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Needs of terminally ill cancer patients in an in-patient hospice unit

Marylynn C. Oldham
Edith Cowan University

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NEEDS OF TERMINALLY ILL CANCER PATIENTS IN AN IN-PATIENT
HOSPICE UNIT

By

Marylynn C. Oldham, RN

A Thesis Submitted in Partial Fulfilment of the
Requirements for the Award of

Bachelor of Nursing with Honours

at the School of Nursing.

Edith Cowan University

Thesis Supervisors: Gerry Farrell
Janet Reinbold

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USE OF THESIS

The Use of Thesis statement is not included in this version of the thesis.

Abstract

In Western Australia, in-patient hospice/palliative care units are caring for increasing numbers of terminally ill cancer patients. Hospice philosophy is based on the belief that the terminally ill patient's individual needs are of paramount importance. The needs of advanced cancer patients have been researched in the home, for patients continuing or having completed curative treatment, and for patients receiving palliative care. However, there is a lack of literature about the needs of terminally ill cancer patients in in-patient hospices. Using a descriptive approach, this study investigated the needs of six terminally ill cancer patients in a 26 bed in-patient hospice unit. Semi-structured interviews based on Henderson's (1964) 14 fundamental needs were used to elicit information about these patients' needs. Data was analysed using thematic analysis to determine common categories of need. Findings suggest that terminally ill cancer patients in an in-patient hospice unit have seven common need categories. These are physiological, psychological, sociological, spiritual, informational, financial and environmental categories of need. Three overriding needs are described as the need to feel safe, to maintain family contact and to reduce the impact of visitors. Implications of the findings for nurses are discussed.

Declaration

"I certify that this thesis does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any institution of higher education; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text."

Signature'

Date..... 21st May. 1993

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Table of Contents

	<u>Page</u>
Abstract	ii
Declaration	iii
Acknowledgments	iv
List of Tables & Figures	vii
 Chapter	
1 INTRODUCTION	1
Significance of the Study	2
Purpose of the Study	3
Definition of Terms	4
Concern	4
In-Patient Hospice Unit	4
Need	4
Palliative Care	4
Terminally Ill Cancer Patient	5
2 LITERATURE REVIEW	6
Patients at Home : Curative Treatment	6
Patients at Home: Palliative Treatment	8
Patients in an In-Patient Hospice:	
Palliative Treatment	11
Summary	13
3 CONCEPTUAL MODEL	15
4 METHODOLOGY	18
Design	18
Sample Selection	18
Setting	19
Negotiating Access	20
Development of the Instrument	20
Data Collection Procedures	23
Acceptability of the Interview	25
Data Analysis	26
Category Development	26
Management of the Data	28
5 FINDINGS and DISCUSSION	30
Characteristics of the Sample	30
Categories of Need	31
Physiological	33
Psychological	36
Sociological	39
Spiritual	44
Informational	45
Financial	48
Environmental	49
Overriding Needs	51
Conclusion	52

Implications for Nursing Practice	53
Limitations of the Study	54
Retrospective Thoughts	55
Further Research	55
References	56
Appendices	
A. Demographic Information	65
B . Interview Guide	66
C . Participant Consent Form	67

List of Tables and Figures

	<u>Page</u>
Table 1. Selected Characteristics of the Sample	30
Table 2. Definition of Seven Need Categories based on Henderson's (1964) Needs	31
Table 3. Physiological Needs of Terminally Ill Cancer Patients	33
Table 4. Psychological Needs of Terminally Ill Cancer Patients	37
Table 5. Sociological Needs of Terminally Ill Cancer Patients	40
Table 6. Spiritual Needs of Terminally Ill Cancer Patients	44
Table 7. Informational Needs of Terminally Ill Cancer Patients	46
Table 8. Financial Needs of Terminally Ill Cancer Patients	48
Table 9. Environmental Needs of Terminally Ill Cancer Patients	50
Table 10. Overriding Needs of Terminally Ill Cancer Patients	51
Figure 1. Conceptual Model of Care for Terminally Ill Cancer Patients	17
Figure 2. Sociological Needs sorted into Family, Friend and Recreational Needs	27

Chapter 1

Introduction

Cancer is the second highest cause of death in Western Australia (W.A.) (Waddell & Lee, 1991), and is "forecast to increase, becoming the principal cause of death by disease in Australia" (Liveris, 1992, p. 2). Cancer is not a single disease. Cancer can originate in almost any organ in the body and spread, causing a multitude of symptoms, progressive illness and frequently death (Porth, 1986). When the person with cancer reaches the stage at which no further curative medical treatment is administered, s(he) will often have 6-12 months of dealing with the difficult and diverse symptoms and emotions that can accompany progressive malignancy (Brescia, Adler, Gray, Ryan, Cimino & Mantani, 1990).

Frequently, the terminally ill patient can remain at home, cared for by family and/or a Hospice Home Care Service (H.H.C.S.) but there is a growing demand for care of these patients in an in-patient hospice setting too. In the Perth metropolitan area, two in-patient hospice care units have been built to support home care programs. These in-patient units provide the following services: respite care to support the family carers; symptom control; continuing hospice care when the family are no longer able to cope; and, an environment in which patients can die, when home is seen to be inappropriate (Barn, 1985).

Fitzgerald and Thomson (1992) estimate that from January 1986 - December 1989, a total of 9665 people died of cancer in W. A.; of those people 435 patients died in hospice care units. The number of admissions to these units is likely to increase. One of the units alone reported a 20% increase in admissions in 1991, with 285 deaths during that one year period (Macadam, 1992). Gates (1991) suggests that the ever increasing demand for hospice care indicates that the level of palliative care offered by in-patient hospice units is superior to that provided by busy hospital oncology wards.

Although clinical experience, and anecdotal evidence provided by Charmaz (1980) and Ross (1969) suggests that in-patient hospice care is more conducive to the needs of terminally ill cancer patients than hospital care, there is little empirical evidence that hospice patients' individual needs have been adequately described from the patients' perspective. Without this knowledge, nurses cannot determine, if, hospice care is in fact, meeting the patients' needs.

Significance of the Study

While the needs of nurses caring for the terminally ill patient in hospital have been examined (Kincade & Powers, 1984) and the needs (Wright & Dyck, 1984) and concerns of relatives of terminally ill patients have been studied (Seale, 1991) surprisingly, no studies have been found that specifically address the needs of the terminally ill cancer patient receiving palliative care

either in a hospital or a hospice setting. Two studies are reported that examine patients' concerns in the hospice setting but neither explore just what needs patients have with respect to a particular concern. For instance, a patient may be concerned about the effect of her/his illness on her/his family, but this does not necessarily tell us what her/his specific needs are in relation to this concern - such as, the need to know that her/his partner still loves him/her or that her/his children will continue to visit.

The needs of patients at home, who are receiving either curative treatments or palliative care, have been studied but there is no evidence that hospice in-patients' needs will be similar to those patient populations. Also, it is difficult to compare one study with another as each use different methodologies, including asking patients to either respond to a predetermined list of items, or, asking patients a single, general open-ended question.

This study attempted to identify terminally ill patients' needs in a hospice setting by using a methodology that allowed patients to identify their own needs and asked patients about needs that have been identified in the nursing literature. In doing so, a comprehensive assessment of patients' needs could be described.

Purpose of the Study

The purpose of this study is to identify and describe the needs of terminally ill cancer patients in an in-

patient hospice unit. This knowledge will provide nurses, who often assume a primary role in the care of terminally ill people, with a better understanding of the individual needs of this patient population.

Definition of Terms

Concern

Something affecting one's interest or welfare (Webster Comprehensive Dictionary, 1982). For example, a patient may express concern about sleep, whereas her need may be for eight hours sleep at night or to talk about the nightmares she is having while she sleeps.

In-Patient Hospice Unit

An in-patient hospice unit is a carefully created environment of care which openly recognises the inevitability of a person's dying, yet works with the person, to fully live the life remaining. Patients are admitted for respite care, symptom control, or terminal care (Brann, 1985).

Need

A need is a requirement or a necessity (Henderson, 1964). A fundamental need is a requirement common to all human beings, well or ill - for example, all human beings need to sleep (Maslow, 1970). People meet their needs in a variety of ways.

Palliative care

A program of care for terminally ill patients (and their families). The goal is to alleviate suffering and

prolong meaningful living. No active curative therapies are undertaken (Amenta & Bohnet, 1986).

Terminally Ill Cancer Patient

A terminally ill cancer patient is an individual with cancer, who is receiving palliative care for the disease, and has an expected survival of six months or less (Ajemian & Mount, 1982).

Chapter 2

Literature Review

Patients with advanced cancer receiving curative treatment at home.

Using a descriptive design, Wingate and Lackey (1989) studied the needs of 10 cancer patients, living at home, and their caregivers. The patients had been diagnosed with cancer from three months to nine years. All had experienced one or more of the common modalities of cancer therapy. Patients and caregivers listed their needs using open-ended questionnaires. Findings showed that both patients' and caregivers' needs were represented by six categories: 1) psychological; 2) physical; 3) informational; 4) spiritual; 5) legal and financial; and 6) household. The greatest number of patient needs were, in descending order of importance, psychological, physical and informational, while the greatest caregiver needs were psychological, household management and informational. Psychological needs were described as; to be able to talk with someone who listens, to have the emotional support of friends, and to be able to cope with feelings of dependence. Physical needs of the patients included; needing help with getting dressed, and both patients and caregivers wanted extra rest. Regarding their informational needs, people wanted clear, detailed facts about the patient's condition in a language the patient understands. Spiritual needs reflected the need for the opportunity to speak with a spiritual counsellor and the

need to believe in the hereafter. Legal or financial needs included how to pay doctor bills, help with legal matters and filing insurance forms. Household needs were the need for help around the house, and cooking. The need for respite, i.e. needing a break from caring for the patient, was found to be an additional category for the caregiver.

