence that is not determined wholly by physical factors.

Weisman postulated three phases of personal response to the course of fatal illness and claimed them to be distinctive enough to be called psychosocial stages:

1. **Primary recognition** - covering the period from the patient's first awareness that something is amiss, to the time of definite diagnosis;

2. **Established disease** - embracing events between a patient's initial response to the diagnosis and reactions prior to the onset of the terminal period. This stage also pertains to the periodicity of
illness, its relapses, remissions, progress, and periods of arrest; and

3. Final decline - begins when a patient undergoes unmistakable decline towards death. It ends with death.

An important factor to recognise is that, although organic changes have some influence on these psychosocial changes, the influence is not determined with any predictable regularity. In other words, individuals with the same disease need not follow the same psychosocial sequences. They do not die at the same rate, in the same way, of the same causes, or within the same context of circumstances. Some patients die with comparative peacefulness, with few regrets or complaints and with no "unfinished business" (Kubler-Ross 1970); others are resigned to their destiny, asking only for relief, not survival; still others cling desperately to the remnants of life, fearing the next-to-last moment, struggling until they lapse into oblivion; whereas some individuals wish to terminate their life while they still possess some vestige of dignity and control. Thus the vicissitudes of organic disease alone do not explain the distinctive ways in which individuals with a terminal illness pass through the final stages. Dying is not only a physical process; it is a psychological, emotional, social, and spiritual process and is an integral
part of the process of living (Buckingham 1983). Each patient's personality and psychosocial conditions impose traits upon terminality that are distinctively his/her own (Weisman 1972).

In these circumstances it is logical that health care providers, who are generally highly trained in one particular area of competence, may have considerable difficulty in accepting the influence of factors outside their own field of expertise. For example, a specialist oncologist could be expected to diagnose, prescribe treatment, and predict the possible outcome of the organic disease from a medical perspective, but be unable to predict with any degree of accuracy the influence personality, social and spiritual factors might have on the outcome of the individual's dying trajectory. Other professionals, such as counseling psychologists, can also make inappropriate assessments of an individual's situation by basing their findings on false premises. Whelan and Warren (1980) developed a death awareness workshop on the false theoretical foundation that Kubler-Ross' five stages of dying were a "sequentially defined process of adjustment to death" (p 62). This implied or stated misconception (Kubler-Ross 1987 personal communication that stages are not sequential) is held by others (Kastenbaum & Costa 1977) who have read Kubler-Ross' first monograph (1970). This error is commonly made by a number of health care providers
who believe that patients must pass through each of the five stages before finally dying in acceptance. When misconceptions such as this occur problems arise for both the patient and health care providers.

**Development of Death Education.**

Since the 1960s there has been an emerging humanitarianism surrounding the problems inherent in all types of infirmities, illnesses, and disabilities (Pine 1986). The mounting evidence that health care workers were uncomfortable with those individuals who were dying (Edwardson 1985) and the general disenchantment with traditional health care of individuals with a terminal illness was partially responsible for this changing atmosphere. In the light of this, it is not surprising that there has been an increasing concern for adequate social human services, including psychiatric and social work care of individuals with a terminal illness and their families. Innovators such as Quint (1967), Kubler-Ross (1970, 1971) and Saunders (1977) have pioneered the specific area of dying, death and terminal care; Quint examined the issues relevant for nursing personnel; Kubler-Ross examined the issues from the perspective of the dying person; and Saunders, in reviving the concept of hospice care, examined the issues involved in a holistic
approach to the care of families who have a member with a
terminal illness.

The work that evolved from these authors became known as
Death Studies and was concerned with a wide range of topics
such as death education, death-related counselling,
terminal care, death-related research, hospice development,
bereavement counselling, as well as death-related ethical,
legal and other professional issues. An important strand
within this area, and one that concerns this research
project, is the Hospice movement.

The importance of this work has increased significantly
over the last two decades and has exerted an influence on,
and fostered a collective attitude change toward, dying,
terminal care and death. This is demonstrated by the
emergence of specific journals such as Omega, Death Studies
(formerly Death Education), and Thanatology Librarian,
which reflect the changing interest in, and concern about
dying, increased consideration of the bereaved, and the
general interest in terminal care and death. Consequently,
formal death studies are not just a beneficial addition to
the education system (Pine 1986), but can also provide an
essential component for the socialisation of the medical
profession (Coombs & Powers 1975), nurses (Chodil & Dulaney
1984), social workers (Moore 1984, Zelensky & Thorson
The development of death education has occurred in response to the changing face of death in Western society and its presence in our consciousness more than ever before at the public, media, academic, and clinical levels. Some of the death issues and interests that reside in the popular culture are important because public pressure for and about death-related information continues to grow (Pine 1977, 1986). However, an important question arises: Has the direction of death-related research been to the advantage of the patient and family?

Previous Direction of Research

to enable them to work as effective members of the health care team. To this end considerable effort has been invested in developing and evaluating death education programs, with most studies focusing on the effectiveness of various programs. These are usually concerned with the effect of death education programs on changing attitudes toward death or death anxiety of a variety of health care professionals - predominantly nurses (Chodil & Dulaney 1984, Durlack & Burchard 1977, Laube 1977, Mullins & Merriam 1983, Murray 1974, Quint Benoliel 1982, Snyder et al 1973, Tamlyn & Caty 1984, Telban 1981, Yarber, Gobel & Rublee 1981). Some research studies have concerned themselves primarily with examining the different methods of material presentation; attempting to establish the relative merits of didactic, experiential or non-conscious presentation (Durlack 1978, Combs 1981, Vargo & Batsel 1984). Other studies have examined the issue of duration of presentation; whether death education programs are best presented in short, one-off sessions, short sessions over a few days/weeks, or several hours per session for an extended period (Mullins & Merriam 1983). Finally, another researcher has been interested in both length, and type, of presentation (Murphy 1986).

While all this research has been of great value, it places primary emphasis on the health care professional. The casual reader of the literature may be excused for forming
the opinion that health carers are the only, or most important, people involved in dying, terminal care and death. It appears that this research has moved away from some of the important issues, from the patient's perspective, raised by Kubler-Ross (1971). One possible explanation for this over representation of professional carers as subjects for research might be that they are the most accessible and least emotionally threatening for the researcher. It is relatively easy to obtain access to a group of health care professionals and to substantiate research into ways of improving health care services. While some subjects, particularly those taking part in studies that emphasise experiential learning, may become emotional during the course of the research, it is likely that the researcher will not have to deal with this situation too often. On the other hand, death studies that involve individuals with a terminal illness, or their family members, are highly likely to evoke emotional issues for subjects. Assuming that access to these people has not been stopped by over zealous medical practitioners (Kubler-Ross 1970), or nursing staff, then researchers will doubtless be faced with how to deal with emotional issues that arise for participants as well as themselves, and that may 'interfere' with study results.

One of the major deficiencies in previous death-related research is the lack of studies that actually involve
patients with a terminal illness. Minimal research has been directed at examining patient needs.

**Emergence of Hospice**

The development of hospice programs, with their roots in the work of Dame Cicely Saunders during the 1960s, as an alternative form of care for the terminally ill is, to a large extent, a manifestation of the heightened awareness of death and an expression of growing disenchantment with the traditional system of health care (Paradis 1984). While the first hospitals or hospices were a sanctuary for the poor wayfarer, the sick and dying, the woman in labour, the orphan, the needy, and the religious pilgrim (Buckingham 1983), the present day hospice movement is a concept that has come to represent a care system for persons with a terminal illness, their families, and their health care providers. As a philosophy rather than a facility, the hospice concept is a distinct and cohesive outlook for assisting human beings at what has become one of the most stressful times in life, the "final decline" in the dying trajectory.

For complex reasons, the hospice movement has given most of its attention to those who are dying, and within that group to persons who have cancer (Corr & Corr 1983, Zimmerman 1986). Although hospice principles are not limited to
cancer or dying, they represent an effort to re-establish guidelines for caring whenever cure is no longer a likely prospect. This constitutes a non-judgmental program to maximise quality of living as long as life continues. Thus, hospice care is continuous with a broad historical and contemporary tradition of palliative care.

Unfortunately, with the rapid development of the field over the last three decades the two terms, hospice and palliative care, have merged in the minds of many people and are now often considered as synonymous. However, since palliative care is defined as:

\begin{quote}
\textit{care addressed to the amelioration of distressing symptoms even where the underlying pathology cannot be reversed} (Corr & Corr, 1983, p. xi).
\end{quote}

it is not identical to, but an integral part of, the hospice concept. Symptom control is not simply a synonym for pain management. Bowel function is important to patients on analgesics which have constipation as a frequent side effect; nausea, vomiting, shortness of breath, urinary problems, sleeping problems, diarrhoea, oedema, pressure sores, mouth infections, and ascites (fluid collecting in the abdominal cavity) are other important symptoms that can cause problems for the patient with a terminal illness. Since palliative care is predominantly undertaken by medical personnel who have developed specialised skills in the technical aspects of symptom control and is usually concerned with the
maintenance of physical comfort, it is only one component, albeit a significant element, of a hospice program.

Hospice philosophy

According to the National Hospice Organization Standards (in Corr & Corr 1983), the philosophy of hospice care is as follows:

Hospice affirms life. Hospice exists to provide support and care for persons in the last phases of incurable disease so that they might live as fully and comfortably as possible. Hospice recognizes dying as a normal process whether or not resulting from disease. Hospice neither hastens or postpones death. Hospice exists in the hope and belief that, through appropriate care and the promotion of a caring community sensitive to their needs, patients and families may be free to attain a degree of mental and spiritual preparation for death that is satisfactory to them. (p 105)

In short, hospice is a philosophy of care oriented to meeting the needs of those patients who cannot realistically expect to be cured and whose needs are primarily for physical, emotional, spiritual, and social comfort and relief for the limited time of life they are expected to have. It is focusing on the quality of living remaining for those who have minimal quantities of time left. Since quality of life is such a personal matter, and one that is difficult to quantify (Martocchio 1986), hospice is very much a need-oriented program of care in
which the dominant priority is that the patient and the family have a primary role both in defining their needs and in being participants in the process by which they will be treated (Hadlock 1983). To realise this philosophy in practice, it is necessary for hospice professionals to understand the needs and wants of their clients. Knowing the clients' concerns allows the available services and style of care provided to come closest to meeting their needs. Therefore, it is imperative that the perceptions of needs and wants held by the clients be made clear.

In its ideal form, hospice assists its users with any need they might have. Unconditional and nonjudgmental care includes accepting a variety of behaviours such as allowing patients to either accept, deny, or be indifferent to their impending death, or supporting patients' and families' decisions on where they wish to receive their care. Ultimately, non-judgment means allowing the patients and their families to maintain control over treatment of the illness (Bass 1982-83).

Characteristics of the hospice concept

In general the hospice concept is characterised by six major components.
1. Care for the individual rather than treatment of the disease
Hospice care recognises that a patient is more than a malfunctioning organ and responds to the needs of the whole person. While the disease threatening the life of a patient is not ignored in a hospice program, it does not take on the all consuming interest given it in an acute treatment hospital. Rather the care-providers' interest is in all aspects of the patient's care. Thus, not only is physical distress of interest to the team, but also the accompanying mental attitudes of tension, fatigue, and dread. (Kastenbaum 1979, Hays & Arnold 1986).

2. The patient/family being the unit of care
Because persons are always at the centre of a web of psychosocial relationships, adequate care-giving must always take into account family and friends, both as within the unit receiving care and as included among those who can give care in important ways. Close relatives of the dying patient face a variety of problems that appear to them to be insurmountable. Some of these problems relate to their impending loss; some are practical problems such as financial and living arrangements; other difficulties are psychological problems related to understanding and adapting to their altered circumstances in life (Kastenbaum 1979, Molter 1979, Woodson 1979, Bass 1982-83, Buckingham

3. Palliative rather than curative care
Hospice is a philosophy of care oriented to meeting the needs of those patients who cannot realistically expect to be cured and whose needs are primarily for comfort and relief for the limited time of life they are expected to have. It focuses on the quality of living remaining for those who have minimal quantities of time left. Consequently, aggressive treatment programs aimed at remission or cure are not appropriate within the hospice philosophy, nor are frantic exercises in medical "heroics" practised by staff members (Corr & Corr 1983, Hays & Arnold 1986).

4. Pain management and symptom control as high priorities
A key feature of hospice care is that it is directed primarily at alleviating the stress caused by a variety of symptoms associated with a terminal illness (Woodson 1979, Buckingham 1983, Corr & Corr 1983, Hays & Arnold 1986, Zimmerman 1986).
5. Concern for interpersonal over technical aspects of medical care
Hospice care uses a minimum of diagnostic studies and invasive therapeutic measures. Care includes psychosocial problems as well as physical complaints and as a result hospice patients receive relatively little technological, but a great deal of personal attention (Hays & Arnold 1986).

6. Care is provided by an interdisciplinary team
The term interdisciplinary refers to the fact that the team has certain basic characteristics in structure and function. Firstly, it consists of individuals from multiple disciplines who meet together at least weekly to review each patient and family's progress and thus have the opportunity to continually share perspectives in both assessment and management. Secondly, and as a consequence of the first point, a phenomenon of role blurring not only takes place, it is encouraged. In effect, whenever any members of the team are directly involved with a patient or family, they approach them with a personal, as well as professional, awareness of the contributions of all disciplines. Thirdly, through such personal and professional interaction, staff support is taking place even as patient care is being administered. This allows the team to be more comprehensive and innovative in its delivery of care. It also makes the team more resilient.
and self-sufficient as it seeks to meet the demands and stress intrinsic to working closely with the grief and suffering of others (Hadlock 1983).

