The information needs of the families of patients with advanced cancer in an acute hospital

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The Information Needs of the Families of Patients with Advanced Cancer in an Acute Hospital

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Abstract

A diagnosis of cancer has a major impact on the family as well as the patient. The families of patients with advanced cancer have many needs. In particular, a number of researchers have identified family members' needs for information as a priority. Most of this research, however, has been undertaken in the context of Palliative Care settings. Few empirical studies have been undertaken to examine the information needs of these families in an acute hospital setting.

The aim of this study is to modify an existing tool, The Family Inventory of Needs (FIN), to more precisely assess the information needs of these families in an acute hospital setting and to measure the extent to which these needs are met.

A three-phase study was conducted.

Phase I involved interviews conducted with eight bereaved family members of patients who had received care at a 600-bed teaching hospital in Perth, Western Australia. The purpose of this phase was to describe the amount and usefulness of information given to these families while the patient was in hospital.

Phase II involved modification of the FIN, based on the interviews and the current literature, to more precisely assess the information needs of this population. Clarity and content validity of the FIN was assessed by calculating percent agreement (80%) amongst the families interviewed in Phase I. Several modifications were made to the FIN based on family feedback and this modified FIN was assessed for clarity and content validity by six specialist nurses.

Phase III was a descriptive quantitative pilot study, which involved administering the modified FIN to 60 families of patients with advanced cancer at the 600-bed teaching hospital in Perth, Western Australia. Internal consistency reliability of the tool was tested using Cronbach's alpha coefficient (Part A: r=0.91 and Part B: r=0.92). Stability of the instrument was tested using test-retest reliability procedure estimated using the intraclass correlation coefficient (Part A: r=0.91 and Part B: r=0.91). The self reported information needs and the extent to which these needs have been met were described.

There is evidence that in the terminal phase of an illness the families of advanced cancer patients suffer mentally and physically. Patients cope better with
their illness if their families are coping well; therefore, it is imperative that families’ needs are assessed and responded to appropriately. It is anticipated that the modified questionnaire will be a useful and straightforward clinical tool that can be used by health care professionals to better assess the information needs of the families of patients with advanced cancer in an acute hospital. Health care professionals who are better able to assess families’ needs would then be able to respond more appropriately and precisely to assist these families.
I certify that this thesis does not, to the best of my knowledge and belief:

(i) incorporate without acknowledgement any material previously submitted for a degree or diploma in any institution of higher education;

(ii) contain any material previously published or written by another person except where due reference is made in the text; or

(iii) contain any defamatory material.
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Chapter One: Introduction

Background and Significance

In 2000, 7317 people in Western Australia were diagnosed with cancer and 3064 people died from the disease (Threlfall, 2002). If each of these individuals has only one family member, the number of people affected by cancer in this year alone is notable.

There is evidence that in the terminal phase of an illness the families of these patients suffer mentally and physically (Kissane, Bloch, Burns, McKenzie & Posterino, 1994; Kristjanson & Ashcroft, 1994). Patients cope better with their illness if their families are coping well (Kristjanson, 1994), therefore, it is imperative that families’ needs are assessed and responded to appropriately.

Prior studies related to care of dying patients and their families in acute hospitals have highlighted the many difficulties faced by staff in providing this care (Bond, 1982a; Bond, 1982b; Dunne & Sullivan, 2000; Hampe, 1975; Northouse & Northouse, 1987). Many of these studies describe poor communication with staff as a major difficulty for families.

A study by Davis, Kristjanson & Blight (2003) described the difficulty nurses at a large Australian tertiary care teaching hospital experienced communicating with these families. A major problem identified by nurses was poor communication within the team and between the team and families, which resulted in families not having adequate information, particularly with respect to the plan of care and the patient’s prognosis. This lack of information may cause distress to families and create communication difficulties between families and nursing staff and within the health care team. Accordingly it is essential that the information needs of these families are assessed and that these needs are met.

Subsequent studies arising from this research will include the development and testing of a family information intervention to ensure that the families of patients with advanced cancer in acute hospitals receive the information they need.
Aim

The aim of this study is to develop and test an instrument to assess family information needs in the context of advanced cancer in an acute hospital situation.

Research Questions

Two sets of questions were posed: methodological and clinical.

Methodological Questions

1. To what extent does the modified Family Inventory of Needs (FIN) demonstrate clarity and content validity as measured by percent agreement (80%) amongst the families and expert nurses in Phases I and II?

2. To what extent does the modified FIN demonstrate internal consistency reliability as measured by Cronbach’s alpha coefficient, (r = >0.80)?

3. To what extent does the modified FIN demonstrate stability over time as measured by the intraclass correlation coefficient (r = >0.80)?

4. To what extent does the McMaster Family Assessment Device (FAD) demonstrate internal consistency reliability as measured by Cronbach’s alpha coefficient, (r=>0.80)?

5. To what extent does the FAMCARE scale demonstrate internal consistency reliability as measured by Cronbach’s alpha coefficient, (r=>0.80)?

6. What is the association between family functioning as measured by the FAD and the extent to which information needs are met as measured by Pearson’s Correlation Coefficient?