Wingate and Lackey's (1989) findings were supported by Hileman and Lackey's (1990) descriptive study which examined the needs of 15 cancer patients at home and their caregivers. The length of time since the diagnosis of cancer ranged from 2 to 30 months. The patients had experienced at least one of the following treatments: surgery, radiotherapy or chemotherapy. Patients and caregivers were asked to write down their own needs as patients or caregivers. Participants were not prompted beforehand. Psychological needs comprised the greatest number of needs of both patients and caregivers, followed by physical, informational and household needs. Psychological needs included anything that preserved, supported, and/or developed their relationships with others. Physical needs were described as anything that continued, preserved, maintained, or retained each individual's body functions. Informational needs included, knowledge about the disease process, and dietary requirements. Household needs were described as help with housework and cooking.

Patients with advanced cancer receiving palliative care at home.

When the disease process advances to the point where a terminal diagnosis is made, the cancer patient may continue to remain at home. Frequently at this stage, curative treatment is no longer an option, and palliative care is offered to meet the needs of the terminally ill cancer patient at home. Although psychological and physical needs of this patient population are consistent with the findings of Wingate and Lackey (1989) and Hileman and Lackey (1990), different needs have also been described.

Grobe, Ahmann and Ilstrup (1982) interviewed 30 terminally ill cancer patients at home. All patients were receiving palliative care. In response to a structured interview, patients were asked to identify their needs and their knowledge of resources available in the community to meet those needs. Findings of this study were grouped into service needs, symptom management needs and care preferences. Service needs identified by the patients, comprised the need for medical/nursing care in the home, home care equipment, transportation and assistance with personal care. Patients also described the need for recreation and emotional support. Patients depicted symptom management needs as including the need for better management of constipation, pain, vomiting, incontinence (both bowel and bladder), sleep disturbances, dyspnoea and lack of appetite. Care preferences described the desire of this patient population to be looked after, and to die

at home, rather than in an institution. In-patient hospice units were not an optional choice in this study setting in 1982.

The need for home care equipment and the wish to be cared for, and to die at home, expressed by the terminally ill cancer patients in Grobe et al's (1982) study was not evident in previous studies (Hileman & Lackey, 1990; Wingate & Lackey, 1939). These results may be explained by the advanced nature of this patient population's disease and the different data collection methods used. While Grobe et al. used a structured interview guide, Wingate and Lackey used open-ended questionnaires, and Hileman and Lackey elicited patients' needs with one open question.

A differing perspective of terminally ill patients needs was described by Arblaster, Brooks, Hudson and Petty (1990) in exploring what nursing behaviours 40 terminally ill patients, at home, desired. All patients were in the palliative stage of their disease. From a predetermined list of items, patients ranked, in order of priority, their attitudes and judgements of nursing behaviours, and in doing so, they also identified their individual needs. Their needs included, the need to remain at home as long as possible, to retain dignity and respect, to be included in decisions and discussions about care, to maintain a sense of humour and stay alert as long as possible, and to be treated as a person, not a patient.

For the terminally ill cancer patient, the need to retain dignity and respect, the need to be treated as a

person, not a patient, and the need to maintain a sense of humour reflect the differences between Arblaster et al's (1990) study and previous findings (Grobe et al, 1982; Hileman & Lackey, 1990; Wingate & Lackey, 1989).

And although both Arblaster et al. (1990) and Grobe et al. (1982) found that terminally ill cancer patients needed to remain at home for as long as they were able, differences in the needs between study groups was evident. Whereas the need for better management of physical symptoms was described by the patients in Grobe et al's study, this need was not raised in Arblaster et al's study. Unfortunately, neither studies provided adequate demographic (i.e. diagnosis) information about the participants which might have explained the differences in the symptom management needs of these two patient populations.

The varying results between studies might also be due to different data collection methods. Grobe et al. (1982) used a structured interview guide, while Arblaster et al. (1990) elicited patient needs using a predetermined list of items which primarily sought to describe nursing behaviours acceptable to terminally ill patients. Further explanation for the lack of needs relating to physical symptom control in Arblaster et al's study may reflect the advances in the management of physical symptoms in terminal illness (Amenta & Bohnet, 1986; Amesbury & Dunphy, 1989; Hogan, 1990; Saunders & Regnard, 1989; Twycross & Lack, 1986; Watson, Rhodes & Germino, 1987;) during this eight year period. No other studies were

found which considered the needs of terminally ill cancer patients at home.

Patients with advanced cancer admitted to an in-patient hospice for palliative care.

There is a paucity of information surrounding the needs of terminally ill cancer patients in an in-patient hospice. Only two studies were found which described the concerns of this patient population. These two studies focused on concerns, not needs and although they provide insight into the terminally ill cancer patient's worries, concerns are not easily translated into needs. For example, a patient may voice concern about loneliness, whereas his need may be to have his family or someone else to talk freely with or, to have his pet with him (see Definition of Terms).

Ellerton and Down-Wamboldt (1987), using a descriptive approach, interviewed 13 terminally ill cancer patients soon after admission to an in-patient hospice. Patients were asked to respond to a structured interview which measured the degree of loneliness, anxiety, depression, fear of pain, and perceived degree of feeling understood. Anecdotal information provided by the patients was also included. Loneliness and depression were found to be major concerns, while anxiety and fear of pain were reported to be minor concerns. Patients' assessments of feeling understood were varied. Their "responses ranged from 'They understand cancer and what it does to people' through 'The staff are very helpful' to 'They understand

how I feel, but only in physical terms'" (Ellerton & Down-Wamboldt, 1987, p. 20). The study found that almost half of the patients identified a nurse as the person, compared to all other caregivers, who understood them the best.

Using an ethnographic approach, Lev (1991) interviewed 10 terminally ill cancer patients in an in-patient hospice unit, and their families, about their concerns. Patients and families identified health, communication, existential, environmental, job, and psychosocial concerns. Areas of health concerns centred on treatment, prognosis, and fear of dying. Patients expressed concern about the lack of information offered to them about their disease and treatment from health professionals, and reported difficulties in this area of communication. Existential concerns included questioning the meaning of their lives, or the lack thereof. Environmental concerns related to the worry of being discharged to a nursing home or home as compared to being in a hospice setting. Some patients expressed concern over their loss of role as their jobs had been critical to their self-esteem and a source of satisfaction. Psychosocial concerns voiced by the patients included support or lack of support and mixed emotional responses; feelings of guilt, anger and depression, fear of dying, a sense of hope and hopelessness, decreased self esteem and the worry of having unfinished business.

Both Lev (1991) and Ellerton and Down-Wamboldt (1987) found that patients were concerned with difficulties in communicating openly with carers and with feelings of

depression. However, differences in concerns between study groups were also apparent. While anxiety and fear of pain were found to be minor concerns for the participants in the Ellerton and Down-Wamboldt study, these concerns were not voiced by participants in Lev's study.

The different results between studies may be due to the variation in data collection methods. Ellerton and Down-Wamboldt (1987), combined a structured interview with anecdotal information from the patients, whereas Lev (1991), used a semi-structured interview guide based on questions devised by a group of oncology nurses whose views may not be representative of what patients think (Lilley, 1987).

This study attempted to overcome some of these difficulties by eliciting patients' needs using a semi-structured interview technique. Question items were based on a comprehensive list which evolved from nursing research on patients' needs. As well as this, patients were also given an opportunity to discuss their individual needs, thereby providing a comprehensive account of patient's needs.

Summary

The literature review reveals that patients with advanced cancer living at home have many needs throughout the disease process. These include the need for symptom control, honest information about disease progression and treatment, open communication, support and tenderness,

respect, autonomy, and assistance with activities of daily living and financial affairs. To date none of the studies have specifically addressed the needs of the hospice in-patient. The literature reflects a lack of knowledge about the needs of terminally ill cancer patients in an in-patient hospice, and more specifically, an Australian in-patient hospice. Nearly all the studies reported thus far have been set in North America or England and it is not clear that the issues discussed there will be similar here. The needs of terminally ill cancer patients need to be described in order to provide individualised and comprehensive nursing care.

Chapter 3

Conceptual Model

The conceptual model chosen for this study is Henderson's (1964) concept of nursing. This model identifies 14 fundamental needs that are common to all human beings: breathing, eating and drinking, elimination, movement and posture, sleep, suitable dress, control of body temperature, clean body, avoiding dangers, communication, free worship, meaningful activity, recreation, learning and discovery.

These 14 fundamental needs can be grouped into physiological, psychological, sociological, and spiritual components. Physiological needs encompass breathing, eating and drinking, eliminating body waste, movement and posture, sleep and rest, suitable dress, controlling body temperature, a clean body, and avoiding dangers. Psychological needs are described as the need for communication, learning and discovery. Sociological needs comprise meaningful activity and recreation, while spiritual need is expressed in the concept of free worship (Furukawa & Howe, 1990). It is recognised that these needs will have different meanings according to the individual's age, personal and social habits, and health state (Adam, 1986; Henderson, 1960).