This idea of using an interdisciplinary team approach is perhaps the linchpin in the overall concept of hospice care. Everyone who participates in the patient's care is part of the interdisciplinary team: patient, family, specialist physician, oncologist, GP, nurse, social worker, counsellor, occupational and physiotherapist, volunteer, chaplain, music therapist. All participants may have critical roles to play in the care of some terminally ill patients. Roles within the team vary according to skills, education, title, and individual patients receiving care. Each patient has different needs and will choose to relate to each team member accordingly. Since symptoms can come from a variety of sources - physical, emotional, social and spiritual - a team approach is best suited in this situation (Woodson 1979, Buckingham 1983, Hadlock 1983, Zimmerman 1986).

In practice this process places all team members under an obligation to continually reassess the needs of patients and family members. During each and every visit to the patient, team members must constantly observe what is happening within the patient's environment. They must be aware, at all times, of signs and signals that might be
preliminary indicators of changes in circumstances in either the physical, emotional, social or spiritual well-being of any member of the family unit. The team member has the responsibility to bring any information regarding changed circumstances back to the other members of the team. This exchange of information can occur either at the weekly team meetings or via the use of the office file for each family.

**Fourfold approach to hospice care**

All six of the above characteristics are based on the underlying assumption that hospice care is a holistic, "comfort-care" orientation to the provision of health care services to the terminally ill. This is interpreted as including careful assessment of all aspects of the patient's total condition (Kastenbaum 1979) and that of the other members of the family unit. To this end there is a fourfold approach to hospice care that takes into consideration the physical, emotional, social, and spiritual needs of patients and family members. Although there are many needs that can be examined using this fourfold approach, perhaps the best example is that of pain.
In terms of the hospice concept pain may be either physical, emotional, social, spiritual, or any combination of these four. Consequently, the task of the skilled team in alleviating pain is to tease out which of the four components of pain are present, active, in what combination, and to what degree. This can be accomplished through careful observation and examination of the patient and sifting through feedback from other team members. Once the combination has been determined, the most appropriate combination of intervention strategies can be initiated (Woodson 1979). Since the experience of pain is a very subjective encounter, pain control measures must be adjusted to each individual patient's needs. Therefore, any assessment of pain must consider the individual's social-cultural response and his/her own unique autoplastic pain process. Thus, in terms of the hospice approach, pain control becomes one of pain management encompassing several forms of intervention all ideally aimed at maintaining the patient completely comfortable, pain-free, and fully alert until the moment of death. This is achieved through addressing the four aspects of pain.

1. Physical pain

Physical pain can be defined as:
a sensation in which a person experiences discomfort, distress, or suffering due to irritation of or stimulation of sensory nerves, especially pain sensors (Thomas, 1985, p. 1206)

The success in achieving the goal of maintaining the patient pain-free, comfortable and mentally alert until death occurs is not so much a question of the specific drugs used as it is of the principles underlying their use (Woodson 1979). The most important principles are:

1. the successful management of the patient's pain is both an art and a science. The art component involves:
   . the careful assessment of the patient's symptoms;
   . the selection of the appropriate drugs administered at an optimum dosage; and
   . the sensitivity to appreciate the fact that the dying patient's needs may change rapidly during the final stages of life and the medication regimen must keep pace with these changes.

The science of treating the patient's physical pain needs include:

   . a thorough knowledge and mastery of the drugs used in palliation; and,
   . a genuine clinical understanding of their interaction and side effects.

2. the concept of addiction does not apply in the treatment of terminal illness; and
3. there is a need for flexibility in both the variety of drugs used and their dosage levels.

2. Emotional pain

Emotional pain can be defined as:

an affective state of consciousness in which a person experiences discomfort, distress, or suffering as a result of the level and intensity of their own mental processes.

The dying patient experiencing emotional pain is often frightened, anxious, lonely, depressed, emotionally hurt, or angry. These emotions frequently occur as the consequence of loss of control over his/her life, especially associated with the new experience of learning how to die (Woodson 1979). The hospice approach to treating the patient experiencing emotional pain is first to recognise that these emotions, and particularly anxiety, depression and agitation are normal, fight-flight reactions to coping with the process of dying and the thought of approaching death. When viewed as normal reactions, given the nature of a terminal illness, rather than abnormal responses, these symptoms take on a very different kind of pain profile. Consequently, their treatment is vastly different when considering the hospice approach. A frequent mistake made by members of the team who are not
trained in the psychological aspects of care, is to use the medical model and equate depression with sadness or grief (Volkan 1975, Worden 1984). The result of this misdiagnosis is that the individual is given antidepressant medication for their "depression" and sedatives for their anxiety or agitation. Neither sedatives nor antidepressants facilitate working through sadness, anxiety or agitation associated with normal grief (Raphael 1984). It has been the author's professional experience that too frequently such medication is prescribed as the normal course of events at the beginning of the grieving process, whereas, thirty minutes of cathartic grieving with a family member, skilled nurse, counsellor, or other team member can have a more profound positive effect than any antianxiety or antidepressive chemotherapy.

3. Social pain

Social pain may be defined as either:

1. a patient's mild-to-severe discomfort with man's inhumanity to man; or
2. simply a patient's discomfort with the level and intensity of his/her interpersonal relationships during the process of dying (Woodson 1979).

The importance of anticipatory grieving, grief work and worry work (Parkes 1986) and unfinished interpersonal business (Kubler-Ross 1970) for the dying individual and
other family members has been well documented. Being denied the opportunity, or not attempting to resolve such issues, can result in significant social pain for both the dying individual and family members. This kind of pain frequently appears as a passive-depressive set of presenting symptoms that frequently is diagnosed as emotional pain and, in being inappropriately treated with antidepressive agents, further separates the dying patient from close family and friends and the opportunity to complete any unresolved issues.

4. Spiritual pain

Spiritual pain can be defined as:

> distress, or discomfort with the level and intensity of belief or faith in a theological or philosophical concept.

Spiritual pain is particularly idiosyncratic and depends on the individual’s specific religious, spiritual, racial, or cultural background. It is often the most difficult of the four types of pain to identify and treat. It has been the author’s professional experience, through numerous observations of clerics from a variety of religions and feedback from patients, that contrary to popular belief the clergy, despite their theological learning, are not always able to provide spiritual healing for the patient. Many
patients with a terminal illness begin to question their lifelong religious beliefs when facing their inevitable death. Similarly, family members experiencing grief after the death of the patient, often wish to express their anger at what they now consider an unjust and unloving God (Lewis, 1966). These comments are frequently difficult to listen to for those who have a strong religious faith. Also the strong expression of these thoughts can prove to be very confronting to those who have not worked through their own feelings of anger and injustice. Unless the clergy have specific education in dealing with death, fears about their own mortality, and their own beliefs, may lead to the inevitable platitudes and alienation of the patient.

**Hospice program definition**

A hospice program has been defined, as early as 1978, by the American National Hospice Organization as:

>a medically directed, nurse coordinated program providing a continuum of home and in-patient care for the terminally ill patient and family. It employs an interdisciplinary team acting under the direction of an autonomous hospice administration. The program provides palliative and supportive care to meet the special needs arising out of the physical, emotional, spiritual, social ... stresses which are experienced during the final stages of illness and during dying and bereavement (Zimmerman, 1986, p. 17).
Translated into a program, hospice care is a comprehensive system of management that offers an opportunity to provide palliative care for terminally ill patients. Its interdisciplinary team approach is designed to relieve the patient's symptoms and to provide physical, emotional, social, and spiritual support to both the patient and family. This type of care can be rendered in any one of a number of settings: the patient's home (often referred to as a home-based program), a free-standing hospice unit (usually referred to simply as the Hospice), or a unit within a hospital (generally known as a Palliative Care Unit) (Buckingham 1983, Zimmerman 1986).

Goals of hospice care

Hospice programs share the following common goals:

. to keep the patient pain-free, comfortable and as alert as possible during the final phases of illness;
. to help patients remain viable family members in their chosen environments;
. to strive to help each patient retain a sense of personal identity;
. to support the preservation of the right to self-determination; and,
to encourage active participation in managing the problems of one's remaining life span and death.

(Morgan & Hart 1987)

These goals also relate to the four areas of patient/family needs, namely, physical, emotional, social, and spiritual (Rossman 1979, Buckingham 1983, Gonda & Ruark 1984).

As outlined previously the philosophy, characteristics and goals of Hospice care place additional burdens on all members of the team. The most arduous task for this team of specialists is to be constantly alert for signs of change either in their own area of expertise or the areas covered by other team members. Consequently the specialist oncologist, or nurse, for example, must be aware not only of the signs of emerging physical problems but also symptoms of emerging emotional, social or spiritual issues. Similarly other team members must be aware of the emergence of symptoms indicating physical problems as they arise. When these are noticed it is the responsibility of that team member to acknowledge and verify such symptoms. If the assessment is accurate it is vital that the team member with the appropriate expertise be alerted. For nurses this is an integral aspect of the nursing process of assessment, planning, implementation and evaluation (Bellack & Bamford 1984, Carnevali 1983, Carpenito 1987) that encourages nursing staff to implement nursing interventions to the level of their expertise, then refer to other specialist health care professionals as soon as the nurse recognises
that the patient's problem is outside the area of his/her own expertise.

**Empirical research**

The substantial increase in interest in the various aspects of terminal care over the last two decades is illustrated by the growing number of articles appearing in related professional journals, such as the American Journal of Nursing, Nursing Research, Military Medicine and Heart and Lung. Further evidence of this growing interest in care for individuals with a terminal illness is the recent introduction of journals specifically related to the hospice philosophy such as The Hospice Journal and The American Journal of Hospice Care.

Although this considerable body of literature related to various aspects of hospice philosophy and program delivery contains much written about the needs of terminally ill patients, their family members and those who provide care for them, little empirical research has addressed this issue. The literature readily available in Australia concerning empirical research related to needs of patients can be broken into two major groups:

1. those who are concerned with critically ill patients; and,
2. those who are concerned with terminally ill patients. The focus of these groups can be further divided into three categories:

1. those that examine what is considered to be the most appropriate nursing behaviour for the situation (Arblaster, Brooks, Hudson, & Petty 1987, Freihofer & Felton 1976, McGinnis 1986)

2. those that focus on the needs of family members or relatives (Daley 1984, Hampe 1975, Leske 1986, Molter 1979, Norris & Grove 1986, O'Brien 1983); and,

3. those studies which highlight the needs of the patient (Garland, Bass and Otto 1984).

Family members

One of the main reasons researchers avoid focusing their studies on the needs of the terminally ill individual is a commonly held belief that patients involved in a palliative care or hospice program are too ill and under too much stress to respond to a questionnaire (Garland et al. 1984) or participate in any way. It appears that health care providers become very protective of "their" terminally ill patients and suggest that the very thought of conducting research on such individuals in a time of crisis is demonstrating insensitivity and total lack of regard for the patient's well-being. This reaction was common from
other professionals with whom the author discussed his proposed research during its early developmental stage. As a consequence, prior research in the area of needs of receivers of health care services has concentrated on the family members of critically ill patients (Leske 1986, Molter 1979, Norris & Grove 1986), family members of patients in intensive care settings (Daley 1984), and family members of terminally ill patients (Garland et al 1984, Hampe 1975, O'Brien 1983), rather than the patients themselves.

**Terminally ill patients**

Garland *et al* (1984) claim to have examined the needs of hospice patients but have done so indirectly. These researchers asked the primary caregiver, "as the person closest to and most familiar with the patient" (Garland *et al*, 1984, p. 41), to respond to a questionnaire about the patient's needs. At a superficial level this appears to be the most sensitive action to take, on the patient's behalf, and may appear to be supported, albeit indirectly, by much of the relevant literature. One of the common themes in such literature is that the unit of care is not simply the patient but the patient and family (Bass 1982-83, Buckingham 1982, 1983, Corr & Corr 1983, Hays & Arnold 1986, Kastenbaum 1979, Molter 1979, O'Brien 1983, Zimmerman
1986). However, this literature does not imply that the patient and family unit are to be considered as one entity, having all needs in common. It clearly states several propositions:

1. that the patient and family are the focus of care and treatment plans are to be developed with the patient and family as part of the team (Kastenbaum 1979);

2. the patient must be considered as a member of a family unit when assessing the patient's needs within the concept of total care (O'Brien 1983);

3. considering the patient and family as the unit of care implies that the needs of the family as well as those of the patient are equally important (Hays & Arnold 1986).

Garland et al (1984), in assuming that the primary caregiver is able to accurately perceive the needs of terminally ill patients, have based their research on methodologically unsound foundations. They appear to have ignored the possibility that the primary caregiver, experiencing their own crisis associated with the impending death of a spouse or close family member may have needs that conflict with those of the patient. Living with a member who has a terminal illness is a critical time for all family members. Each individual family member will have unique, personal needs as well as sharing common needs with other family members. Each family member will be
experiencing their own unique response to the stress of terminal illness. Therefore, primary care givers, along with other family members, may not necessarily be accurate in their perception of the patient's needs because of the possible overriding strength of their own needs. While some primary care givers may be able to identify some of the patient's needs that differ from their own, it is not appropriate to generalise, as Garland et al appear to have done, and say that all primary care givers are capable of recognising the variety and strength of the patient's needs.

Personal experience as a loss and grief Counsellor leads the author to believe that there are a number of situations where a family member's needs conflict with those of the patient. The author has encountered many instances where the patient may need to talk about aspects of his/her impending death but his/her spouse may need not to hear such talk. An example of this situation arose with an elderly couple, Harry and Grace (names changed), who had been married for over 50 years. Throughout their married life Grace had relied on Harry for all her support and care. She had never worked outside the home and was very dependent on Harry who was now dying from lung cancer. During the last weeks of Harry's life, Grace was constantly stressed and emotional about Harry's illness. She continually encouraged him to eat large amounts of food to
enable him to "regain his strength and get better". Harry, emaciated and constantly struggling for breath, spent most of his time in bed without talking but showed signs of distress about Grace's behaviour. Whenever the subject of Harry's impending death was raised, or was alluded to, Grace left the room. At these times Harry would talk about his illness and his fast approaching death. Outside Harry's bedroom Grace would say that she didn't want "to hear Harry talk like that". At one time when Harry stated he thought he didn't have many days left to live Grace shook his knee roughly stating "Don't talk like that! You have a lot longer to live yet!"