According to Henderson, the unique function of the nurse is to understand and address the fundamental needs of each individual in order to assist in meeting her/his needs. This general notion of needs is in keeping with

current nursing perspectives about patient care needs and nursing care (Bower, 1977; Brunner & Suddarth, 1988; Potter & Perry, 1989; Snowball & Green, 1987).

The modern hospice concept is a philosophy of care aimed at meeting the individual needs of the terminally ill patient. In fact, the needs of patients (and their families) are of paramount importance in hospice care (Campbell, 1986).

Henderson's (1964) model was chosen for the study because it identifies basic human needs, it considers the concept of the individual as having physiological, psychological, sociological and spiritual components (Henderson, 1960) and it fits with the philosophy of hospice care (Fig. 1). In addition, the interview guide, based on this model, does not constrain patient's responses. While need items are grouped under specific headings, the interview guide does not preclude patients from raising their individual needs and concerns.

Figure 1. Conceptual model of care for terminally ill-cancer patients in an in-patient hospice.

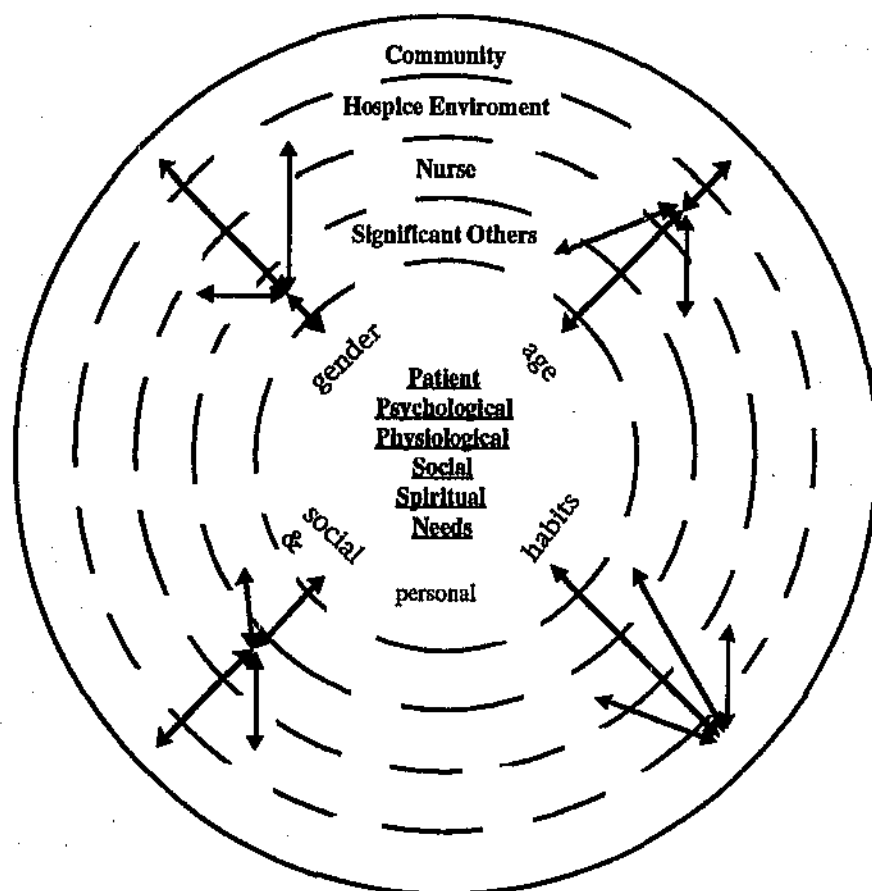


Figure 1 - Explanation:

The terminally ill cancer patient is the focus of care and so is represented by the "inner circle". Significant others include the patient's family, friends and/or partner. The nurse is situated between the patient/significant others and the hospice environment/community). The hospice environment consists of the physical setting, other members of the interdisciplinary team and the hospice philosophy of care. The community includes social attitudes to, and financial support of, terminally ill cancer patients.

The "broken line" circles signify that this is an open systems model. The arrows represent the continuous interactions between patients, significant others, nurses, hospice environment and the community.

The patient's individual needs are met when nurses understand the continuous reactions between patients, significant others, the hospice environment and the community and provide care based on these reactions.

Chapter 4

Methodology

Design

A descriptive design was used for this study in order to gain information about the needs of terminally ill cancer patients in an in-patient hospice unit. According to Burns and Grove (1987), the purpose of descriptive research is to gather information on situations as they occur naturally. This type of research design aids development of theory, and is particularly useful when nurses are developing a knowledge base. A descriptive approach also reveals the relationship between behaviours, individuals or events as they occur, and thus a better understanding of the relationship between variables (Barnard, 1981).

Sample Selection

A convenience sample of six patients were interviewed. This number was chosen to be large enough to determine patients' views, and it was the maximum number that could be obtained in the time available to complete the study. To ensure representativeness of the sample, only patients who fulfilled the following selection criteria were interviewed. These criteria included patients: 1) with a diagnosis of terminal cancer with an expected survival of six months or less; 2) eighteen years of age or older; 3) able to understand and speak English and 4) orientated to person, place, and time.

Patients who were judged by the "key"¹/primary nurse too ill, either physically or mentally, to be interviewed were excluded. Of the 13 patients who fulfilled the selection criteria and were approached by the nurse for interview, eight agreed to participate. Four of the five patients who did not want to be part of the study said they were not well enough. The fifth patient originally agreed to be in the study then changed her mind after reading the consent form. She stated that she did not have cancer (even though this was her diagnosis) and therefore would not be able to answer any questions! Because of this patient's response, the words "advanced cancer" were omitted from the study title on the consent form for subsequent patients. Thus the last four participants were given the revised form which read: The needs of patients in an in-patient hospice.

Of the eight patients who agreed to be interviewed, one patient's condition deteriorated in the time between making the interview appointment and the day of the interview. Another patient did not fit the selection criteria. It was later discovered that she had been an in-patient at the unit for three months and had an expected survival of more than six months.

Setting

The study took place in a 26 bed in-patient unit located in Perth, W.A. This is a free standing, purpose built unit. This hospice is a non-profit organisation

¹ Key Nurse: Nurse responsible for co-ordinating all patient care services at the unit.

which admits patients with private or public health insurance.

Negotiating Access

Initially, permission to undertake this study was sought from the Higher Degrees Committee at Edith Cowan University. Once granted, permission was sought from the Director of the hospice to conduct the study and access the medical records.

Informed consent was obtained from patients following admission to the unit (Appendix C). As there was no intervention planned and interviews were undertaken at a time convenient to the patient, there were minimal risks to the participants.

Confidentiality was maintained as only the researcher and thesis supervisors had access to the recorded audio tapes and transcribed material. Each interview was coded with an identification number. During analysis the recorded audio tapes and computer discs were kept secure in a locked safe. The audio tapes were erased and the computer disc files were deleted on completion of the study. The transcripts will be kept for five years and then shredded.

Development of the Instrument

A semi-structured interview, based on Henderson's (1964) concept of nursing, was used to elicit information about the patient's needs (Appendix B). This type of interview was chosen because it is focused and participant time is carefully used (Patton, 1990). The researcher developed open-ended questions based on each of

Henderson's (1964) 14 basic needs. The opening question asked of each participant, was "What is important for you in the hospice?" As this was a semi-structured interview guide, this opening question was intended to act as a 'grand tour', with the general question and prompts for each need item characterising the 'mini tour' (Spradley, 1980). The general questions and prompts were designed to elicit the patient's individual needs, in their own words and allow free response. For example, the general question about sleeping at night was "How have you been sleeping at the hospice?" The prompts were "What helps?" "Does music help?" "Do you need company?" "Is it quiet here at night?" "Do you need medication?" "Does a sense of security help?" "Do you need to sleep all through the night?" "Is there anything else that you need in relation to your sleeping?"

Patient needs were ascertained on each need item by reading aloud each question in turn. To help ensure that all individual needs of each patient were ascertained, at the end of each set of prompts, patients were asked if there was anything more that was important to them which had not been discussed. This was also asked at the completion of each interview.

The ordering of the questions was designed to start with the least sensitive areas of need. These were felt to be questions about the patient's environment, appetite and sleep. The researcher's intention was, that by broaching the less sensitive topics first, this would enhance the early development of rapport and trust,

subsequently enabling the patient to communicate openly about more sensitive needs.

The interview guide was pre-tested with three terminally ill cancer patients at the hospice to establish clarity of language, acceptability and relevance of the questions to the patients, and the overall response to the approach used by the researcher. Three more questions were added to the interview guide after the first pilot test. These were "Do you need a single room?" , "Have you had a job?" and " Do you miss not having a job ? The third pilot interview was included in the data as there were no changes made to the interview guide following the interview.

Questions were asked in a relaxed fashion in a language familiar to the patients. For example, the patient need with regard to dressing had a general opening question "How do you manage getting dressed?" This was followed up by "Do you need help with dressing?", "What kind of help do you need?" , and "Who helps you?"

The interviews were tape recorded and varied in length from 45 to 60 minutes. Each interview was transcribed verbatim. Following each interview notes were made on the ease of interaction, non verbal communication, and the subjective impressions of the interviewer. Notes were also made at the end of each interview on any interesting comments voiced by the participants about individual needs and were followed up in subsequent interviews. Tapes were replayed and verbal passages were matched with any

significant shift in non-verbal communication including posture.