The most logical explanation for this couple's actions and statements was that Grace's need was not to hear Harry confirm his impending death by talking about it, while Harry had a need to talk about his death and what he wanted for his funeral arrangements. Harry also had a conflicting need not to upset Grace anymore than she was already. He had looked after her all their married life and wanted to continue to do so. Eventually, Harry's need to convey to Grace important information about his wishes concerning his funeral overruled his need not to upset Grace further. Had this couple been included in the sample of Garland et al (1984) Grace, because of the strength of her need not to talk about Harry's death, would not have considered that Harry may have had the opposing need. Consequently,
answering on Harry's behalf, Grace would not have indicated that Harry's need was to talk about factors concerning his impending death.

There are numerous other personal examples that could be used to illustrate the point that, for any family group in the crisis of terminal illness, the needs of individual family members may conflict to such a degree that one family member, no matter how "close" or "familiar" with the patient, is unable to accurately identify the needs of the patient or even other family members. While it is important to recognise that at this time patients can have periods where they may be very ill and unable to participate in research programs, they may also have relatively good periods when they are able, and indeed very willing, to fully participate. Therefore, if the principles of the hospice concept of care are to be followed, not only is it necessary to believe that the patient can identify his/her own needs, but it is imperative that the patient be sensitively encouraged to do so in a manner acceptable to him and within the limitations imposed by the disease process. (All but two patients approached to participate in this research project not only agreed to participate, but were pleased to be able to actively contribute to it in what they saw as a meaningful way.)
Summary

The conclusions drawn from previous research have emphasised the responsibility nurses have in caring for those individuals with a terminal illness and their families. Hampe (1975), by concluding that her study demonstrated the need to teach "nurses" the needs of the dying patient's family, implied that nurse's were not able to accurately identify needs.

This author believes that Freihofer and Felton (1976) have gone too far by concluding:

\[
\text{it is the responsibility of the nurse to assist individuals and families to find meaning in illness and suffering and death (p 332).}
\]

This places an unrealistic burden on nurses, by expecting them to be involved in what may be the individual patient's, or family member's, search for meaning in life. This aspect of terminal care may be better accomplished by those team members with specialised skills and education in this area, namely the spiritual adviser.

A more realistic conclusion was drawn by Garland et al (1984) when they concluded that the success of a hospice program depends on the ability of health care providers to accurately assess the needs of both patients and family members. This relates not only to nurses but to all
members of the interdisciplinary team involved with the patient and family.

O'Brien (1983) supported this view when she concluded that it was essential to identify needs. Although she was specifically discussing the needs of family members who have a member in hospital with a terminal illness, the point may be generalised to all individuals with a terminal illness and their family members.

Importance of the study

Reviewing the literature has indicated that changes in social conditions and life styles have distanced both the general community and health care professionals from dying and death as a normal aspect of life. The emergence of the hospice philosophy, with its emphasis on the importance of the whole individual rather than the cure of a specific disease, was a response to the increasing concern with finding a medical cure at all costs. However, with the hospice philosophy emphasising a four-fold approach to care of individuals with a terminal illness, greater expectations can be placed on staff to be capable of addressing all these issues. In programs that do not utilise an interdisciplinary approach to care, administrators and staff may expect existing personnel to be able to identify all four aspects of the patient's
needs. The conclusions drawn by Freihofer and Felton (1976) support this view. On the other hand, other researchers (Garland et al 1984, O'Brien 1983) have stressed the importance of identifying patients' needs. However, previous research has obtained information on patients' needs via primary care-givers or other family members.

The importance of the present study was twofold:

1. Patients, rather than family members, were asked to rank their own needs; and,

2. An investigation of the correlation between the individual patient's perception of their own needs and the nurse's observation of the patient's perceived needs.
CHAPTER 3

RESEARCH DESIGN

Statement of the problem

Are palliative care and community nurses who provide nursing care to patients on the ACT Home Based Palliative Care Program able to identify individual patient's perceived emotional, social, physical, and spiritual needs?

Definitions

Palliative care nurse - a qualified nurse who is employed to work only with patients who have a terminal illness and are accepted onto the Home Based Palliative Care Program.

Community nurse - a qualified nurse based within the general community and responsible for the provision of nursing care for a variety of community based health needs.

Physical need - that which is required to maintain the general health of the body.

Social need - that which is required to maintain an individual's sense of well-being in their relationships with significant others and their environment.
Emotional need - that which is required to maintain the individual's sense of well-being regarding their mental health.

Spiritual need - that which is required to maintain an individual's sense of well-being regarding their value system.

Purpose of the study

The purpose of the study was to investigate the relationship between individual, terminally ill patient's perception of their needs and the nurses' perception of the needs identified by individual patients in their care.

Theoretical assumptions

1. Patient needs can be categorised in four groups, namely spiritual, physical, emotional, and social.

2. Patients are able to accurately identify their needs within these four categories.
Questions to be asked

The questions asked in this research were:

1. Is there a relationship between a patient's perception of their needs and the nurse's observation of the patient's perceived needs?

2. Is this relationship significant and important?

3. Do individual patients identify, as most important, needs from one group more frequently than needs from the other groups?

4. Do nurses observe, as most important, one group of patients' perceived needs more frequently than needs from other groups?

Limitations of the study

The research was subject to the following limitations:

1. Only seven patients on the ACT Home Based Palliative Care Program and who were well enough took part in the research;
2. Four community nurses providing nursing care within the patient's home;

3. Four palliative care nurses providing care within the patient's home;

4. Lack of a random sample;

5. The degree to which subjects truthfully ranked the 80 item Q-sort;

6. Selection of patients for inclusion in the study determined the selection of nurses;

7. The interval between patients and nurses completing the Q-sort was not constant and varied from one to three days;

8. No effort was made to establish the test-retest reliability of the 80 item Q-sort;

9. The final sample size was too small to allow any firm conclusions to be drawn; and,

10. The reluctance of palliative care nurses to continue with the study.
As the research was concerned with the study of individuals, the methodology used emphasised examination of individuals and, therefore, does not allow results to be generalised to other patients on the same program or other patients on other palliative care or hospice programs.

Methodology

As this research project was primarily concerned with the needs of patients, and what on an individual basis was most or least important to them, two important questions arose early in the developmental stage of the research:

1. what instrument would be the most appropriate to gather data on patients' needs?; and,

2. how would the ranking be best achieved?

It is the author's belief that the results from previous studies have not achieved the specific objectives of the research because of the confusion surrounding these two issues.

Past research in the assessment of patients' needs, or those of their family members, has relied on the respondents rating a number of items on a 4 point, Likert-type, scale delivered in either a structured (Daley 1984, Molter 1979, Norris & Grove 1986) or a semi-structured (Leske 1986, O'Brien 1983) interview situation.
Individuals were asked to respond to each need statement by rating its importance to them on a scale of 1 (not important at all) to 4 (very important).

Three major dangers, that are likely to affect results, are associated with this method of data collection (Moser & Kalton 1971, Oppenheim 1968):

1. unless the extremes of the scale are defined, or preferably each step, ambiguous responses will result as each respondent uses their own concepts to define the categories;
2. the error of central tendency where respondents generally avoid the extremes; and,
3. the errors of leniency, occurring when respondents dislike being critical, and severity, occurring with respondents who set high standards.

Apart from these difficulties there is the intrinsic difference between the tasks of rating items and that of ranking those same items. Rating gives a numerical value to some kind of judgment; each item is considered in isolation and scored accordingly. However, in ranking, items are arranged in order with regard to some common aspect, i.e. importance of needs to individual patients. In ranking, each item is examined in relation to its position with all other items in the scale. Although ranking does not provide information about the differences
between ranks, it does indicate the order or sequence of the items in question. In essence it indicates whether one need is considered by the individual as more important than another need, irrespective of the probable variation in the respondents' definition of concepts such as "most important" or "least important".

The basic difference in the rating and ranking tasks was demonstrated during this research project. All respondents, when making initial decisions in their Q-sort, placed many items at the "most important" end of the sorting box. In effect respondents were "rating" all these items as important. Respondents then proceeded to work through these items "rated" as important and actually order them according to their perceived importance to the individual, i.e. each person then ranked the 80 items.

A further problem with previously cited research on patient needs is that not only have the researchers bypassed the person most informed about patient needs - patients themselves - but they have also used a variety of techniques in manipulating the rating responses, given by individuals, to identify the "most important" need for the sample. In using this methodology they have in effect asked their individual subjects to do one task then used those results to draw conclusions about an entirely different task relating to the general group of patients.
with a terminal illness. The researchers began by asking subjects to rate each item then, after statistical manipulation of the data, drew conclusions about the ranking of needs in order of importance. In one instance (Arblaster et al. 1987), the researchers calculated the mean for each item with inappropriate data. (These researchers allocated a score of 5 for the middle group of items - the "don't know", "doesn't relate", or "ambiguous" responses - instead of 0. See page 113 for detailed discussion of this point.)

The most significant problem with the type of methodology described above is that it is highly likely that if asked to rank the same items in order of importance for themselves, the subjects' responses would have achieved different results. Another important problem is that by summing all the responses to each item and discussing a group ranking of importance, these researchers have ignored one of the most important philosophical approaches to the provision of terminal care - the individual. Since one of the major components of the hospice philosophy focuses on care for the individual the question requiring investigation, is not What do patients with a terminal illness, as a group, perceive as the most important need? but rather What does this individual patient rate as the most important need?
Although Garland et al (1984) stated they used a Likert scale in their assessment of terminally ill patients' needs, it appears they used a scale of self-assessment ratings or Likert-type scale. Since Likert scales are designed to measure individuals' attitudes, for example favourableness to hospice care, rather than their needs, it is a requirement that the final items included in the scale measure the same thing (Oppenheim 1968) and range over all the various aspects of the attitude being measured (Moser & Kalton 1971). Consequently, the score obtained indicates the subject's position, in relation to other people scored, on the continuum of the specific attitude being measured. In the assessment of needs it is inappropriate to use a Likert scale.

**Q Methodology.**

Since the dominant priority of hospice care is to respond to patients as individuals, it was important to utilise a research technique that emphasised the individual. Q methodology was considered to be the most appropriate.

Q methodology is a general name used by W. Stephenson (1953) to characterise a set of philosophical, psychological, statistical, and psychometric ideas oriented to research on the individual. Q technique is a set of
procedures used to implement Q methodology and centres particularly in sorting a set of items, objects, or a deck of cards, called Q-sorts, and in the correlations among the responses of different individuals to the Q-sorts. This technique is a sophisticated way of rank-ordering items (Kerlinger 1973) according to the importance to the individual, and may be used to compute a correlation showing how similar one subject is to another (Cronbach 1970).

Q technique uses a rank-order procedure of piles or groups of objects. An individual is requested to sort a set of objects, verbal statements, single words, phrases, pictures, musical compositions, or, as in this research, need statements, into groups according to some specified criterion. In this research the subject was asked to sort cards with a single need statement typed on each card, according to the importance each statement was to the individual. To overcome the difficulty in rank ordering the large number of cards usually associated with Q-sorts (between 60 and 140), and for statistical convenience, the sorter is instructed to place varying numbers of cards in several groups, with the whole making up a normal, or quasi-normal, distribution.

Although Kerlinger (1973) claims to have "gotten good results with as few as 40 items" (p. 584), it is suggested
that for statistical stability and reliability the number of items should not be less than 60 nor more than 140 items, with the number of items to be sorted typically between 60 and 90 (Polit & Hungler 1983). Since in the current research there were to be four groups of need statements, namely spiritual, physical, social and emotional, it was decided to have 20 items in each group, making a total of 80 items for the Q-sort to be distributed in the following groups, 4, 6, 9, 13, 16, 13, 9, 6, 4.

Q methodology versus rating scales

There are two advantages of the sorting procedure used in Q methodology over a rating form or printed checklist:

1. subjects are not restricted to their original placement of items in specific groups but can shift them back and forth as they proceed with the project (Cronbach 1970); and,

2. subjects' definition of a category such as "definitely true" may shift while working down the list, but in a Q-sort it can be expected that the items placed in the same group will be equally important (Cronbach 1970).
Strengths of Q methodology

The strengths of Q methodology, as discussed by several authors (Block 1961, Cronbach 1953, Kerlinger 1973), are:

1. it is a methodology peculiarly suited to intensive study of the individual;

2. its heuristic quality;

3. its usefulness in exploratory research;

4. that analysis of variance and correlational methods can both be used;

5. it is an interesting task for individuals to undertake, perhaps because the Q-sort is both challenging and realistic.

6. it is much more penetrating than the common questionnaire where the respondent can say "yes" to all the favourable items and "no" to unfavourable ones. The forced choice requires all respondents to put themselves on the measuring scale in much the same manner. Consequently, it is free from the idiosyncracies of response which cause some individuals to respond "cannot say/don't know" twice as often as others, which makes their scores noncomparable;

7. the requirement to place statements in the middle categories frees respondents from making many difficult and unimportant choices that they would be
forced to make by being required to rank every item; and,

8. the importance of the difficulty in discriminating near the centre of the scale is reduced by the fact that the product-moment correlations, calculated for the Q-sorts, apportion greatest weight to the end cells.

Disadvantages of Q methodology

Disadvantages with Q methodology are:

1. it is not a method well-suited to cross-sectional or large sample purposes. The researcher using Q methodology does not draw a random sample of persons to study using Q and can not generalise results obtained using Q to populations of individuals (Kerlinger 1973);

2. care must be taken when using statistical tests with Q data. Most statistical tests assume independence, that is, the response to one item should not be affected by the responses to other items. However, because Q is an ipsative, forced-choice procedure it violates the independence assumption; because it is a rank-order method the placement of one Q card affects the placement of other cards. However, this problem can be overcome in two ways:
a) by instructing subjects that they can move cards around from one pile to another until their desired distribution is achieved (Kerlinger 1973, Polit & Hungler 1983); and,
b) by raising the requirements for statistical significance from the .05 level to the .01 level (Kerlinger 1973).