Data Collection Procedure

Data was collected over a one month period in December, 1992. The researcher was employed as a nurse at the hospice and well known to the staff. The research study was received with interest and co-operation from all members of the interdisciplinary team. Before commencing data collection, the researcher encouraged interested staff to read the study proposal. In addition, a meeting was arranged to explain the research process and purpose. The researcher also informally discussed aspects of the research when asked to by interested colleagues at the unit.

Initial contact of potential participants was made by the key nurse at the hospice three to six days after they were admitted to the unit. The researcher chose this time period to give the patient time to settle in to the unit and achieve symptom control, as needed. The key nurse described the purpose of the study along the lines of wanting to improve the patient's nursing care at the hospice. If patients said they would be interested in being part of the study they were then contacted by the researcher. The researcher introduced herself to each participant explaining that she was a nurse and described her interest in contributing to patient care. An explanation of the study, including potential benefits, (i.e. improving the quality of nursing care), and an

estimated length of time of involvement for the study was also given, and informed consent was obtained (Appendix C). A time was then arranged with the patient for the research interview. Each participant was interviewed once. Three participants chose to be interviewed immediately after reading and signing the consent form. The other three chose to be interviewed two to three days after consenting to be involved in the study.

The interviews took place in the patient's private room, with only the researcher and the patient present. To ensure minimal interruptions, the patients' telephone was disconnected during the interview period with the patient's permission. The patients were told that the questions did not necessarily refer to activities that had been done for her/him. It was also explained that the patient may respond in terms of the importance that s(he) attached to each item in terms of her /his needs. It was emphasised that different patients have different views and that it was important to find out each patient's views. Finally, patients were reassured that they were perfectly free not to answer any question.

Although all of the participants were enthusiastic in their desire to contribute to the study, "I'll do anything to help other people in the same situation as me", the researcher found that the early interviews did not go as smoothly as the ones that followed. Two patients stated that they had nothing to complain about regarding their care and did not think that they could answer any questions as they knew nothing about nursing. At this

point, the researcher focused the interview back to the patient's needs. This was achieved by gently saying that the researcher was more interested in wanting to know about the patient, and not about their care. Later interviews flowed more freely. The researcher felt more comfortable with the interview questions and experienced a heightened sensitivity to the participants' non-verbal responses. Only one patient chose to be interviewed sitting up in a comfortable chair facing the researcher. The other five participants preferred to lie in bed in a semi upright position. Each patient was asked if they were comfortable prior to starting the interview. All participants were observed to have their call bell either in their hand or close by under their pillow throughout the interview.

The researcher believed that it was important to note the changes in the tone of voice and significant pauses when the patients discussed their needs, as well as the ease of interaction and non-verbal responses, because all these responses may have indicated an important or highly emotional area of need. As Abercrombie (1968) suggests "We speak with our voice but communicate with our whole bodies" (p. 56).

Acceptability of the Questionnaire/Interview Format

For all participants, once the interview got underway, all were willing to speak to the interviewer. The tape recorder did not seem to impede the interview. None of the participants mentioned its presence and judging by the spontaneity and candour of disclosure, further evidence

for the acceptability of the format was provided. Some patients said how helpful it was to be interviewed " It helps to talk to you about how I feel", "It will do me good" and "It's been lovely, you know to talk to you."

And during the data collection, the researcher was approached by medical staff to interview a patient because of the apparently beneficial effect of the interview guide on an earlier participant. It had been noted that, since the interview, this person had started going to Occupational Therapy and was talking more with other patients and staff.

Data Analysis

Descriptive statistics were used to analyse the demographic data.

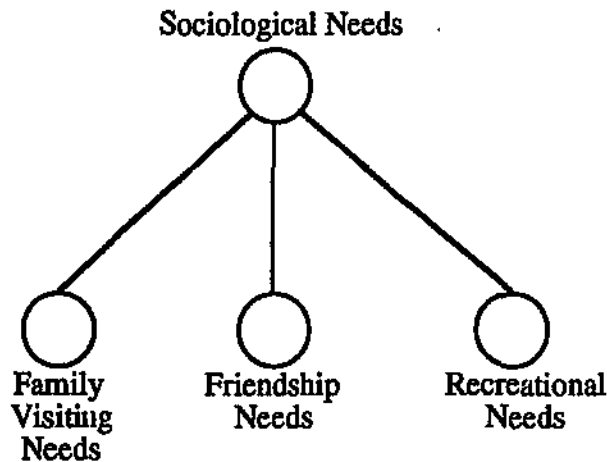
Category Development

At completion of each interview, the tape was replayed by the researcher and notes were made about the tone of responses and any changes in body posture. Following transcription of each interview, the tapes were replayed and the accuracy of transcription was checked.

As the needs were identified they were placed in the four categories described by Furukawa and Howe (1990). These were physiological, psychological, social and spiritual categories of need. Initially, the categories of need were kept as broad as possible without overlapping. As more information was gathered from the transcripts, the major categories were sorted into sub-

categories (Figure 2). For example, sociological needs were sorted into family, friend and recreational needs.

Figure 2. Sociological needs sorted into family, friend and recreational needs.



Several copies of the data were made as one segment often fitted into two or more categories. When this occurred, a new category was formed from the overlapping segment in order to focus the data. The category of environmental need was formed from overlapping data from the physiological, psychological, and social categories. Also the transcripts were examined for any recurring themes surrounding patients' needs which may or may not have been highlighted elsewhere. Segments of the data which did not fit into any existing categories were placed into a category of their own, for example, financial needs.

To verify that the categories made sense and that the data had been appropriately arranged in the category system, two researchers (both qualified registered nurses)

were given a list of all need statements and asked, independently, to sort them into what they considered were appropriate need categories. To see how well the researchers agreed with one another regarding the categorisation of need items, the formula of :-

No. of agreements

No. of possible agreements

was used.

The percentage of agreement in matching all need statements to categories, among the researchers was 85%. When the independent researchers could not agree on the categorisation of need items a consensus agreement was sought until accord was reached.

Management of the data

Each interview was coded with the participant's number. Each page of the interview was colour coded in the left margin. One coloured stripe was used for each participant. As the data was analysed, the significant passages were cut from the interview, glued onto a full size sheet of paper and filed in a folder for each individual category. This method allowed the researcher to rapidly identify all data and trace pieces coded for analysis back to their original source.

In addition, two copies of each need statement were made, cut out and glued onto a separate card for each statement. The two independent nurse researchers were each given a copy of the need statements and category

definitions and invited to fit the need statements to the categories.

Chapter 5

Findings and Discussion

Characteristics of the Sample

While only one patient had a caregiver living at home, all of the participants had lived at home prior to admission. Three patients had experienced a brief admission (2-3 weeks) in an acute care hospital before transferring to the hospice. Reason for admission to the unit included symptom control(3), respite(2) and terminal care(1). Diagnoses were gastric carcinoma, lung cancer, carcinoid syndrome, cervical cancer, multiple myeloma, and pancreatic carcinoma. Marital status and cultural origin of the participants was varied, as were other sample characteristics shown below in Table 1.

Table 1. Selected characteristics of the sample (n=6).

<u>Gender</u>		<u>Age in years</u>	
M	1	Mean	60
F	5	Range	38-79
<u>Marital status</u>		<u>Cultural origin</u>	
Mar.	1	Australian	3
Wid.	3	English	1
Div.	1	Irish	1
Sep.	1	Yugoslav	1
<u>Health Insurance</u>		<u>Length of diagnosis</u>	
Private	2	Mean	24 months
Pension	4	Range	1 month - 8 years
<u>Time since admission (days)</u>			
Mean		8	
Range		3 -14	

Categories of Need

Initially, need items were grouped under four categories based on Henderson's (1964) 14 basic needs. These were physiological, psychological, sociological and spiritual categories. On further analysis, some need items did not seem to fit either of these four categories. Eventually, seven need categories were developed. As stated previously, to help verify these categories, two nurses were asked to independently categorise individual need items. The definitions of the seven major categories of need are described in Table 2.

Table 2. Definition of Seven Need Categories based on Henderson's (1964) 14 Fundamental Needs.

Categories	Definitions
1. Physiological needs	A need for anything that enables the body to function at a level of comfort unique to each individual.
2. Psychological needs	A need for anything that stimulates the intellect and assists and supports the expression of feelings.
3. Sociological needs	A need for anything that maintains self esteem, allows the individual to feel useful within their community and enjoy periods of recreation.
4. Spiritual needs	A need for anything that sustains, supports and preserves the individual philosophy of each person.
5. Informational needs	A need for anything that provides insight and understanding of the person's present life situation.
6. Financial needs	A need for anything relating to financial concerns.
7. Environmental needs	A need for anything that provides shelter, a place from which to retreat and advance, with access to the outside world.

Physiological needs encompass sleep and rest, physical symptom control and assistance in maintaining bodily function. Psychological needs relate to patients' care and their ability to communicate their emotions. Sociological needs include the need to feel productive, independent and the need to fulfil a designated purpose in life. Keeping in touch with family and friends and maintaining the usual role within the family is needed to preserve the individual's sense of self. Spiritual needs are described as the need to believe in hope for cure and the need for a philosophy which sustains the patient throughout the dying process. The informational needs are separated into the need to know how the disease is progressing, the need for open communication about the length of time left, and the need to know how each individual will die. Financial needs involve the need to have trust in family to manage the bills and the need to know the current extent of the individual's financial obligations in relation to health care. Environmental needs include the need for the means to access nursing staff (call bell within reach) and the "outside world" (telephone), a private room, freedom to rearrange/bring in their own furniture and peaceful surroundings.

Of particular note are three overriding needs that patients had. Firstly, all patients needed to feel safe. Secondly, all patients needed to maintain family contact. And thirdly, all patients needed help to reduce the impact of visitors.

Physiological Needs

All patients had similar physiological needs. Needs common to all patients are shown in Table 3.

Table 3. Physiological needs of terminally ill cancer patients

<u>Physiological needs</u>
Need to sleep at night
Need to rest in the day
Need to achieve pain control
Need to control nausea/vomiting
<u>Need to maintain body function</u>

All patients expressed the need to sleep at night and required medication to help them achieve this. Participants spoke of their need and difficulties of getting to sleep and of the quality of sleep they experienced. One patient stated "One night I just couldn't stop thinking and worrying - my mind wouldn't relax", and another "Of course, since I've been sick they've not been dreams, they've been nightmares." Yet another said "I toss and turn for as long as I can then I ring and ask for a sleeping tablet". Patients also expressed the need to have someone to talk to when their sleep was disturbed "It helps to talk when my mind is busy." and "It's lovely to talk...it's very consoling." These varying reasons for sleep disturbances indicate that nurses need to be aware of what is going on for patients and be able to provide individual support by listening, or

simply being with the patient, as well as administering medication.

The need for frequent rests during the day was common to all participants, particularly after their bath/shower and visitors. Several patients were tired all the time "Today I'm tired, really weary", "Being tired all the time is a difficulty", and " I feel so sleepy and tired all the time that it's really hard to get motivated to do anything". These findings are consistent with the needs expressed by cancer patients across all stages of the disease (Blank, Clark, Longman & Attwood, 1989; Hileman & Lackey, 1990; Wingate & Lackey, 1989; St. Pierre, Kasper & Lyndsey, 1992). Although it is not clear if it is in fact the disease process which is responsible for this common tiredness, opioid medication may also contribute to the need for rest.

All patients needed analgesia for pain control. Two of the patients were on subcutaneous Morphine infusion pumps and the other four were taking regular oral Morphine. Adjuvant medication was also being taken by all patients for pain which was unresponsive to opioids. However, pain was not described as an overwhelming concern "I could do without the pain" and "It's just the pain in my back when I'm horizontal" and "I get pain now and again...but the last two days I've had no pain at all". So while these patients had pain, it was not intolerable because the pain had been mainly controlled to meet the individual need of each patient. This need for individual, physical pain control, is consistent with clinical evidence (Twycross &

Lack, 1990) and other study findings (Arblaster et al, 1990; Lack & Buckingham, 1978). At the same time, it is important for nurses to be aware of the psychological (Amenta & Bohnet, 1986; Parry, 1987) and spiritual (Swift, 1982) components of pain, while alleviating the physical symptoms. Amenta and Bonnet (1986) relate psychological pain to other worries and concerns (i.e. fear of the extent of the disease and/or the inability to communicate these fears). An example of psychological pain was given by one of the participants when she talked about the breakdown of her marriage "He doesn't see me now...it's very hard. Because even though I had cancer, for three years he used to tell me that he loved me...then I find out he's having this affair ...I knew he was lying to me". While Swift (1982) identifies spiritual pain as the feeling of abandonment by God. Based on this definition, spiritual pain was not evident among the participants in this study. However, this is a very narrow definition and it does not mean that patients did not have concerns for the hereafter (see Spiritual needs, page 42).

All patients' records showed that nausea and /or vomiting had been a problem for them on admission to the unit. Thus the need for anti-emetic medication was common to all participants. This need to control nausea and /or vomiting associated with terminal cancer is consistent with the findings of Grobe et al (1982) and clinical experience (Grant, 1987; Hogan, 1990; Twycross and Lack, 1986; Wood, 1990).

The most pressing need for these patients related to the maintenance of body function was the need for regular aperients. Comments like "I've been having constipation", "I have to take a lot of opening medicine", "They give me Coloxyl for my bowels", "I can't afford to get any more constipated" emphasise this need. Constipation is a common side effect of opioid medication. Here, the implications for nurses is to frequently assess and assist the patient to maintain this body function.

Four of the participants needed help with many of their activities of daily living i.e. washing, dressing, sitting up for meals and walking to the toilet. Statements such as "Mainly because I feel nervous, I'm always afraid that I might faint, "I just like to have that little bit of support" and "I've got no balance, I want to go back all the time" reflect their need.

Psychological Needs

For the terminally-ill cancer patient, psychological needs described are outlined in Table 4. For the purpose of this study, psychological needs were grouped under two headings, care needs and communication needs. While it was possible to isolate specific concerns and needs relating to care, all of the patients also voiced general needs to express emotions.

Table 4. Psychological needs of terminally ill cancer patients.

<u>Care needs</u>
Need a sense of belonging
Need to be cared for by informed nurses
Need individual care
<u>Need to feel safe</u>
<u>Communication needs</u>
Need to express emotions, generally and specifically, in relation to their dying and death

Care needs were described differently by participants. Some patients defined care as giving a sense of belonging and safety to the individual "They (nurses) make you feel very much that you're part of them and part of the actual situation, and they are very friendly...you feel that you're part of the whole institution". This patient needed to belong to feel confidently cared for. Whereas another patient needed nurses to be well informed and professional in their delivery of care "To feel assured that we are in good hands...We need to be in the hands of people who know what they're doing and care about what they're doing." Another patient defined her need as being one of individualised care "The individual care...the devotion and attention...I feel safe here, oh yes, very safe".

These findings are similar to the needs reported by Arblaster et al.(1990) for terminally ill patients at home. Patients' needs for safety, belonging and well informed, professional and individualised care indicate

that nurses who care for these people require time, education and the ability to be competent, confident and friendly at work.

Patients need to communicate how they feel. This is clearly illustrated by a young mother who voiced her concern for her child "That she (daughter) is going to miss me and how is she feeling now about Mum being in hospital...how is she going to feel, how is it going to affect her schoolwork and the rest of her life - being 8 years old when her mother dies?" Discussions with other family members, the patient and perhaps a social worker might go a little way toward meeting the concerns arising from such a need.

Three other patients also needed to discuss their feelings about dying with their families and exhibited problems in this area " Yes...we (wife) talk together. It's very difficult to talk about (fear of dying), very difficult to talk about those things" and "My daughter, we discuss *things*" and "I talk to my family...they know I'm going to die and they're quite good about it". This need for some patients to talk about their feelings about dying suggests that successful care of these patients involves sensitive nursing skills which include being able to communicate with empathy and sensitivity. Similar nursing requirements are also mentioned in Degner, Gow and Thompson's (1991) study when they described critical nursing behaviours in care for the dying. To further help patients express their needs, nurses need to be aware of moments when, by providing opportunity and privacy,

patients' feelings may be more easily voiced. Nurses also need to be aware that these opportunistic moments can occur anytime, day or night. Anecdotal evidence suggests that patients will sometimes voice their concerns to "the most junior nurse who is helping them bath" (Cassidy, Burns & Smeardon, 1988).

But it is also important to realise that some patients may not want to talk about their impending death, or may prefer to talk to someone other than the nurse, as evidenced by the following patient responses: Two patients closed their eyes when asked about any fears they may have, and one patient changed the subject saying she felt "secure". Another patient felt she had "come to the end of the road" and needed to talk with her doctor. This suggests that perhaps it is better to offer patients the opportunity to express their needs and help them to do so only when they are ready (Taylor, 1986), or find out who they would prefer to talk to and help facilitate the arrangements.

Sociological Needs

The sociological needs (Table 5) expressed by the participants in this study reflect the need to maintain family contact, the need for sensitive friendship, and the need to feel worthwhile and preserve the individual's sense of self throughout the experience of terminal cancer.

Table 5. Sociological needs of terminally ill cancer patients.

<u>Sociological needs</u>
Need for self concept / social status
Need for independence
Need to fulfil a purpose in life
Need for family contact
<u>Need for sensitive friendship</u>

Individual needs described by patients included the need to be productive in and contribute to the hospice unit "I also think there's a need for a library here and I think there's things that people like myself can do about that...I'm quite sure that there's people who could do with them (books)". The need to talk about the loss of their role or lifestyle is also evident "I don't feel bitter about it (job loss)... it's just the way things are. He doesn't deserve to have the job. I created the job, created the whole situation of the job and I can't get near it now" and "Well, I wish I hadn't left (job). I left through stubbornness, really, because my husband, after 30 years, decided to have an affair with a young girl...that's what started off all my sickness really".

Another patient described her need for independence "I have a need to be very independent and that's a problem for me, not being able to drive my car and go out".

Maintaining contact with family and receiving support through this contact was important to all of the participants. Patients clearly defined their need for

family visitors in the following responses. "I'm very close to Nicky's girls (grand-daughters)...we have had lots of fun together"; "I've got my kids here and they're very good" and "I'm seeing quite a bit of my son but when he goes back to work, well it won't be quite so often...but he'll fit it in, I know he will, but he's got his work, it comes before anything". Patients also needed to know that they would receive regular family visits which they could anticipate and enjoy "My daughters...someone pops in every day...it's a pleasure." Perhaps the regular family visits, while providing enjoyment for the patient, also contribute to the individual's sense of self and the continuation of life.