3. the forced-choice feature of Q-sorting. Some critics comment that the forced procedure is unnatural, that it requires the subject to conform to an unreasonable requirement (Kerlinger 1973). However, Block (1961) sets out cogent reasons why the forced-choice distribution is preferable to unforced distribution of items. In this study nurses frequently complained that being forced to choose between items imposed unrealistic boundaries on their responses. None of the patients completing the Q-sort made this type of comment, but instead, most stated that the requirement to rank items made them think more critically about their needs.
Construction of statements for Q-sort

A pool of prospective statements for possible inclusion in the final Q-sort were developed using a tripartite approach:

1. reading relevant literature;
2. discussions with other professionals involved with terminal care, e.g. nurses, social workers, co-ordinator of hospice volunteers, and volunteers; and,
3. personal interviews with:
   a) individuals whose terminally ill family member had used the Palliative Care Program, but had died less than six weeks prior to the interview; and,
   b) individuals with a terminal illness who were not yet on the Palliative Care Program.

Molter's (1979) 45 needs statements were modified to relate to terminal care rather than critical care and used as the original pool of items. After discussion with family members and prospective patients the number of items rose to 63. These items were then circulated to the Assistant Director of Nursing/Community responsible for the Home Based Palliative Care Program, the Clinical Nurse Consultant co-ordinating the program, and the Co-ordinator.
of Volunteers with the ACT Hospice Society Inc., for their comment. This action resulted in a revised pool of 103 items.

Two judges (the researcher and the Co-ordinator of Volunteers) then independently grouped the items into four groups relating to spiritual, physical, social and emotional needs.

The judges then compared groupings, retaining items that both had independently assessed as falling into the above defined groups, and revising those items that did not have common assessments, until a final pool of 80 items, with 20 items in each of the four groups, was achieved (See Appendix 2). To facilitate scoring, each statement was assigned an identification number which was placed on the reverse side of the card so as not to influence the participant's ranking in any way. The numbers corresponding to each group were:

1. 00-19 spiritual items;
2. 20-39 physical items;
3. 40-59 social items; and,
4. 60-79 emotional items.
Reliability

Reliability refers to the consistency of scores obtained by the same persons when reexamined with the same test on different occasions, or with different sets of equivalent items, or under variable examining conditions (Anastasi 1982). Test-retest reliability is concerned with the temporal stability of an instrument, i.e. a high correlation coefficient will be achieved for the same person given the same test after an interval of time. The error variance corresponds to random fluctuations from one test session to the other. One source of these variations may result from the uncontrolled testing conditions; distractions such as sudden noises, and extreme changes in weather conditions. Yet another source of variations is the changes in the condition of the respondent such as fatigue, emotional strain, and illness.

Since needs are generally considered to be dynamic it is expected that changes would occur over time; some needs may be of short duration while others may be one-off situations and once met, do not arise again. In the context of this research project change is to be expected; it is inherent in the dying trajectory as outlined in the previous discussion on the psychosocial process of dying (Weisman 1972). Consequently, in this project, test-retest reliability is not considered to be an important issue.
Validity

Validity of measurement is the extent to which observational systems, questionnaires, ratings, and tasks are effective, truthful, and genuine in serving their stated purpose (Asher 1976). The validity of any scale, test, instrument, etc., concerns what it measures and how well it does so (Anastasi 1982). Although there are several types of validity the one of greatest importance to this research is content validity.

In the context of this research, content validation essentially involves the systematic examination of the items included in the Q-sort to determine whether they cover a representative sample of the behaviour domain to be studied. Moser and Kalton (1971) state that essentially, the assessment of content validity is a matter of judgment and suggest that this may be made by the researcher or, more appropriately, a team of judges. In this project content validity was promoted by firstly involving other professionals concerned with the care of patients with a terminal illness, families of former patients, and some patients themselves, to develop the need statements. These were then judged by the researcher and a professional colleague for validity.
Sorting box

To facilitate the sorting procedure for participants a perspex sorting box was constructed. This consisted of 9 compartments, or cells, in which to place the cards with the need statements typed on them, attached to a backplate on which the corresponding number of cards to be placed in each compartment was inscribed, e.g. 4, 6, 9, 13, 16, 13, 9, 6, 4. The left hand end of the backplate was labelled Most important and the right hand end of the backplate labelled Least important. To remind the participant that the statements related to needs the words "I need ..." were inscribed on the middle top section of the sorting box backplate.

Information for participants

To enable patients to make an informed decision on whether they would participate in the research an Information Page was prepared (See Appendix 3). This page briefly outlined the following points:

1. that the study was being undertaken, under supervision, as part of the requirements for the Master of Education degree at the Canberra College of Advanced Education;
2. the aims of the research;
3. the task to be undertaken; 
4. that participation in the research was voluntary; 
5. conditions under which participants could withdraw from the study; 
6. the confidential nature of the research; and, 
7. contact numbers for both the researcher and his supervisor if further information was required by individuals before deciding to participate.

This information page was designed to be given to prospective participants during the initial contact visit by the researcher.

Agreement to participate

To safeguard the rights of patients and to ensure there would be no misunderstandings concerning the conditions of participating in the research an Agreement to Participate form was developed (See Appendix 4). This agreement form indicated that the participant:

1. had read the Information Page and was willing to participate in the research;
2. understood that confidentiality would be maintained at all times;
3. understood that questions concerning the study could be asked at any time;
4. understood the conditions under which withdrawal from the study was possible; and,
5. understood that further clarification could be gained from either the researcher or his supervisor (both contact numbers were again provided).

This agreement was signed, at the time of the Q-sort, by both the participant and the researcher. The original was kept by the researcher and a copy made available to the participant upon request. (No-one took up this offer.)

**Instructions to research participants**

Instructions to research participants, outlining the task required of them, were developed by modifying those used by Arblaster, et al (1987). Two sets of instructions were developed; one for the individual with the terminal illness (See Appendix 5) and one for nurses (See Appendix 6).

**Sociodemographic data**

Sociodemographic data was obtained prior to completing the Q-sort for patients (See Appendix 7) and for nurses (See Appendix 8).
Scoring sheets

To facilitate scoring and data analysis for each Q-sort a four page score sheet was designed. The Q-sort was scored as follows:

<table>
<thead>
<tr>
<th>Most important</th>
<th>Least important</th>
</tr>
</thead>
<tbody>
<tr>
<td>4   6   9   13  16  13  9   6   4</td>
<td></td>
</tr>
<tr>
<td>+4   +3   +2   +1   0   -1  -2   -3   -4</td>
<td></td>
</tr>
</tbody>
</table>

Those four cards placed in the "most important" category were each assigned a score of +4; each of the 6 cards placed in the next category were each assigned a score of +3, etc.. For most respondents the extreme judgments are the easiest ones to offer. At the same time discrimination of the items in the middle portion of the continuum are difficult, less reliable (Block 1961) and placement of an item in a middle category implies that it is relatively unimportant. It was decided to select the items allocated in the cells scored ±4 and ±3 for further scrutiny.

Pilot testing

The proposed Q-sort was piloted using three individuals who were not ill (Hospice volunteers) and the researcher. The
decision to pilot test using these four people was based on two factors:

1. the approval of the Institutional Ethics Committee was necessary before patients could be approached to participate in the research in any way and this Committee would not consider a request for approval without having the details of the items that would be used in the final Q-sort. (This Catch 22 situation was overcome by seeking the assistance of the researcher's personal friends who met the criteria outlined in the third component of the first paragraph in the Construction of statements for Q-sort section above.); and,

2. the fact that the number of terminally ill patients, well enough to participate in the research, and nurses available, was strictly limited. To use patients in the pilot testing would have placed strict limitation on the number of available participants for the full study.

The researcher took part in the pilot testing to gain an appreciation of the ease, or difficulty, of the proposed task. This proved to be a valuable exercise as it enabled the researcher to be more sensitive to the difficulties experienced by both patients and nurses.
As a result of pilot testing minor adjustments were made to the instructions to participants. Although there were no problems with the 80 items during the pilot test, in hindsight, it would have been preferable to change item number 78, "I need not to be told what is happening to me." The negative aspect caused confusion for some patients. This confusion was likely to have resulted from the medication regime of those particular patients.

Approval to conduct the research

Two types of official approval were required before the research could commence.

1. The Institutional Ethics Committee's approval was necessary before patients could be contacted. This required a detailed submission setting out the background to the proposal, the aims of the study, exactly what was to be asked of patients (including the final form of the Q-sort), what use would be made of the resultant information, how confidentiality would be maintained, how the patients' rights would be protected, and personal information on the researcher. As outlined above, the requirement to supply details of the final version of the Q-sort provided some obstacles, that fortunately did not prove to be
insurmountable. This approval took 4 weeks to obtain as the Committee meets on a monthly basis.

2. Approval from the Director of Nursing/Community of the ACT Community and Health Service was necessary for two reasons:
   a) to gain access to patient information held by the Home Based Palliative Care Program; and,
   b) to approach community and palliative care nurses to participate in the research.

Verbal approval was given immediately on receipt of the author's written request, and followed with written confirmation within a week.

Sample selection

In order to generalise the results obtained by studying a sample of responses, careful consideration must be given to the selection of that sample. Generalisations may be made with the help of statistics if the selection of the sample is based on a probabilistic strategy (Lin 1976). However, there are a number of factors that precluded following standard sample selection procedures with this study:

1. the state of the patient's health influenced whether or not they were included in the sample, therefore random sampling techniques could not be employed; and,
2. the choice of patients included in the sample determined which nurses would be included; once a patient completed the Q-sort there was no alternative but to have both the palliative care nurse, and the relevant community nurse, involved with care of that patient also complete the Q-sort.

Two more factors made random selection procedures less important:

1. the choice of research methodology - Q methodology was chosen because it was peculiarly suited to the intensive study of the individual and does not require random sampling; and

2. the aim of the research was to concentrate on the needs of individuals, in line with the philosophy of Hospice and Palliative care, rather than attempt to make generalisations about the population.

Since the total number of patients included on the program at any one point in time was limited to 20, the original intention of the study was to undertake a population survey. However, for the following reasons this was not feasible and a sample size of 10 patients was eventually decided upon:

1. at any one time many of the patients were too ill to take part in the study. In some instances patients' symptoms were not sufficiently well controlled to
allow the patient to concentrate on the Q-sort; other patients were not approached to take part in the study because their current drug treatment affected their cognitive processes to such a degree that any results obtained from these patients would be open to serious question (e.g. oral morphine often produces side effects such as confusion, nausea, hallucinations, etc.); still other patients were within days of their death and had neither the strength nor inclination to take part in the study and even approaching these patients to participate in the research would be grossly insensitive and a serious invasion of their privacy;

2. some patients were requested, and agreed, to take part in the study but their health status suddenly changed and rapidly deteriorated to the degree where they were no longer able to participate effectively in the study. (In all these situations the patient died within a matter of 2 to 3 days of having agreed to participate in the study.)

3. time restraints placed on the length of time allowed for completion of the research project precluded any more than 10 patients being included in the study. The time taken to complete each individual Q-sort posed no problem. Rather, it was one of the following two, frequently occurring, logistical problems that
caused delays - one relating to patients and the other relating to the nurses:

a) patient related difficulties - it was either difficult to make an early appointment time because of the patient's condition, or because the patient was not feeling well enough to complete the Q-sort when the researcher arrived at a previously arranged, mutually convenient appointment time. In this situation, and depending on the patient's condition, one of two courses of action was taken, either:

i) a new appointment time was arranged, if the patient anticipated being well enough; or,

ii) the patient was dropped from the sample, if it appeared that the patient would not recover sufficiently to complete the Q-sort.

b) nurse related difficulties - the nurses' work schedules (4 days on and 4 days off) and work loads were such that it was often difficult to arrange times for the nurses to complete the Q-sort within 24 - 48 hours of the patient completing the Q-sort. Although a 24 hour nursing service was provided to patients, only nurses working on the day roster were available to participate in the research.
Hypotheses

It was hypothesised that if nurses were concentrating on the individuality of patients, and were accurately perceiving each patient's unique needs, there would be a high correlation between the Q-sorts of the patient and the nurse. If the same nurse then accurately perceived the needs of a second patient another high correlation between the Q-sorts of the nurse and this patient would result.

Given that these high correlations existed, it was further hypothesised that the correlation between the nurse's two Q-sorts would reflect the correlation between the Q-Sorts of the two patients, i.e. if the correlation between the patients was high, then the nurse's correlation between her Q-sorts would be high. Diagramatically these hypothesised relationships are shown in Figure 3.1.
Procedure

Prior to the commencement of fieldwork the palliative care nurses were informed of the research during one of the regular team meetings and given the opportunity to ask questions. At this time they were reassured by the Assistant Director of Nursing/Community that the research had the approval of the Director of Nursing/Community.

When the field work began, in November 1988, the researcher was employed as a loss and grief counsellor with the
Community Nursing Section of the ACT Community and Health Service and, therefore, not only had access to all patients on the program but was often involved with visiting them in a professional capacity. This enabled the author to know how well each patient was and whether they might be able to undertake the Q-sort.

Once a patient was identified as possibly well enough to participate, a visit to the patient in their home was arranged to explain the background to the study and provide them with an Information Page (Appendix 3). All patients read the information immediately and were then given the opportunity to ask questions. Although it was intended that patients be given time to consider whether they wanted to participate in the research, most patients, at the initial visit, readily agreed to take part and made mutually convenient appointment times to complete the Q-sort. (Only two patients wanted time to consider their decision; one declined to participate when contacted again; the other agreed to participate at the next session, then rang later declining involvement. A third patient agreed to take part during the initial visit, partially completed the Q-sort before declining to continue. As this person was extremely concerned about confidentiality the sociodemographic data sheet for this patient was shredded in view of the patient and the remaining pieces handed to the patient to destroy completely.)
Once the patient had agreed to participate and the date set to complete the Q-sort both the palliative care nurse and the patient's community nurse were contacted to arrange mutually convenient times for them to complete the Q-sort as soon as possible after the patient. Although only one community nurse was likely to be involved with the patient, the 4 x 4 rosters of the palliative care nurses meant that several nurses might be involved with care for the one patient. In these situations every effort was made to have the palliative care nurse with the most frequent, and recent, experience with the patient, complete the Q-sort.