Several patients reflected the need to have a limited number of family visitors at any one time, and found it difficult to deny them, as evidenced by "I don't like to turn them away... actually, what I would like is for them to come and only stay for a short time and then go, instead of staying too long. But I don't want to say that to them either because then another day I might want them to stay longer and they won't" and "On Monday night I had visitors and I didn't really want them" and "I've got two or three (visitors) coming this afternoon. Sometimes you get an overload". Nurses need to be sensitive to patient and family visiting needs. If the patient is part of a large family, the nurse could assist the patient and family to arrange a roster of visitors which might go toward improving the quality of visiting time for all concerned.

Clinical experience of the researcher has shown that some terminally ill cancer patients are admitted for in-patient care because they have no family to care for them at home. Hospice nurses need to be aware of the lack of family support and be able to offer the patient friendship and alternative enjoyments, i.e. drive to the beach, picnics, cinema, depending on the individual patient's need.

Responses to the need for visitors other than family were varied. One patient actively avoided visits from friends at times and thus maintained his need for privacy "Sometimes I even go out into the garden (after breakfast) to get out of the way...so they can't find me. If they want me, then it's too bad". This man also believed "It's important for people in situations such as I am to be in a single room".

Other patients described friends who visited as tiring or over solicitous: "I get very tired very quickly with visitors...about an hour is all I can stand" and "Sometimes I don't want them at all, and at other times I do...depending on who it is...you get some who come in and they want to do too much for you...they want to touch you and rub your hand, but you don't want that. But you can't very well say to them...".

All patients reflected the need for visitors to be sensitive to their deteriorating health and limit the length of visiting times "I have too many...talking too long. They don't realise that"; "I don't want to stop

them visiting because I like seeing them...they come from so far away...they usually stay a little bit too long".

Nurses also need to be sensitive to visitors staying too long and discuss this with the patient in order to help the patient plan for maximum enjoyment and minimum fatigue. This may also help to empower the patient to maintain some control over her/his quality of life. This need to help the patients regulate their visitors is not consistent with the study by Arblaster et al, (1990), in which terminally ill patients at home indicated a desire to control their own visitors without nursing input. It is possible that disease progression and physical tiredness (see physiological needs) might contribute to the need for nurses to help terminally-ill patients cope with their visitors. The very fact that the patients are terminally-ill may also contribute to the *over solicitous behaviour* of some visitors.

In the study setting, one day per week (Wednesday) is designated as a "quiet day", where family and friends are encouraged not to visit thereby allowing respite for both patients and visitors. It is important to note however, that if a patient is dying, or the family need to be with a patient, access is never denied. Despite this "quiet day", and because of the overriding need for sensitive visiting behaviours expressed by the patients in the study, there may be a need to look at other ways to reduce the impact of visitors while maintaining the individual contact necessary to each patient. Perhaps, nurses could act as intermediaries between the patient and

family/friends, reflecting sensitivity to each individual's need. The nurse could also answer any queries that patients, family and friends may have so that open dialogue is facilitated. In this way, the length of visiting time and the number of visitors received each day could be discussed and mutually agreed upon, thereby enabling visitors to continue to contribute to the patient's quality of remaining life.

Spiritual Needs

The spiritual category of need (Table 6) for terminally ill cancer patients describes the need for individual beliefs and the need for a belief that provides hope.

Table 6. Spiritual needs of terminally ill cancer patients.

<u>Spiritual needs</u>
Need for the hope for cure
Need for a sustaining philosophy
<u>Need for an individual philosophy</u>

Most patients stated that they had a faith and that it provided some comfort for them "Yes, I have a strong faith...it's had a few knocks, mind you" and "Religion is important to me" and "Oh yes, I do believe in faith, yes, we must have that". One patient described the need to "have a spiritual adviser when you want them and not when they want you". He also described his religion as

providing hope for cure "If there's a chance...of hoping". This supports Herth (1990) who suggests that hope is actively present in many terminally ill people. Other patients described their need for their own individual philosophies "You have your own religion, you know...and your own beliefs" and "No, I've got my own philosophies on life...I don't need any organised religion". These statements indicate that hospice nurses need to be aware of and sensitive to the individual philosophies of patients in order to assist them in meeting their needs. While some patients may exclude "organised religion" they may nevertheless have their own faith in the hereafter which sustains them throughout the dying process.

Informational Needs

Although some patients did not want to talk about their death (see page 37), they all wanted more information about the extent of their illness. Three patients expressed the need for open communication relating to how much time they had left, and two patients needed to know what they might experience when they were dying. Table 7 lists these informational needs.

Table 7. Informational needs of terminally ill cancer patients.

<u>Informational needs</u>
Need to know about disease progression
Need to know what time remains
Need to know how the individual will die

All patients expressed a need to know more about the progression of the disease "I would like to be told in layman's terms what's going on...I would like people in the medical profession, in all professions to be absolutely up front in everything they tell me", "I would like to know more...yes, it would be better to know more...if I knew more about what was happening I probably would understand", "I'd like to know how far my disease has progressed, what to expect in the next stages" and "I'd like to find out what's causing my symptoms and why I've been having these falls". These statements indicating that patients need clear information about disease progression, are consistent with other studies examining cancer patients needs throughout the disease continuum (Arblaster et al, 1990; Hileman and Lackey, 1990; Lev, 1991; Longman, Atwood, Sherman, Benedict and Shang, 1992; Wingate and Lackey, 1989). This patient need for information about the disease progression and not always the death may indicate that patients choose to remain in a state of "middle knowledge" (Hackett & Weisman, 1985). Thus patients might enjoy pleasurable

moments in their lives as long as no concrete information regarding their death is offered (Taylor, 1986).

Individual patients indicated that they needed to know how much time was left for them "Well, like anybody, I'd like to know how long I've got", "If I knew a bit more about what was happening...Two years ago I nursed a girl who was dying of cancer and they said she could last six to eight months and she died in a month...it would be better to know more" and "'Yes, I think you've got x number of weeks to live'...that's what I want to know". These patients also acknowledged that nurses may be unable to accurately respond to questions about the length of remaining life, and asked only that they be "open in everything they do - in absolutely clear language". The need for patients to be given honest information about all aspects of their life threatening illness is supported by Young-Brockopp's (1982) study. Young-Brockopp found that patients in the middle stage of a life threatening illness also needed honest answers to their questions and did not want to be protected from the truth.

Two patients, in discussing their fears, identified a need to know how they would die "I'm not scared of dying. They have assured me that in the end I won't be in pain. You know, because of my lungs...I won't be gasping for breath and all that, so that's eased my mind heaps" and "I've just spoken to him (doctor) and said to him 'I want to go and I want to go quickly' ". The responsibility for nurses, in this instance, is to be able to communicate with knowledge and sensitivity. This would not only allow

the patient to discuss her/his fears about death, but also provide the patient with the information s(he) seeks.

Financial Needs

The financial needs of terminally ill cancer patients, listed in Table 8, were influenced by family support, health insurance cover and communication.

Table 8. Financial needs of terminally ill cancer patients.

<u>Financial needs</u>
Need to trust
<u>Need for current information</u>

Most patients had handed over their financial commitments to a family member. However two patients spoke of the need to have someone in the family s(he) could trust to manage her/his affairs "I trust them...we've got trust in all our family" and "No, my daughter's handling that".

One patient described the concern he felt about staying at the hospice longer than originally planned "It (symptom control) could take any length of time...if they let you stay here till you die it could leave families with very large (financial) worries and these worries could be transmitted to the patient...I was concerned about how much time H.B.F.(private health insurance) actually gave patients in a situation like this". It is ironic that this patient was concerned because, for people with private health cover, whatever amount the health

insurance fund pays out is accepted by the hospice and no further payment is required. While it is likely that this patient had been given accurate information about payment when first admitted, patients sometimes need information repeated several times before they can comprehend it (Derdarian, 1986).

Financial concerns or needs were not voiced by three uninsured patients even though they could not be described in any sense as wealthy. The cost of care for uninsured patients is \$23.70/ day (+ Medicare rebate) at the hospice. However, for patients unable to meet this financial commitment, assistance is available from the Cancer Foundation, which will meet outstanding bills. A lack of overall financial need in this patient group is perhaps due to the commitment of the Cancer Foundation and the community to the support of the hospice unit.

Environmental Needs

Environmental needs described by these hospice in-patients are listed in Table 9. These needs are related to ways of keeping "in touch", while maintaining their privacy and individual surroundings.

Table 9. Environmental needs of terminally ill cancer patients.

<u>Environmental needs</u>
Need contact with nurses
Need contact with the outside world
Need privacy
Need freedom to create own habitat
<u>Need peaceful surroundings</u>

All of the patients said that the call bell was important to maintain contact "... we need that umbilical cord, really". All patients had their call bells either tucked under their pillows or in their hand, always within reach during the interview. The telephone was also described as their contact with the outside and this helped the patient maintain a sense of control "When I want to see them I'll let them know". Their beds were placed in the centre of the room allowing them to gaze out of the window into a garden, or through the door into the corridor. This bed placement is common to all rooms at the unit, however, the patients are free to rearrange their rooms to suit their individual needs. All the participants had their doors open, at the commencement of the interview, and curtains drawn back, which perhaps, also indicates a need to maintain contact with others, at least at arm's length. All patients had brought some belongings from their homes into their rooms. These included family photographs, favourite paintings, a foot stool, pillows and duvets. These possessions indicated

the patients' need to maintain their sense of "who they are" in relation to their surroundings. Most patients described the need for a single room and a peaceful environment. Rooms can be opened up to form double rooms, however none of the participants had requested to do so.