The procedure for actually administering the Q-sort was the same for both the patient and nurses. At the outset of the session the researcher completed the patient sociodemographic data prior to reading the Instructions (Appendix 5) to the patient; nurses were requested to complete the sociodemographic data sheet themselves. Once the patient, or nurse, had exhausted their questions concerning the procedure, the researcher shuffled the need statement cards, then invited the participant to start the Q-sort and notify the researcher when they were completely satisfied with their placement of the items. Each participating nurse was requested to complete the Q-sort by ranking the items according to how each thought the patient
would rank the items. The start and finish times were noted.

Once the participant was satisfied with their distribution of the items, they were given the opportunity to rest for a short period while the researcher checked that the compartments in the sorting box held the correct number of cards and scored the placement of each card. Once scoring was completed the ten cards from the two most important groupings were selected and the participant asked to indicate two things about each statement:

1. what the statement meant to them, i.e. how did they interpret the written statement?; and,
2. who did they want to meet that particular need (nurses were asked who they thought the patient would want to meet each of these ten most important needs).

As it was possible that some of the items might raise personal issues for the patient, they were given the opportunity to discuss these with the researcher prior to his departure. All patients were invited to call the researcher if at a later time personal issues arose resulting from their participation in the research or they had further questions or concerns in relation to the study. All patients were asked, on completing the Q-sort, whether they had any comments about the task.
Problems associated with data collection

The problems outlined in the Sample selection section were exacerbated when the researcher ceased working as a loss and grief counsellor with the Community Nursing Section of the ACT Community and Health Service. Not only was the regular contact with patients and the daily contact with the nurses lost, hence making it harder to make mutually convenient arrangements for individuals to complete the Q-sort, but also some palliative care nurses declined to participate in the research once the researcher was no longer a member of the palliative care team.

Considerable apprehension was experienced by some of the palliative care nurses concerning the research. After completing the Q-sort, one nurse commented that she was concerned that someone might use the results of the research against her as an individual or against the team. This situation continued despite the constant reassurances concerning confidentiality given by the researcher throughout the project. In an attempt to allay this anxiety the researcher and his supervisor attended a meeting of palliative care nurses on 1 May 1989 where an overview of the research project was again given along with the aims of the study. Nurses were encouraged to voice
their concerns with the project and clarify any issues that were causing them trouble, and if necessary contact either the researcher or his supervisor on an individual basis after the meeting.

Although the Assistant Director Nursing/Community emphasised the value of research in the area of Hospice and Palliative Care and the meeting agreed to support the research by a vote of 8 to 3, anxiety about the research began to rise again within a matter of weeks. Some palliative care nurses, when approached, were again reluctant to participate in the research. The tension reached a point where the researcher believed a potentially harmful situation for the palliative care team was rapidly developing.

At a meeting on 29 June 1989 with the Director of Nursing/Community and her Assistant Director, the researcher expressed his concern about the continuing level of tension among the team, apparently resulting from the research. The Director agreed and indicated that some unspecified concern had continued to be expressed. At this point the researcher suggested that in the interests of the palliative care nurses' welfare he would discontinue the research.
None of these problems were experienced with the community nurses who all stated that they found the task thought provoking.
CHAPTER 4

Results and discussion

In total eight patients agreed, and were well enough, to participate in the research. One of those patients (P₆) partially completed the Q-sort before declining to continue on the grounds that she thought the task was "silly". Another patient (P₄) completed the Q-sort but the nurse who regularly visited this patient declined to participate in the research for "personal reasons" and other nurses declined because they had only visited the patient a limited number of times.

Four different Palliative Care nurses took part in the research. One of these nurses completed a Q-sort in relation to two different patients. An identical situation existed for Community nurses; four different nurses participated, with one Community nurse completing a Q-sort in relation to two patients. Consequently, the final sample consisted of only six patients and eight different nurses - a disappointingly small sample.

The limited size of the sample placed severe restrictions on the analysis of results derived from this research project. While no definite conclusions can be drawn from
such a small sample, attempts have been made to identify trends that may have proved significant had they continued in a larger sample. Had a larger sample been available detailed analysis of results would have included:

1. investigation of relationships between Q sorts and sociodemographic data for both patients and nurses;
2. thorough investigation of meanings of most important items for each respondent;
3. who the patients wanted to meet the ten needs most frequently identified by them as most important; and,
4. who nurses thought patients wanted to meet the ten needs, most frequently identified by nurses, as most important.

Analysis of the results from this research were threefold and confined to:

1. investigation of the individual relationships between:
   a) patient's and corresponding nurse's Q sorts;
   b) different nurses' Q sorts for the same patient;
   c) patients' Q sorts; and
   d) the responses of nurses who completed Q sorts for two patients and Q sorts for those two patients;
2. comparison of the items most frequently ranked as important by patients, palliative care nurses and community nurses; and,
3. item analysis of the 80 Q-items that constituted the instrument used in this research in an attempt to increase its validity and reliability (Anastasi 1982).

**Correlation coefficients**

Block (1961) indicated that when the forced distribution is employed with Q-technique it is appropriate to utilise a product-moment correlation coefficient to index the extent of correspondence between two orderings of Q-items. Kerlinger (1973) suggested that calculation of correlation coefficients with Q-sorts is quite simple due to a convenient formula that has qualities that never change. He recommended the following formula:

\[
    r = \frac{\Sigma xy}{\sqrt{(\Sigma x^2)(\Sigma y^2)}}
\]

where \( x \) stands for the deviation scores of one person, and \( y \) for the deviation scores of another person (in this project the deviation scores are the same as the actual scores assigned). Since \( \Sigma x^2 = \Sigma y^2 \) for any given set of Q-data, the denominator of this equation stays the same and simply requires the calculation of either \( \Sigma x^2 \) or \( \Sigma y^2 \). Correlation coefficients were calculated using the above formula.
1) Patient : nurse correlations

Correlation coefficients were calculated to indicate whether there was any correspondence between each patients' Q-sort and corresponding Q-sorts for nurses. These are provided in Table 4.1.

**Table 4.1 Correlation coefficients between patients and nurses**

<table>
<thead>
<tr>
<th>Nurses</th>
<th>N_1</th>
<th>N_2</th>
<th>N_3</th>
<th>N_4</th>
<th>N_5</th>
<th>N_6</th>
<th>N_7</th>
<th>N_8</th>
</tr>
</thead>
<tbody>
<tr>
<td>P_1</td>
<td>.62</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>P_2</td>
<td></td>
<td>.56</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>P_3</td>
<td>.22</td>
<td></td>
<td>.28</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Patients</th>
<th>P_5</th>
<th>P_6</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>.55</td>
<td></td>
</tr>
<tr>
<td></td>
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<td>.41</td>
</tr>
<tr>
<td></td>
<td>.41</td>
<td>.27</td>
</tr>
<tr>
<td></td>
<td></td>
<td>.52</td>
</tr>
</tbody>
</table>

Having assumed the null hypothesis that the value of the correlation coefficient was equal to zero, or $H_0: r = 0$, there are two methods of deciding the critical values necessary to reject the null hypothesis. One procedure is to calculate tests of significance which can be applied to each correlation coefficient using the distribution of Student's $t$ as suggested by Block (1961) and using the appropriate table, generally available in most elementary
statistical texts (Ferguson 1966, Minium 1970), to obtain the critical value of $t$.

An alternative to calculating Student's $t$ for all correlation coefficients was to use a table indicating critical values of the correlation coefficient required for different levels of significance (Minium 1970). Using this method a correlation coefficient of greater than .29 was required to reject the null hypothesis at the .01 level. From the data supplied in Table 1 it can be seen that 7 of the 10 correlations were greater than .29 and thus significant at the .01 level. Hence the null hypothesis was rejected for these 7 correlation coefficients. This indicated that there was a significant, positive relationship between the Q-sorts of nurses $N_1$, $N_3$ (both patients), $N_4$, $N_6$ (patient $P_2$ only), $N_6$ and $N_7$.

2) Different nurse's Q-sorts for the same patient

Correlation coefficients were calculated between the Q-sorts for the two nurse's who attended the same patient. Results are shown in Table 4.2.

Using the critical value of $r > .29$ as the point at which the null hypothesis is rejected, it can be seen from Table 4.2 that the null hypothesis is rejected for three of the four correlation coefficients. This indicates that there
is also a significant, positive relationship between the Q sorts of nurses attending the same patient except in one instance. A point of particular interest is the significant correlation (.61) between nurses N₂ and N₅ and their non significant correlation with the patient P₃ (.22 and .28 respectively in Table 4.2). This point will be taken up further in the Discussion section below (p. 101).

<table>
<thead>
<tr>
<th>Table 4.2 Correlation coefficients between nurses</th>
</tr>
</thead>
<tbody>
<tr>
<td>Palliative Care Nurses</td>
</tr>
<tr>
<td>N₁      N₂       N₃     N₄</td>
</tr>
<tr>
<td>N₅      .61</td>
</tr>
<tr>
<td>Community Nurses</td>
</tr>
<tr>
<td>N₆      .46</td>
</tr>
<tr>
<td>N₇      .44</td>
</tr>
<tr>
<td>N₈      .18</td>
</tr>
</tbody>
</table>

3) Between patients

Correlation coefficients between patients are shown in Table 4.3. Using the critical value of $r > .29$ to reject the null hypothesis it can be seen that in Table 4.3 only five (bold italics) of the twenty-one correlation coefficients are significant at the .01 level.
Table 4.3 Correlation coefficients between patients

<table>
<thead>
<tr>
<th>P_2</th>
<th>P_3</th>
<th>P_4</th>
<th>P_5</th>
<th>P_7</th>
<th>P_8</th>
</tr>
</thead>
<tbody>
<tr>
<td>P_1</td>
<td>.46</td>
<td>.16</td>
<td>.14</td>
<td>.18</td>
<td>.46</td>
</tr>
<tr>
<td>P_2</td>
<td>.23</td>
<td>.04</td>
<td>.11</td>
<td>.16</td>
<td>.37</td>
</tr>
<tr>
<td>P_3</td>
<td>.03</td>
<td>.28</td>
<td>.10</td>
<td>.02</td>
<td></td>
</tr>
<tr>
<td>P_4</td>
<td>.16</td>
<td>.10</td>
<td>.26</td>
<td></td>
<td></td>
</tr>
<tr>
<td>P_5</td>
<td></td>
<td>.11</td>
<td>.00</td>
<td></td>
<td></td>
</tr>
<tr>
<td>P_7</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>.49</td>
</tr>
</tbody>
</table>

4) Between nurses who completed Q Sorts for two patients and Q Sorts for those two patients

As indicated in the methodology section it was predicted that if nurses' perceptions of patients' needs were accurate (i.e. the correlation between the nurse's Q-sort and each patient's Q-sort was high), the correlation between her separate Q Sorts for two different patients would be similar to the correlation between the Q Sorts of those two patients (See Figure 3.1 page 87). Unfortunately this could only be tested twice. These results are shown in Figure 4.1.
As can be seen in Figure 4.1 the predicted variations between the same nurse's Qsorts and the corresponding patient's Qsorts was not achieved. Although the correlations between the Qsort of nurse N₃ and both patients were strong, there was no correlation between the patients' Qsorts. However, there was a strong positive correlation between the nurse's Qsorts. This would suggest that nurse N₃ made similar assessments of both patients; that she did not effectively discriminate between the needs of each patient, but rather saw them as having similar needs. Manual comparison of the Qsorts completed by this nurse for both patients did not support this explanation. The information on correlation coefficients for each category of need, as shown in Table 4.4, also does not support this explanation. The data contained in Table 4.4 relating to this nurse and these two patients indicates that she had perceived both patient's physical needs with reasonable accuracy but with patient P₅ she accurately
perceived the patient's social needs, while with patient Pₚ she accurately perceived his spiritual needs. Consequently, the reason for this discrepancy remains unexplained.

The situation is slightly different for nurse Nₛ and can be explained by the circumstances surrounding completion of the Q-sort by patient Pₚ. This particular patient had agreed to take part in the research and several appointments were made to complete the Q-sort. However, at each appointed time the patient felt unwell and not able to undertake the task but always wanted to make another time available. This continued for several weeks. Although the patient's health was deteriorating during this time, he wanted to maintain as normal a lifestyle as possible and steadfastly maintained that he would soon beat his illness. On the day he eventually completed the Q-sort the patient said he was feeling very well (despite his appearance to the contrary) and that he wanted to do the Q-sort. After approximately twenty minutes of sorting the items he became very tired but insisted on continuing the task. His time for sorting the items was only 30 minutes; half the time normally taken by other patients.

It is the author's opinion that this particular patient was not well enough to participate in the research. However, because he was firmly denying the seriousness of his
illness he needed to take part in the project to support
his belief that he was well; his participation in the
research was in a way supporting his denial. It is also
the author's opinion that the task proved to be more
demanding than this patient anticipated and, considering
the status of his health, was more exhausting than he was
prepared to admit, even to himself. Consequently, he had
to complete the task as quickly as possible to maintain his
own image of wellness. This action meant that his final
sorting of the items was not an accurate indicator of his
needs. It appears that the research task may have
confronted this patient with the reality of his illness and
these thoughts may have been paramount during the Q-sort,
rather than concentrating on accurately sorting his needs.