Overriding Needs

Three prevailing needs were expressed by all the terminally ill cancer patients in this study. Each patient discussed these needs at length and referred back to them during the course of the interview. The needs are listed in Table 10.

Table 10. Overriding needs of terminally ill cancer patients.

<u>Overriding needs</u>
Need to feel safe
Need to maintain family contact
<u>Need to reduce the impact of visitors</u>

Firstly, the need to feel safe, as evidenced by patients' comments "I feel safe here, oh yes, very safe" and "To feel assured that we are in good hands". Secondly, the need to maintain family contact as evidenced by comments such as "I'm very close to Nicky's girls", "I've got my kids here and they're very good" and "I'm seeing quite a bit of my son but when he goes back to work...he'll fit it in, I know he will". Thirdly, the need to reduce the impact of visitors as evidenced by

patients' comments which included "I don't like to turn them away...what I would like is for them to come and only stay for a short time", "On Monday night I had visitors and I didn't really want them" and "Sometimes you get an overload". Patients' behaviour also provided evidence of the need to minimise the impact of visitors "Sometimes I even go out into the garden to get out of the way...so they can't find me". The researcher also noted that these needs were expressed both forcefully and spontaneously by the patients.

It is perhaps not surprising that patients needed to feel safe and maintain contact with their families. However, there was a clear message from patients about the impact of visitors, which was at times, physically tiring and emotionally draining. Previous studies have not identified the possible negative effect of visitors on terminally ill cancer patients.

Conclusion

Based on the findings of this study, nurses need to be aware of seven need categories. As well as this, there were some needs common to all patients. These were the need: for sleep and rest; for symptom control; for individual care; for communication; for individual beliefs; for clear information about the disease process; to keep "in touch" both with nurses and the outside world; and to create their own environment. Of particular impact on the researcher were three overriding needs i.e. the need to feel safe, to maintain family contact and to

reduce the impact of visitors. Awareness of these needs may go some way toward providing a focus of care for hospice nurses.

Implications for Nursing Practice

For nurses to be effective, based on the findings of this study, nurses need a comprehensive knowledge of disease process and symptom control and the ability and desire to be competent, confident and friendly at work. Nurses need to be able to communicate with empathy and sensitivity, being alert for opportune moments which may occur at any time. The ability to communicate sensitively with patients may mean not openly discussing their imminent death. Nurses may need to wait for the patient to broach the subject in their own time (see "middle knowledge", page 45), and then offer the patient as much information as s(he) appears to need.

Some patients may like to contribute to the "life" of the hospice and nurses could help by finding out what they might like to do and assisting them. For example, planning and planting a small garden or starting an "in-house" library. In this way, nurses could nurture some of the positive quality of life attributes including usefulness and making others happy (Padilla, Ferrell, Grant & Rhiner, 1990).

The three overriding need areas suggest the following nursing interventions. To help patients feel safe nurses can, when the patient is admitted, allow enough time for the patient to define her/his own identity/paint a picture

of her/himself so that an understanding of what safety means to each individual is reached. Nurses might assist patients maintain family contact by acting as intermediaries between patients and families. This could be achieved by offering friendship and support to both patients and their families, thus providing a welcoming environment in which contact can be maintained. Suggestions for strategies to reduce the negative impact of visitors on patients might include nurses organising a roster of visitors to meet the individual needs of each patient; sensitively educating visitors about the need for extra rest among these patients; limiting the number of visitors at any one time; and knowing when the patient is tired, and tactfully conveying this to the visitors.

Limitations of the Study

While the findings of this study will have limited generalisability because of the small sample size, and the fact that the study was conducted in one in-patient hospice in a specific geographic location, the possibility of such a design lends itself for a larger study. The questionnaire was easy to administer and generated individual patient responses.

The researcher was unable to obtain further verification from the participants themselves as only one patient was alive at the time of data analysis.

Due to the high drop out rate of the sample, this study's findings may not be representative of the larger population. This may indicate that there is a group of

people whose needs may be different from the needs addressed in this study.

Retrospective Thoughts

For the researcher, interviewing these six terminally ill cancer patients, proved to be an enriching experience. Their generosity and honesty and their wish to help others by sharing their thoughts and feelings gave the researcher a sense of involvement in their lives and a strong resolve to complete the task. It also made me consider the value of talking to patients about their concerns and needs. Anecdotal evidence (Hewa & Hetherington, 1990) and professional experience suggests that many nurses do not see this as being valuable in terms of work. Perhaps, by planning a working day to include time to talk and listen, nurses may be able to provide more satisfying care, that is, care which meets the needs of both patients and nurses.

Further Research

A study with a larger sample size would enable greater generalisability of the findings, as would studies in more than one setting. A study which compares hospice nurses' perceptions of terminally ill cancer patients' needs with their patients' perception of their own needs would help establish how well nurses know their patients as individuals. Additional studies could focus on the impact of visitors (both family and friends) on terminally ill cancer patients in an in-patient hospice unit, and how best to facilitate optimum visiting.

References

- Abercrombie, K. (1968). Paralanguage. British Journal of Communication, 3, 55-59.
- Adam, E. (1980). To be a nurse. Artarmon, NSW: W. B. Saunders Co.
- Ajemian, I. & Mount, B. M. (Eds.). (1982). The Royal Victoria Hospital manual on palliative/hospice care. Salem, NH: The Ayer Company.
- Amenta, M. O., & Bohnet, N. L. (1986). Nursing care of the terminally ill. Boston: Little, Brown and Company.
- Amesbury, B. D. W. & Dunphy, K. P. (1989). The use of subcutaneous midazolam in the home care setting. Palliative Medicine, 3, 299-301.
- Arblaster, G., Brooks, D., Hudson, R., & Petty, M. (1990). Terminally ill patients expectations of nurses. Australian Journal of Advanced Nursing, 7(2), 34-43.
- Barnard, K. (1981). Research designs: Descriptive method. American Journal of Maternal Child Nursing. 6(4), 17.

- Blank, J. J., Clark, L., Longman, A. J., & Actwood, J. R. (1989). Perceived homecare needs of cancer patients and their caregivers. Cancer Nursing, 12 (2), 78-84.
- Brann, J. (1985). Hospice care in Western Australia - The role of the Cancer Foundation. Cancer Forum, 9(3), 98-100.
- Brescia, F. J., Adler, D., Gray, G., Ryan, M. A., Cimino, J., & Mantani, R. (1990). Hospitalised advanced cancer patients: A profile. Journal of Pain and Symptom Management, 5(4), 221-227.
- Bower, L. (1977). The process of planning nursing care. A model for practice. St. Louis: C. V. Mosby.
- Brunner, L. S. & Suddarth, D. S. (1988). Textbook of medical-surgical nursing. Philadelphia: J. S. Lippincott.
- Burns, N. & Grove, S.K. (1987). The practice of nursing research: Conduct, critique and utilisation. Philadelphia: W.B. Saunders.
- Campbell, L. (1986). History of the hospice movement. Cancer Nursing, 9(6), 333-338.
- Cassidy, S., Burns, G. & Smeardon, K. (1988). The Cancer Journey (Video). Croydon: Rivermill House.

Charmaz, K. (1980). The social reality of death: Death in contemporary America. Reading: Addison-Wesley.

Degner, L. F., Gow, C. M., & Thompson, L. A. (1991). Critical nursing behaviours in care for the dying. Cancer Nursing, 14(5), 246-253.

Derdarian, A. K. (1986). Informational needs of recently diagnosed cancer patients. Nursing Research, 35(5), 276-281.

Ellerton, M. & Down-Wamboldt, B. (1987). The concerns of hospice patients and the role of hospice volunteers. Journal of Palliative Care, 3(1), 16-20.

Fitzgerald, P., & Thompson, J. (1992). Incidence of cancer in Western Australia 1986-1989. Perth, WA: Health Department of Western Australia.

Furukawa, C. Y. & Howe, J. K. (1990). Virginia Henderson. In J. B. George (Ed.), Nursing Theories. The base for professional nursing practice (3rd ed.) (pp. 61-78). Sydney: Prentice Hall International Inc.

Gates, M. F. (1991). Transcultural comparison of hospital and hospice as caring environments for dying patients. Journal of Transcultural Nursing, 2(2), 3-15.

Grant, M. (1987). Nausea, vomiting and anorexia.
Seminars in Oncology Nursing, 3(4), 277-286.

Grobe, M. E., Ahmann, D. L., & Ilstrup, D. M. (1982).
Needs assessment for advanced cancer patients and their
families. Oncology Nursing Forum, 9(4), 26-30

Hackett, T.P., & Weisman, A. D. (1985). Reactions to the
imminence of death. In A. Monat & R. S. Lazarus
(Eds.), Stress and coping. An anthology (2nd ed.).
(Ch. 17). New York: Columbia University Press.

Henderson, V. (1960). Basic Principles of Nursing Care.
Geneva: International Council of Nurses.

Henderson, V. (1964). The nature of nursing. American
Journal of Nursing, 64(8), 62-68.

Herth, K. (1990). Fostering hope in terminally ill
people. Journal of Advanced Nursing, 15, 1250-1259.

Hewa, S. & Hetherington, R. W. (1990). Specialists
without spirit: Crisis in the nursing profession.
Journal of Medical Ethics, 16, 179-184.

- Hileman, J.W. & Lackey, N.R. (1990). Self identified needs of patients with cancer at home and their home caregivers: A descriptive study. Oncology Nursing Forum, 17(6), 907-913.
- Hogan, C. M. (1990). Advances in the management of nausea and vomiting. Advances in Oncology Nursing, 25(2), 475-495.
- Kincaide, J. E. & Powers, R. (1984). An assessment of palliative care needs in a tertiary care hospital. Q. R. B., August, 230-237.
- Kubler-Ross, E. (1969). On death and dying. New York: Macmillan.
- Lack, S. & Buckingham, R. (1978). The first American hospice. New Haven, Connecticut: Hospice Inc.
- Lev, L. (1991). Dealing with loss: Concerns of patients and families in a hospice setting. Clinical Nurse Specialist, 5(2), 87-93.
- Lilley, L. L. (1987). Human need fulfilment alteration in the client with uterine cancer. The registered nurses' perception versus the clients perception. Cancer Nursing, 10(6), 327-337.

Liveris, M. (1992). President's Report. 1991 annual report of the Cancer Foundation of W. A. (Inc.). West Perth, WA: Cancer Foundation.

Longman, A. J., Atwood, J. R., Sherman, J. B., Benedict, J. & Shang, T. C. (1992). Care needs of home based cancer patients and their caregivers. Cancer Nursing, 15(3), 182-190.

Maslow, A. (1970). Motivation and Personality (2nd ed.). New York: Harper & Row.

Macadam, D. (1992). The Cottage Hospice. 1991 annual report of the Cancer Foundation of W. A. (Inc.). West Perth, WA: Cancer Foundation.

Padilla, G.V., Ferrell, B., Grant, M. G. & Rhiner, M. (1990). Defining the content domain of quality of life for cancer patients with pain. Cancer Nursing, 13(2), 108-115.

Parry, J. K. (1987). The significance of flexibility and symptom control as elements of a health care model in working with the terminally ill. Journal of palliative care, 3(1), 23-29.

Patton, M. Q. (1990). Qualitative evaluation and research methods (2nd ed.). London: Sage.

Potter, P. A. & Perry, A. G. (1989). Fundamentals of nursing: Concept, process and practice. St. Louis: C. V. Mosby.

Porth, C. M. (1986). Pathophysiology: Concepts of altered health states (2nd ed.). Sydney: J. B. Lippincott.

Saunders, J., & Regnard, C. (1989). Management of malignant ulcers - a flow diagram. Palliative Medicine, 3, 153-155.

Seale, C. (1991). A comparison of hospice and conventional care. Social Science Medicine, 32(2), 147-152.

Snowball, J. & Green, W. H. (1987). Nursing principles. Guide for practice. Oxford: Blackwell Scientific.

Spradley, J. P. (1980). Participant observation. New York: Holt, Rinehart & Winston.

St. Pierre, B. A., Kasper, C. E., & Lyndsey, A. M. (1992) Fatigue mechanisms in patients with cancer: Effects of tumour necrosis factor on exercise on skeletal muscle. Oncology Nursing Forum, 19(3), 419-425.

Swift, J. K. (1982). Meeting spiritual needs. In Ajemian, I., & Mount, B. M. (Eds.). The Royal

- Victoria Hospital manual on palliative/hospice care.
Salem, NH: The Ayer Company.
- Taylor, S. E. (1986). Health psychology (1st ed.). New York: Random House.
- Twycross, R. G., & Lack, S. A. (1986). Therapeutics in terminal cancer. Melbourne: Churchill Livingstone
- Twycross, R. G., & Lack, S. A. (1990). Therapeutics in terminal cancer (2nd ed.). Melbourne: Churchill Livingstone.
- Waddell, V.P., & Lee, N.A. (Eds). (1991). Our state of health: An overview of the health of the Western Australian population. Perth, WA: Health Dept. of W.A.
- Watson, P. M., Rhodes, V. A., & Germino, B. B. (1987). Symptom distress: Future perspectives for practice, education, and research. Seminars in Oncology Nursing, 3(4), 313-315.
- Webster comprehensive dictionary (Encyclopedic ed.) (1982). Chicago: J. G. Ferguson Publishing Co.
- Wingate, A.L., & Lackey, N.R. (1989). A description of the needs of non-institutionalised cancer patients and their primary caregivers. Cancer Nursing, 12(4), 216-225.

Wood, B. (1990). Intractable symptoms. In C. Saunders (Ed.), Hospice and Palliative Care (pp. 55-59). Melbourne: Edward Arnold.

Wright, K., & Dyck, S. (1984). Expressed concerns of adult cancer patients' family members. Cancer Nursing, 7, 371-374.

Young-Brockopp, D. (1982). Cancer patient's perceptions of five psychosocial needs. Oncology Nursing Forum, 9(4), 31-35.

APPENDIX A

DEMOGRAPHIC INFORMATION

Code :

Date of interview:

Marital state:

Culture:

Age :

Gender :

Occupation:

Family composition:

Caregiver at place of residence:

Place of residence prior to admission :

Health insurance	Public
	Private

Reason for admission :	Respite
	Symptom control
	Terminal care

Number of admissions to hospice:

Date of admission:

Date of diagnosis :

Diagnosis :	Primary site
	Metastases.

Current medical treatment :

APPENDIX B

INTERVIEW GUIDE

Code :

Tell me about what's important for you in hospice ?

- 1) What are your feelings about the environment ?
Setting / single room/temperature / bed / rails / call bell / anything else?
TV/ Occupational Therapy / activity room/ telephone /feel safe / other / ?
- 2) How has your appetite been here ?
Need to eat / family pressure / alcohol / enough / like the food / culture /
time / help / what helps ?
anything else ?
- 3) How have you been sleeping at the hospice ?
What helps / music / company / quiet / medication / sense of security / what
kind / anything else?
What about during the day ? Do you need to rest ?
Much / am. pm. / before visitors / after shower/spa?
anything else ?
- 4) How do manage with your shower / bath / hair / make-up / shave ?
Need help / wash too often / time / privacy ?
anything more ?
- 5) Are you able to go to the toilet OK ?
Need assistance / privacy / medication ?
Pass urine / bowel movements / any other problems ?
- 6) Are you able to get around / go for walks ?
Pain / need help / walking posture / assistance / opportunity / anything
else ?
- 7) How is your breathing ?
Need any help / oxygen / cough / other ?
- 8) How do you manage getting dressed ?
Need help / who / what with / anything else ?
- 9) How have you been feeling at the hospice ?
Afraid / lonely / secure / need to talk to other people / anything else ?
- 10) Who do you talk to about your emotions / fears ?
Nurse / doctor / other patients / family / volunteer / cleaner /
occupational therapist / physio/ chaplain / other / is this helpful/ anyone
else ?
Do you feel people listen / feel understood ?
- 11) Are there any fears you want to talk about ?
Anything else ?
- 12) Have you seen the little chapel ?
Like to sit there / religion important / time ?
is there anything more about your faith ?
- 13) Do you have enough information to make decisions about your care ?
Difficulty making decisions / who provides info ?
Do you discuss your care / finances ?
Who with / important to you / anything else?
- 14) Have you had a job ?
Do you miss not having a job? / anything else?
- 15) Tell me about what a day is like for you, here ?
Relaxing / busy / not enough to do / pleasures / difficult things / other ?
- 16) Is there anything else about your needs / concerns / desires that we haven't
discussed ?

APPENDIX C

PARTICIPANT CONSENT FORM

Study Title: Needs of patients in an in-patient hospice unit.

Investigator: Mrs Marylynn Oldham

Mrs Oldham is a Registered Nurse undertaking the research component of a Bachelor of Nursing Degree with Honours at Edith Cowan University.

The purpose of this study is to gain an understanding of the needs of patients in an in-patient hospice. The information sought will be collected by tape recorded interviews of approximately 30-40 minutes duration. As well, information concerning your medical history will be collected from you and by medical record review. The information obtained during the interview will only be discussed with the thesis supervisors at Edith Cowan University. All interviews will be coded by number to maintain confidentiality. The final report will be available to all interested participants, families and institutions.

The information gained will increase knowledge and understanding of the needs of patients in an in-patient hospice unit. It is important for nurses to understand patient's needs in order to provide individualised quality care.

THIS IS TO CERTIFY THAT I, _____
(please print name)

do voluntarily agree to participate in the above named study. I give permission for these interviews to be taped. I understand that these tapes will be erased when the study is completed. In addition, I give permission for access to my medical records at the Cottage Hospice. I understand that I am free to refuse to answer any questions, should I feel so inclined. I also understand that I am free to withdraw my consent and terminate my participation at any time, without penalty. I know that Mrs Oldham is available at 3818202, if I have any further concerns and that I may contact the Head of the School of Nursing at Edith Cowan University on 3838594, if I am unhappy about any of the research procedures. All my questions have been answered to my satisfaction.

PARTICIPANT :

WITNESS :

DATE :