This situation may also account for the non-significant
correlations between this patient and both nurses. Since
the correlation between the nurses is relatively strong,
.61 ($r^2 = .37$), both nurses had similar perceptions of the
patient's needs. On the other hand the patient, who was
quite unwell when he completed his Q-sort, was not able to
devote sufficient thought to the task to produce reliable
data. Since nurse $N_3$ was reasonably accurate in her
perceptions of another patient's needs ($P_2$, $r^2 = .31$) it is
reasonable to assume that under normal conditions she would
have been able to predict other patients' needs with
reasonable accuracy.
Discussion of correlation coefficients

Several authors (Ferguson 1966, Lin 1976, Minium 1970) have warned that interpretation of correlation coefficients is not a straightforward matter. Firstly, a correlation coefficient is not a proportion. A coefficient of .40 does not represent a degree of relationship twice as great as a coefficient of .20; nor does the difference between coefficients of .30 and .40 equal the difference between coefficients of .70 and .80.

Secondly, there are two types of associative relationships:  
1. the causal relationship, in which one variable is concomitant with, temporally precedes, and is nonspuriously related to the second variable; and,  
2. the covariational relationship, in which the variables have a concomitant and interdependent relationship e.g. positive or negative.

Finally, according to Lin (1976), interpretation of the correlation should differentiate between a significant and an important relationship. A significant relationship does not necessarily indicate an important relationship. While many relationships will be significantly different from
zero, particularly given a sufficient sample size, few relationships are important in the sense that their magnitudes are substantial. The importance of a relationship depends on the extent of the correspondence of a change in one variable with the change in another being strong and systematic (Lin 1976).

In correlational analysis the correlation coefficient $r$ can be used only to test the significance of the relationship, i.e. whether or not the relationship is non-random. However, $r^2$ is used to indicate the explained variance, i.e. the extent to which the variation of one variable contributes to the variation of the other variable.

While 7 of the 10 correlation coefficients between patients and nurses were significant, that is, the relationships between the Q-sorts for the patients and the nurses were not random, it was important to examine the explained variance to provide some indication of the importance of those relationships. Since the number of nurses involved in this research was small and the correlation coefficients ranged from .22 to .61, it was decided to be conservative (Lin 1976) and use the mean of these coefficients to obtain a measure of the explained variance. Since the mean $r$ for this group was .44 the $r^2 = 0.19$. 
Since $r^2$ can quite meaningfully be interpreted as a proportion and $r^2 \times 100$ as a per cent (Ferguson 1966), it can be said that in this research project, the nurses had an accuracy rate of 19\% in perceiving patients' needs.

The question arises as to the quality of this result. Is 19\% accuracy acceptable, a good rate, or excellent? Closer examination of the relationship between the Q-sorts of the patient and nurses clarifies this situation.

**In-depth analysis of correlation coefficients**

Dividing the Q-sort into the four component categories of needs and calculating correlation coefficients for each group provided useful information. These correlations are provided in Table 4.4.

Using the critical value of $r \geq .516$ to reject the Null Hypothesis, it was found that sixteen of the correlation coefficients (bold italics) in Table 4.4 were significant. The mean correlation coefficient for these sixteen significant relationships was .64 with an $r^2 = .41$. In other words, the nurses had a 41\% accuracy rate with these sixteen relationships.
Examining the correlation coefficients for each category of needs highlighted some very interesting points. The physical needs category accounts for the majority (43.8%) of the significant correlation coefficients shown in Table 4.1. In other words, seven of the possible ten correlation coefficients were significant.

The mean for the coefficients for the physical needs category is .56 with a variance of .32. This indicates that on average nurses had a 32% accuracy rate in perceiving patients' physical needs; a very good accuracy rate. However, the situation for the other three categories of needs is not good; only three of the possible ten correlation coefficients for each of the three
categories, were significant. Therefore, it was the strong relationship between the nurses' and patient's perception of physical needs that influenced the strength of the overall relationships detailed in Table 4.1. Similarly, the lack of significant relationships (or small $r^2$ where relationships are significant) between the nurses' and patients' perception of the other three categories of need reduced the importance of the significant relationships noted in Table 4.1.

Why is this so?

The task of ranking 80 items was difficult, particularly given the nature of the circumstances surrounding the events with which nurses were working. Most of the patients on the Home Based Palliative Care Program were usually in the last few months of their life; frequently in the last weeks or days of life. The nature, and progress, of many of the terminal illnesses experienced by these patients caused crises, such as breakthrough pain, nausea, constipation, etc., to occur frequently. Consequently, nurses were often called to see a patient urgently and were required to manage the symptoms precipitating the crisis. It was common to have periods of time where crises seem to occur with several patients at the same time, thus increasing the demands on nurses to react quickly to a
given situation and devote the majority of their time to resolution of the presenting problem.

In these circumstances it was often difficult to establish a detailed knowledge of other areas of the patient's life. A patient in severe pain is not usually interested in anything else other than having the pain controlled. It has been the author's experience that the patient with uncontrolled pain is not likely to want to discuss minor issues, let alone important emotional, social or spiritual needs. In fact some authors (Warburg 1988, Zorza & Zorza 1981) talk of the isolating effects of severe pain for family members with a terminal illness.

Given these common work experiences it is little wonder that nurses concentrated on the patient's area of need for which they are trained, namely physical needs. Under these circumstances of crisis intervention in the management of symptoms, it is reasonable to expect that nurses would in all probability focus their attention on the physical needs of the patient. Since the physical aspects of the illness are primarily responsible for the crises that arise, it seems logical to suggest that nurses would concentrate on this area and be able to accurately identify the most important physical needs of patients, even if they could not accurately identify the patient's lesser needs.
This does not imply that nurses are unable to accurately identify other needs the patient might have. Some evidence from this research exists to suggest that given appropriate circumstances, nurses may well be able to accurately perceive other than the physical needs of patients. The data contained in Table 4.4 clearly indicates that both nurses working with patient P, were able to perceive the other areas of the patient's needs with a reasonable degree of accuracy; ranging from 33.6%, for nurse N, perceiving the patient's emotional needs to 64%, for the same nurse perceiving the patient's social needs. It is interesting to examine why this occurred with this patient and not others.

There was possibly a combination of a number of factors that may have influenced this situation. Firstly, the amount of contact each nurse had with the patient. This patient had been referred to the Palliative Care Program several months prior to completing the Q-sort. Consequently, both nurses had the opportunity to develop considerable rapport with the patient and his family. Nurse N, had been visiting this patient 4 times a week for 4 months, averaging 1 hour per visit, and nurse N, had been visiting twice a week for 18 months, again averaging 1 hour per visit.
Secondly, the type of contact each nurse had with this patient and his family could have influenced the accuracy of their perceptions of his needs. Not all the visits to this patient involved crises. Particularly during the early visits, both nurses were making routine visits to ensure the progress of the illness was adequately monitored. This action was taken to enable the nurses to identify potential problems for the patient and plan appropriate interventions before the development of a crisis. During these routine visits nurses had the opportunity to relate to the patient in a more relaxed, and often more social, atmosphere.

Thirdly, the personality of the patient and family members influenced the interaction with nurses. This patient was a particularly social person, keenly interested to talk with people; to listen to their ideas and interests; to share their experiences often through animated conversations. This particular patient was not reticent to discuss a variety of issues at a variety of levels; some superficial and social; others personal and meaningful.

This experience can be contrasted with that involving patient P3. Although nurse N3 had been visiting this patient weekly for 15 months, it appears that she was able to perceive only his physical needs, and then with minimally significant accuracy (27%). This particular
patient was a very private person who seldom spoke of his thoughts concerning his illness and impending death. During visits by the researcher, the patient would continue listening to the radio rather than entering any type of conversation. When he did talk about any issue it was usually about defeating his cancer.

Both nurses involved with this patient spoke of their difficulty in stimulating any meaningful discussion with this patient. In fact nurse N, said at the time of completing the Q-sort that, although she had visited the patient for a total of 18 hours, she believed that she still did not know what was important for the patient. This patient had not been on the Palliative Care Program very long as he had declined to have the palliative care nurses visit for some time. During his stay on the Program there were often crises that arose with control of his symptoms.

In contrast with patient P₁, all the other patients, with the exception of patient P₈, had not been on the program for extended periods. Thus nurses did not have the opportunity to develop the same type of rapport with these patients. Patient P₈ had been referred onto the Palliative Care Program at an earlier stage in his illness than most of the other patients. It would have proved interesting to have this patient participate in the research at a later
stage in his illness, after the nurses had the opportunity to develop a rapport with him and his family.

Had this trend continued in a larger sample it would appear reasonable to conclude that given the opportunity, nurses are able to accurately perceive a variety of needs experienced by patients.

Alternatively, the data in Table 4.4 could support the concept of the interdisciplinary team approach to care for terminally ill patients. It appears from this data that both palliative care and community nurses are able to accurately perceive the patient's physical needs. However, it also appears that these nurses are not accurately perceiving the other categories of patient needs. Further research is needed in this area before definite conclusions can be drawn.

Given the data in Table 4.4 it would have been interesting to see whether other professionals working with the terminally ill were able to accurately perceive the patient's needs appropriate to their profession, e.g. a high explained variance between:

1. the chaplain's and the patient's perception of spiritual needs;
2. the social worker's and the patient's perception of social needs; and,
3. the counsellor's and the patient's perception of emotional needs.

Had these predicted high explained variances occurred they would also support the concept of the interdisciplinary team approach to hospice care.

**Items most frequently ranked as important**

To gain an understanding of the frequency items were ranked as most important, an analysis of all patients' Q-sorts was undertaken. Previous research has concentrated on ranking items based on the mean score for each item in an effort to identify the ten most important needs.

Previous research (Arblaster et al 1987) totalled the assigned scores e.g. 9 to 1, calculated the mean score for each item, then rank ordered the items according to their mean. The problem with this action is that it is based on the assumption that the Q-sort is a continuum from "most important" to "least important" and those items placed in the middle sections, i.e. assigned scores of 5, are less important than items assigned scores above 5, and more important than items assigned scores less than 5. However, this is not the case.
In the research completed by Arblaster et al (1987), as well as the present research project, respondents were instructed to place in the middle compartment "cards with statements that you do not understand, or seem ambiguous, or about which you cannot make a decision" (Arblaster et al 1987 p.47. See also Appendix 5). This means that instead of using a straightforward continuum both research projects have used the following type of continuum:

"most important ——— don't know ——— least important".

In this situation items scoring 5 (equivalent to "don't know", "don't understand", or "doesn't apply") will have an inflated mean; they will have a mean influenced by irrelevant data.

In this research, ranking items by the mean did not address the immediate issue; the frequency items were ranked in the two extreme positive cells in the Q-sort by each group. Consequently, it was necessary to develop a score that expressed the importance of items placed in these two cells, and ignored the influence of ranking the item in other cells of the Q-sort. It was decided to square the scores to emphasise the extremes, multiply these squared scores by their frequency, then divide by the number of subjects in the group, to achieve a Relative Importance
Score (RIS) for each item. In equation form this can be expressed as:

\[ RIS = \frac{(f_x \cdot x^2) + (f_y \cdot y^2)}{n} \]

where \( x \) is the score for the extreme positive cell, \( f_x \) is the frequency of scores in the \( x \) cell, \( y \) is the score for the next extreme cell, \( f_y \) is the frequency of scores in the \( y \) cell, and \( n \) is the number of subjects in the group.

In this research project the highest possible RIS for each item would occur if all subjects ranked the item in the extreme cell at the most important end of the sorting box, that is, when \( f_x = n \);

\[ 7 \times 16 + 0 \times 9 \]
\[ RIS = \frac{112}{7} \]
\[ RIS = 16 \]

Ranking of items for each group was then based on the RIS.

At the outset of the research it was intended to conduct a similar examination of the ten items most frequently identified as least important. In this situation the RIS would be calculated by squaring the scores, retaining the
negative sign, and using the above formula for the negative extreme two cells of the Q-sort. The lowest possible RIS score, indicating that an item was considered least important by all subjects would be -16.

The occurrence of errors in the ranking of least important items led to abandoning analysis of the ten most frequently ranked least important items. The main problem revolved around some subjects who ranked items as least important when in fact they should have been placed in the middle "doesn't relate" cell. The most obvious example was non-smokers ranking item number 38 ("To continue smoking whenever I wish") as least important.

Since needs were divided into four categories, it was considered important to examine whether any trends existed in relation to these four categories. The point of interest was whether patients or nurses more frequently identified needs from one of the four categories as being most important, and whether there was a difference between patients and nurses. (Had the sample been larger it would have proved useful to investigate whether groups of patients gravitated toward one of the four groups of needs or whether all patients had a cross section of needs, i.e. whether patients were grouped into those whose needs were primarily physical, social, emotional, or spiritual, or had some needs from all groups.)
A note of warning is necessary at this point. The following ranking of items results from manipulation by the researcher. Consequently, it should be considered as an artefact for the purpose of specific analysis of trends in this research project. It should not be interpreted as a catchall directory of the most important needs of all patients with a terminal illness.

The corresponding ranking of the important needs most frequently identified in the two extreme, positive Q-sort cells for patients, palliative care nurses and community nurses are provided in Table 4.5, Table 4.6 and Table 4.7 respectively.

**Table 4.5 Ten needs most frequently identified as important for patients**

1. 26 To have my pain controlled.
2. 27 To have medical help available whenever I need it.
3. 48 To be asked my opinion before decisions involving me are made.
4. 00 To be forgiven.
5. 30 To be physically alert (i.e. not drowsy) for as long as practical.
6. 67 To be included in the decision making process about my care.
7. 60 To believe there is hope.
8. 61 To have my questions answered honestly.
9. 41 To spend as much time as I want with the family.
10. 32 To have all my symptoms controlled.
Table 4.6 Ten needs most frequently identified by palliative care nurses as important for patients

<table>
<thead>
<tr>
<th>Rank</th>
<th>Frequency</th>
<th>Need Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>29</td>
<td>To feel comfortable physically.</td>
</tr>
<tr>
<td>2</td>
<td>32</td>
<td>To have all my symptoms controlled.</td>
</tr>
<tr>
<td>3</td>
<td>60</td>
<td>To believe there is hope.</td>
</tr>
<tr>
<td>4</td>
<td>48</td>
<td>To be asked my opinion before decisions involving me are made.</td>
</tr>
<tr>
<td>5</td>
<td>46</td>
<td>To be given sufficient information to make choices for myself.</td>
</tr>
<tr>
<td>6</td>
<td>50</td>
<td>To be asked how I would like things done for me.</td>
</tr>
<tr>
<td>7</td>
<td>70</td>
<td>To be independent for as long as I can.</td>
</tr>
<tr>
<td>8</td>
<td>49</td>
<td>To be treated as an individual.</td>
</tr>
<tr>
<td>9</td>
<td>61</td>
<td>To have my questions answered honestly.</td>
</tr>
<tr>
<td>10</td>
<td>26</td>
<td>To have my pain controlled.</td>
</tr>
</tbody>
</table>

Table 4.7 Ten needs most frequently identified by community nurses as important for patients

<table>
<thead>
<tr>
<th>Rank</th>
<th>Frequency</th>
<th>Need Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>67</td>
<td>To be included in the decision making process about my care.</td>
</tr>
<tr>
<td>2</td>
<td>48</td>
<td>To be asked my opinion before decisions involving me are made.</td>
</tr>
<tr>
<td>3</td>
<td>49</td>
<td>To be treated as an individual.</td>
</tr>
<tr>
<td>4</td>
<td>47</td>
<td>To stay at home as long as practical.</td>
</tr>
<tr>
<td>5</td>
<td>58</td>
<td>To have family continue to interact normally with me.</td>
</tr>
<tr>
<td>6</td>
<td>30</td>
<td>To be physically alert (i.e. not drowsy) for as long as practical.</td>
</tr>
<tr>
<td>7</td>
<td>40</td>
<td>To die at home.</td>
</tr>
<tr>
<td>8</td>
<td>60</td>
<td>To believe there is hope.</td>
</tr>
<tr>
<td>9</td>
<td>26</td>
<td>To have my pain controlled.</td>
</tr>
<tr>
<td>10</td>
<td>70</td>
<td>To be independent for as long as I can.</td>
</tr>
</tbody>
</table>
Discussion of item ranking

As there were four categories of needs incorporated in the 80 items it was relevant to examine whether there was any trend evident in the number of needs by category of need for each of the three groups. This information is provided in Table 4.8.

Table 4.8 Ten needs most frequently identified as important - rater by category of need

<table>
<thead>
<tr>
<th>Category of Needs</th>
<th>Spiritual</th>
<th>Physical</th>
<th>Social</th>
<th>Emotional</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patients</td>
<td>1</td>
<td>4</td>
<td>2</td>
<td>3</td>
</tr>
<tr>
<td>Palliative Care Nurses</td>
<td>-</td>
<td>3</td>
<td>4</td>
<td>3</td>
</tr>
<tr>
<td>Community Nurses</td>
<td>-</td>
<td>2</td>
<td>5</td>
<td>3</td>
</tr>
</tbody>
</table>

Despite the very small numbers involved, there appeared to be a trend in what patients and nurses perceived as important needs. From the data detailed in Table 4.8 it appeared that nurses more frequently perceived that patients were concerned more with social needs than any of the other categories. It would be extremely interesting to see whether this trend continued in a larger sample.
What does all this mean?

As outlined earlier the numbers involved in this research are too small to draw definite conclusions but had this trend continued in a larger sample there are several questions that are raised by this phenomenon.

The ACT Home Based Palliative Care Program is a program established to provide palliative care within the patient's home and staffed by nurses. Although this group of nurses now has access to an educator in loss and grief, as well as other specialist educators, and works in conjunction with the volunteers from the ACT Hospice Society Inc., it is definitely not an interdisciplinary team. It is primarily a group of community nurses, some of whom specialise in palliative care. Nonetheless, it is the author's belief that the nurses involved in this research project were well aware of the importance of addressing all four categories of needs in patient care. However, in the absence of other appropriate professionals within the team, one may question to whom could nurses make referrals of patients who might have other than physical needs? Did the nurses believe they had to deal with these issues themselves? If this is so, then, do they lack the professional education and skills to enable them to accurately identify other than physical needs? In turn, did this lead them to
over-compensate for this deficiency by concentrating on social and emotional needs?

Although it is only conjecture this situation raises more questions. Firstly, do those who are responsible for the establishment and direction of the Program fully understand the difference between a palliative care program and a hospice program? Since palliative care is aimed at the amelioration of distressing symptoms even where the underlying physical pathology cannot be treated or reversed (Corr & Corr 1983), it is not synonymous with, but rather an integral aspect of, hospice care. As outlined in the literature review section, a hospice has several distinct characteristics other than the palliative approach to care. Thus, did the administrators, believing that the two programs were equivalent, place unrealistic expectations on the nurses? While believing they are providing hospice care, are they in fact providing fiscal and personnel resources to meet the needs of a palliative care program only? Do they have embedded in this policy implicit expectations that nursing personnel are able to effectively meet the very different demands of a hospice program?

On the other hand, the administration may be fully aware that they are simply providing a palliative care program. However, do the nurses believe that this does not adequately meet the patient's and family's needs? Are they
trying to meet these extra needs without the benefit of sufficient education, financial, and interdisciplinary support from other professionals being available to them?

Another question raised by this concentration on other than physical needs is whether nurses go into new family situations with preconceived ideas forged from past experiences with similar situations? Do health care professionals, in this case nurses, build up a wealth of experience with previous families that enables them to perceive problems that might arise even before these problems enter the awareness of the current family, which is dealing with the experience of terminal illness for the first time? This also leads to further questions.

How are nurses responding to the instructions on completing the Q-sort? Are nurses sorting the items based on their knowledge of individual patients and what those patients believe to be their specific needs? Are nurses unknowingly using their past experience of many other similar situations and actually responding by imposing their own concepts of what the patient needs rather than understanding the unique perceptions of the individual patient in question? Is this situation influenced by the length of time the patient is on the Program? Although in this research project length of contact between the patient and nurse was recorded, the sample size was far too small
to undertake any meaningful analysis of the influence of amount of contact on accuracy of the nurse's perceptions.

Are individual nurses influenced by colleagues' perception of the patient's needs? Does the administration of the program allow sufficient time for nurses to meet regularly to exchange information on patients?

Do these results simply reflect the philosophical approach of the two groups of nurses? Since both groups are community based, it is likely that their approach to medical care emphasises a holistic approach. With community medicine based on prevention, and palliative care based on the systematic treatment of symptoms rather than the underlying physical cause of disease, social factors are likely to be seen as important in all aspects of the work of both groups of nurses; hence the concentrated concern for social needs.

Is this concern, with other than physical needs, the seed of role blurring which is one of the characteristics of care provided by an interdisciplinary team?

Further research in this area is necessary before any of these questions can be answered with conviction.
Item analysis

Both the validity and reliability of a test, questionnaire, scale, etc., depend ultimately on the characteristics of its items. Consequently, they can be improved through the selection, substitution, or revision of items which can be analysed qualitatively, in terms of their form and content, and quantitatively, in terms of their statistical properties (Anastasi 1982). Qualitative analysis includes the consideration of content validity, and evaluation in terms of effective item-writing procedures, while quantitative analysis includes the measurement of item difficulty and item discrimination.

High reliability and validity can be built into an instrument in advance through item analysis. In this project qualitative analysis, in terms of content validity was examined during the selection of the 80 items for inclusion in the final Q-sort and has been fully discussed in the methodology section. However, it was not appropriate to undertake quantitative item analysis prior to the main study as patients were not used during piloting of the instrument. Hence, it was essential to examine the items after patients had completed the Q-sort in an effort to increase the instrument's validity and reliability.
For most test purposes, item difficulty has been defined in terms of the percentage of persons who answer the item correctly (Anastasi 1982). However, with a Q-sort there is no a priori basis for assessing a response as right or wrong. Therefore, there is no question of item difficulty being relevant for Q-methodology.

Since item discrimination refers to the degree to which an item differentiates correctly among respondents (Anastasi 1982), it is not only relevant, but important to Q-methodology.

In a Q-sort the emphasis is not on the correctness of an item to differentiate between subjects, but rather on the fact that the item actually does differentiate between individuals. The placement of any item, in any one of the cells of a Q-Sort, is neither right nor wrong. However, if an item is an effective discriminator between individuals, and given a sufficient respondent sample size, theoretically at least, placement of that item could range across all possible Q-sort cells. Concentration of any item at the extremes of the distribution does not preclude its importance as a discriminator in Q-methodology. Using the current research project as an example, items that are persistently placed in the extreme cells are either "very important", or "very unimportant", to most patients. This
information is important in itself as it indicates a common need.

The situation changes dramatically if patients consistently place an item in the middle cells. In this circumstance it is highly likely that the item is either not understood, ambiguous, or does not relate to the respondent's position. Irrespective of the specific reason for all respondents placing the same item in the middle three cells only, for the researcher it is an indicator that the item is not a good discriminator and needs removal from the Q-sort.

If more than one group of subjects is completing the Q-sort then the items that are constantly being placed in the middle cells are likely to vary. Consequently, the type of research being conducted will influence which items will be finally deleted from the Q-sort. As the focus of this research was on the perceived needs of the patient with a terminal illness, it is the patients' placement of items that are important.

Using the same calculations that were used to obtain the RIS for each Q-sort item, it was a relatively simple matter to identify those items consistently placed in the middle three cells. There were only two items identified in this process; number 10 - "To be given spiritual/religious support from family members"; number 20 - "To be taught
relaxation techniques". Although the sample is very small, it was decided to replace these items for any future Q-sort.

Given a larger sample this exercise could be carried out with more stringent guidelines. Those items that were consistently placed in the middle three cells and only rarely placed in the next two cells could also be subjected to intense scrutiny. Such items may require rewording or discarding. However, those items that are placed infrequently in the four end cells of the distribution should be retained as they have some discriminating power for some individuals; their placement in the extreme cells indicate that they are valid indicators of some patients' needs.
CHAPTER 5

Conclusions

Through an examination of the correlations between the Q-sorts of patients with a terminal illness and the palliative care and community nurses caring for them, this research project attempted to investigate whether those nurses could accurately perceive the spiritual, physical, social and emotional, needs of patients in their care.

Perhaps the most important finding arising from this research is that patients with a terminal illness are not only able, but are generally very willing, to participate in the research. Provided patients are approached with sensitivity and awareness of the difficulties that might suddenly arise as a consequence of their illness, they are keen to participate. Most patients who agreed to participate in this research stated that they were only too pleased to be able to do something they thought might be useful for other people. In many instances patients stated they wanted to do something useful and in some small way repay some of the special care they were receiving. Some patients agreed to participate despite their family indicating earlier that the patient was too sick to undertake the research task.
Unfortunately, the constant, high level of anxiety amongst the palliative care nurses caused the curtailment of the study and restricted the final sample size to 7 patients. Consequently, no firm conclusions can be drawn from the small sample used in this study. While the research raised more questions than it answered, it appears that the following trends began to emerge even with this small sample.

1. While there is a significant correlation between the overall Q-sort of individual patients and the attending nurses, in Lin's (1976) terminology, it is not a particularly important relationship. On average, nurses were able to perceive patients' overall needs with an accuracy of 19%.

2. Both palliative care and community nurses were generally able to perceive the physical needs of their patients with the relatively high degree of accuracy of 32%.

3. Neither palliative care nor community nurses were generally able to perceive the spiritual, social or emotional needs of patients with any degree of accuracy.

4. It appears that there are a number of possible factors (not fully explored in this research because of the small
sample size) that influence the degree of accuracy of nurses' perceptions of other than physical needs. These are:

a) length of contact with the patient;

b) type of contact with the patient, i.e. whether there are frequent crises to preoccupy the nurse during her visits; and,

c) personality of the patient.

5. Both community and palliative care nurses tend to more frequently rank social needs as most important, than do patients.

6. All but two of the Q-sort items developed for this research proved to be relevant items for investigating the correlation between patients' and nurses' perceptions of the four categories of patient needs.

7. The ten needs most frequently ranked by patients as most important include some needs from all four categories of need. Thus it would appear that the provision of a palliative care program alone, does not adequately meet the needs of patients.

8. The lack of significant and important relationships between the patients' and nurses' perception of spiritual, social and emotional needs, combined with the fact that
patients' most frequently ranked important needs cover all four categories of need, tend to support the need for an interdisciplinary approach to the care of patients with a terminal illness.

9. It appears that the earlier patients are referred to the palliative care program the better opportunity nurses have to establish a greater understanding of the patient's needs.

Further research suggestions

Apart from verification of the above trends, further research, with a much larger sample, is necessary to investigate some of the questions that arose during this project.

1. Are other health care professionals, involved with the care of patients with a terminal illness, able to perceive the patient's needs relevant to their area of expertise with the same, more, or less accuracy than nurses? Positive results from this type of research would support the concept of the interdisciplinary team approach to terminal care.

2. What are the needs of family members? Do these differ from those of the patient, and if so, are those differences
dependent on the family member's relationship with the patient? Are members of an interdisciplinary team able to accurately perceive the needs of other family members?

3. Do the needs of patients with a terminal illness change as the disease progresses from diagnosis to death? If so, what are these changes; do they follow any predictable course; does one group of needs dominate throughout the dying trajectory or do they vary?

4. Given a sufficient sample size, do groups of patients gravitate to different categories of need, i.e. is there a group of patients who have predominantly physical needs, a group of patients with predominantly emotional needs, etc. If so, do these different groups of patients have characteristics that would facilitate early identification?

5. What factors influence a nurse's accuracy in perceiving the various needs of patients with a terminal illness.
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APPENDIX 1

A.C.T.COMMUNITY NURSING

HOME BASED PALLIATIVE CARE

Criteria for referral (As at 12.05.89)

1. The patient must have a diagnosis of cancer and be in the terminal phase of the disease (i.e. three to six months approximately).

2. Patient and family must be aware of the patient's diagnosis and prognosis.

3. The patient wishes to stay at home and the family are happy for this to occur.

4. The symptoms are such that they can be controlled at home.

5. Someone is willing to accept the responsibility of being the primary care giver in the home, i.e. husband, wife, friend, etc.
6. The patient must have a general practitioner in the ACT and/or specialist caring for them.

7. The patient must live within the A.C.T. "metropolitan area".
Q-Sort Statements

00. To be forgiven
01. To be taught meditation techniques
02. To have the general congregation/spiritual group pray for me/send me positive thoughts
03. To have a Communion service at home
04. To have the minister/priest/ pastor/rabbi/spiritual adviser visit me at home
05. To be given the opportunity to explore my spiritual beliefs
06. To attend religious/spiritual services for as long as practical
07. To have members of my religious or spiritual organisation continue to pray for me
08. To be given the opportunity to share prayer sessions with others
09. To have the family share prayers together
10. To be given spiritual/religious support from family members
11. To be given spiritual/religious support from friends
12. To have a religious/spiritual service in our home
13. To have close friends join a religious/spiritual service in our home
14. To have a strong faith in a Supreme Being/God
15. To have a strong belief in a Supreme Being/God
16. To know that a Supreme Being/God is with me at all times
17. To be given the opportunity to talk about my negativity towards my spiritual beliefs
18. To discuss with my family arrangements I would like for my funeral
19. To discuss my funeral arrangements with my minister/priest/pastor/rabbi/spiritual adviser
20. To be taught relaxation techniques
21. To know that the family can have a short break from the responsibility of 24hr a day caring for me
22. To have family members help with my physical care
23. To have family members taught how best to provide physical care for me
24. To die in hospital
25. To have the doctor visit me at home regularly
26. To have my pain controlled
27. To have medical help available whenever I need it
28. To have my bowels functioning adequately
29. To feel comfortable physically
30. To be physically alert (i.e. not drowsy) for as long as practical
31. To have equipment provided that will improve my physical comfort
32. To have all my symptoms controlled
33. To have my favourite food whenever I wish
34. To eat whatever I wish
35. To drink whatever I wish
36. To continue to express my sexuality
37. To continue to maintain a sensual relationship
38. To continue smoking whenever I wish
39. To maintain physical contact with people, i.e. to be touched
40. To die at home
41. To spend as much time as I want with the family
42. To have relatives available for support
43. To have friends available for support
44. To know what services are available to assist me
45. To be informed about other people who could help with problems which might arise
46. To be given sufficient information to make choices for myself
47. To stay at home as long as practical
48. To be asked my opinion before decisions involving me are made
49. To be treated as an individual
50. To be asked how I would like things to be done for me
51. To have my opinions accepted
52. To have my beliefs accepted
53. To continue visiting friends
54. To be included in daily family activities
55. To maintain interaction with special members of community groups e.g. clubs, associations, etc.
56. To continue to take part in extended family events outside the house
57. To continue to take part in special occasions with friends outside the house
58. To have family continue to interact normally with me
59. To have friends continue to act normally with me
60. To believe there is hope
61. To have my questions answered honestly
62. To have explanations given in terms that I understand
63. To feel accepted as a person by the medical team
64. To be given the opportunity to talk about my death
65. To have some time alone
66. To feel O.K. about expressing my emotions
67. To be included in the decision making process about my care
68. To be able to talk confidentially to someone about how I am feeling
69. To have a choice in when I will take medications
70. To be independent for as long as I can
71. To know that the Specialist will inform my GP about all aspects of my illness and treatment
72. To feel confidence in the professionals who are caring for me (e.g. doctors/nurses etc.)
73. To have someone explain to me realistically what to expect as my illness progresses
74. To know how death might occur
75. To be given full information about medications, e.g. side effects, purpose, etc.
76. To know that I will not be abandoned by the medical team if I refuse to have recommended treatment, e.g. chemo/radio-therapy
77. To know that a bed is available in hospital when I can no longer stay at home.
78. Not to be told what is happening to me
79. To leave all decisions to the medical team e.g. doctors, nurses, etc.
A STUDY LOOKING AT THE NEEDS OF PATIENTS

This is a study being undertaken by a Master of Education student at the Canberra College of Advanced Education to look at the topic of what people with a terminal illness perceive as their needs during the course of the illness, what community nurses perceive as the individual's needs and who both groups see as meeting those needs. It is hoped that the results of this study will enable health care professionals, not only in Canberra but throughout Australia and internationally, to understand more about the requirements of individuals and family members and thus to adapt existing programs, or develop more appropriate services.

Graham Fulton, the researcher, will arrange to visit you at a mutually convenient time. You will be asked to look at cards with statements written on them and then arrange them into various groups. There will be sufficient time for the procedure to be explained first, and Graham will be available to answer any of your questions. It is anticipated that the visit will be of approximately 1½ to 2 hours duration.
Your decision to take part in this study is purely voluntary and you have the right to withdraw at any time. However, if you are like others who have participated in this kind of study in the past you will probably quite enjoy the task. Should you at any time feel unwell, or uncomfortable about continuing the study, Graham will arrange another visit at your convenience, or otherwise respect, and accept, your request to withdraw completely from the study.

The findings of this study will not include any details by which you, or your family members could be identified. All personal details will remain completely confidential. If you so desire, the results will be sent to you on completion of the study. It is anticipated that the study will be completed towards the end of the year.

Should you have any further questions at any time please do not hesitate to contact:

- Graham Fulton, the researcher, on 516777 during business hours, or at home on 584957; or

- Dr Jim Clough, the study supervisor, on 522329 during business hours.
APPENDIX 4

AGREEMENT TO PARTICIPATE

Having read the INFORMATION PAGE, I am willing to participate in this study undertaken by Graham Fulton, a Master of Education student at the Canberra College of Advanced Education. The researcher has described the study to me, explained my involvement to my satisfaction, and I have had the opportunity to ask questions.

I understand that my name and address will not be published in any form and confidentiality concerning personal details will be maintained at all times.

I understand that at any time during the study I do not understand what is happening I may ask questions relating to the study.

I understand that if at any time during the study I feel unwell, unhappy or uncomfortable about the study I can either:
. request that the session be discontinued and another mutually convenient time arranged to continue; or

. I may withdraw my agreement to participate in the study without any ill feeling on the part of the researcher.

I understand that if I feel there is any need to seek further advice or clarification about the study I may contact either:

. Graham Fulton, the researcher, on 516777 during business hours or at home on 584957; or

. Dr Jim Clough, the research supervisor, on 522629 during business hours.

Participant .........................

Researcher .........................

Date .................
APPENDIX 5

INSTRUCTIONS TO RESEARCH PARTICIPANTS

In this research project you will be asked to sort eighty cards with statements written on them, into nine different groups. This may sound a little complicated but I will now go through the process with you step by step. If you have any questions as I explain what you are to do please do not hesitate to ask me.

These are the cards (show participants the complete bundle of cards). This is the sorting box. I will explain how to use the sorting box later. As you can see, each card has a statement typed on it. You will be asked to read the statement on each card very carefully and to read through all the statements slowly. Each statement should be read as though the prefix "I NEED ..." is in front of the statement. (Pick a card from the bundle and show the participant what you mean.) To help you remember the prefix "I NEED ..." it is clearly written on front of the sorting box. (Indicate to the respondent the statement on front of the sorting box.)

Once you have read through all the cards you will then be asked to sort the cards into nine piles. To assist you a box has been constructed with nine compartments, each clearly labelled with the number of cards to be placed into each compartment. You are to put the number of cards into
each compartment to match the number displayed on that compartment. For example, into the compartment labelled 6 please place 6 of the cards.

At one end of the box you will see a label "MOST IMPORTANT" and at the other end a label "LEAST IMPORTANT". You are to place the four cards with the statements that are most important for you in the compartment marked 4 at the MOST IMPORTANT end of the box and the four cards with the statements that are least important for you in the compartment marked 4 at the LEAST IMPORTANT end of the box. If there are some cards with statements that you do not understand, or which seem ambiguous, or about which you can not make a decision, please place them in the middle compartment. This is the compartment marked with the number 16. Are you clear about what you are required to do? (If not show the person what to do.)

Once you have placed all the cards into the various compartments have a rest for a few minutes. You may then go back through each compartment and swap the cards around until you have organised them to your satisfaction. You may change the position of the cards as many times as you wish. Please make sure though that you do not place more cards in the compartment than the number marked on the front of that compartment. For example, the compartment furthest to your right has the number 4 marked on it.
Please do not place more, or less, than four cards in this compartment. When you are happy with the way you have arranged the statements please tell me as you will have then finished the first, and longest part of the research project.

Are you clear about what you are to do? Do you have any further questions? While you are sorting the cards you may not ask any questions about the statements, such as "what does this one mean?". However, you may ask other questions, such as, "how many cards do I place in this slot?"

You may now start reading the cards. When you have finished sorting the cards to your own satisfaction I will tell you about the next part of the project.

Now that you have finished sorting the cards I would like you now to tell me briefly what these statements (top two, and bottom two, groups) meant to you.

Taking the ten most important need statements would you please tell me who you would like to have meet those needs. Who do you think can fulfil those needs most appropriately for you?

Thank you for your cooperation today.
INSTRUCTIONS TO RESEARCH PARTICIPANTS

In this research project you will be asked to sort eighty cards with statements written on them, into nine different groups. This may sound a little complicated but I will now go through the process with you step by step. If you have any questions as I explain what you are to do please do not hesitate to ask me.

These are the cards (show participants the complete bundle of cards). This is the sorting box. I will explain how to use the sorting box later. As you can see, each card has a statement typed on it. You will be asked to read the statement on each card very carefully and to read through all the statements slowly. Each statement should be read as though you are the patient's advocate and answering on the patient's behalf. The prefix "I NEED ..." in front of the statement refers to the patient. (Pick a card from the bundle and show the participant what you mean.) To help you remember the prefix "I NEED ..." it is clearly written on front of the sorting box. (Indicate to the respondent the statement on front of the sorting box.)
Once you have read through all the cards you will then be asked to sort the cards into nine piles. To assist you a box has been constructed with nine compartments, each clearly labelled with the number of cards to be placed into each compartment. You are to put the number of cards into each compartment to match the number displayed on that compartment. For example, into the compartment labelled 6 please place 6 of the cards.

At one end of the box you will see a label "MOST IMPORTANT" and at the other end a label "LEAST IMPORTANT". You are to place the four cards with the statements you think the patient believes are most important for him/her in the compartment marked 4 at the MOST IMPORTANT end of the box and the four cards with the statements you think the patient believes are least important for him/her in the compartment marked 4 at the LEAST IMPORTANT end of the box. If there are some cards with statements that you do not understand, or which seem ambiguous, or about which you can not make a decision, please place them in the middle compartment. This is the compartment marked with the number 16. Are you clear about what you are required to do? (If not show the person what to do.)

Once you have placed all the cards into the various compartments have a rest for a few minutes. You may then go back through each compartment and swap the cards around
until you have organised them to your satisfaction. You may change the position of the cards as many times as you wish. Please make sure though that you do not place more cards in the compartment than the number marked on the front of that compartment. For example, the compartment furthest to your right has the number 4 marked on it. Please do not place more, or less, than four cards in this compartment. When you are happy with the way you have arranged the statements please tell me as you will have then finished the first, and longest part of the research project.

Are you clear about what you are to do? Do you have any further questions? While you are sorting the cards you may not ask any questions about the statements, such as "what does this one mean?". However, you may ask other questions, such as, "how many cards do I place in this slot?"

You may now start reading the cards. When you have finished sorting the cards to your own satisfaction I will tell you about the next part of the project.

Now that you have finished sorting the cards I would like you now to tell me briefly what these statements (top two, and bottom two, groups) meant to you.
Taking the ten most important need statements would you please tell me who you think the patient would like to have meet those needs. Who do you think the patient believes can fulfil those needs most appropriately for him/her?

Thank you for your cooperation today.
APPENDIX 7

PATIENT SOCIODEMOGRAPHIC DETAILS

CODE NO: ....... SEX: ....... DATE OF BIRTH:.............

PLACE OF BIRTH:....... LENGTH OF RESIDENCE IN AUST:.....YRS

MARITAL STATUS: Single 01; Married 02; Separated 03; Divorced 04; Widowed 05;

FAMILY MEMBERS: LOCATION:
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(Use back of page if necessary)

RELIGION: .................. AVERAGE ATTENDANCE:....../MONTH

OCCUPATION:............................................

EDUCATION LEVEL: Some Primary 01; Completed Primary 02; Some Secondary 03; Completed Secondary 04; Some Tertiary 06; Completed Tertiary 07; Trade qualification 05;

DIAGNOSIS:..................................................

DATE OF ORIGINAL DIAGNOSIS: ....... TO PALLIATIVE CARE:........

DATE COMPLETED Q-SORT: ............

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APPENDIX 8

NURSES SOCIODEMOGRAPHIC DATA

CODE NO: ............ SEX: ....... DATE OF BIRTH: ...............  

PLACE OF BIRTH: .......... LENGTH OF RESIDENCE IN AUST: ......YRS  

NUMBER OF YEARS PRACTISED AS REGISTERED NURSE: .... (ACT) ...... TOTAL)  

CERTIFICATES HELD OTHER THAN BASIC REGISTRATION:  
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..........................................................................................  
..........................................................................................  
..........................................................................................  

NUMBER OF YEARS EXPERIENCE:  
Accident and Emergency .......... Community Health ......  
Developmentally Disabled ........ Geriatrics .............  
Intensive Care .................... Medical ..................  
Midwifery ......................... Mothercraft ............  
Neonatal ......................... Nurse Education .........  
Operating Theatre ............... Paediatric ..............  
Palliative Care ................... Psychiatry ...............  
Recovery Room ................... Relief Pool ..............  
Surgical ......................... Other (Please state) ....  

CURRENT NURSING PRACTISE AREA: Community ......  
Palliative Care ..............  

NUMBER OF VISITS TO PATIENT: ...............  

DATE COMPLETED Q-SORT: ...............  

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