7. What is the association between family satisfaction with care as measured by the FAMCARE scale and the extent to which information needs are met as measured by Pearson’s Correlation Coefficient?
Clinical Research Questions

1. What are the information needs of family members of patients with advanced cancer in an acute hospital, as described during interviews with bereaved family members of patients who have received care at a 600-bed teaching hospital in Perth, Western Australia?

2. What are the self-reported information needs of family members of patients with advanced cancer in an acute hospital, as measured by the modified FIN?

3. To what extent are the information needs of family members of patients with advanced cancer in an acute hospital being met, as measured by the modified FIN?

Operational Definitions

Family members: defined as spouse, adult, child, sibling or parent of the patient, who has the most involvement with the patient during their illness.

For the purpose of this study (Phase III) one family member only will be included.

Patients with advanced cancer: patients with advanced cancer who are in the terminal phase of their illness. For the purpose of this study, these are patients who have been identified by the Palliative Care team as well as nursing and medical staff on oncology wards and clinics at a 600-bed teaching hospital in Perth, Western Australia.

Information needs: a lack of or inadequate knowledge, incomplete or unclear knowledge.
Summary

The families of patients with advanced cancer have many needs. Many families have highlighted the need for information and the difficulty in obtaining this information, in an acute hospital. The need for the development of a tool to measure these information needs will be expanded upon in the review of the literature.
Chapter Two: Literature Review

The relevant literature will be discussed under the headings of cancer and the family; the information families need; accessing staff and communication of information; the context setting and family care instruments.

Cancer and the Family

Cancer can have a devastating impact on the family as well as the patient. All members of the families of cancer patients have the potential to experience both mental and/or physical ill-health during the course of a terminal illness and during the time of bereavement (Northouse, 1984; Zisook & Schuchter, 1991; Kissane et al., 1994; Kristjanson & Ashcroft, 1994; Kissane, Bloch, Onghena, McKenzie, Snyder & Dowe, 1996).

During the course of a terminal illness, the families of the patient receive care in the form of information and support. Families who evaluate care negatively experience more stress (Ferrell, Rhiner & Grant, 1991; Kristjanson & Avery, 1994). There is evidence that families who are less satisfied with care do not cope as well. Furthermore families who function poorly during or following the patient’s illness are more likely to require care themselves. Negative care experiences may complicate recovery during the grief process (Steele, 1990; Yancey, Greger & Coburn, 1990; Kristjanson, Sloan, Dudgeon & Adaskin, 1996). Accordingly, health professionals must provide care to the families as well as the patients.

The Information Needed by Families

Families of patients with advanced cancer consistently report the need for information as a high priority (Hampe, 1975; Kristjanson & Ashcroft, 1994; Hanson, Danis & Garrett, 1997; Clumpus & Hill, 1999; Yates, 1999). The need for families to be informed of the prognosis and the patient’s condition has been highlighted by many researchers. In a review of the literature on family needs and supportive
nursing behaviors, Hull (1989) found that families want clear, honest information regarding present condition, prognosis and signs of imminent death. Grbich, Parker & Maddocks (2000), who collected information from 136 bereaved family members, also found that the families wanted information on the diagnosis, treatments and clear information about disease progression. Hanson et al (1997) interviewed 461 bereaved family members of older patients, many of whom had died of cancer, to describe family perceptions of care at the end of life. Fifty percent of the patients had died in hospital, the others at home or in nursing homes. Family members’ recommendations to improve care emphasised better communication. In particular they wanted more information on prognosis, so that they were able to say goodbye to their loved ones. Hampe (1975) reported similar findings in her study on the needs of bereaved spouses in the hospital setting. Adam (2000), in an exploratory descriptive study of the information and practical advice given to carers of terminally ill patients, found that one third of the carers were dissatisfied with the information that they had been given about the patient’s illness.

Information concerning the treatments the patient is receiving, as well as the symptoms which may be caused by the treatment and/or disease have been highlighted as important information for families (Addington-Hall, McDonald, Anderson & Freeling, 1991; Wakefield & Ashby, 1993). Families require information on how to administer medications and on their side effects (Adam, 2000). A lack of information regarding the patient’s medications and fears about morphine can lead to psychological distress in the carers (Rose, 1999).

Families have also identified that they need information about caregiving skills, in order to care for the patient in hospital and at home (Tringali, 1986; Adam, 2000). Addington-Hall et al. (1991) interviewed bereaved spouses and found that families want facts about hospices and home care services, as well information about the availability of financial assistance.

Access to Staff and the Communication of Information

The difficulties that families face obtaining information from health professionals have been well documented. (Northouse & Northouse 1987;
Kristjanson & Ashcroft, 1994; Hanson et al., 1997; Yates, 1999; Grbich et al., 2000). 
It is often the responsibility of the family members to seek information from health 
professionals (Bond, 1982b). Family members must rely on second-hand information 
obtained from the patient or other members of the family, making it difficult for them 
to seek clarification, correct misassumption, or develop rapport with health 
professionals (Northouse & Northouse, 1987). Similar themes emerged from 
interviews of 100 bereaved spouses in South Australia (Wakefield & Ashby, 1993). 
Difficulty in accessing medical care, a lack of communication about the patient's 
progress and dissatisfaction with the way in which the patient's terminal condition 
was communicated were identified by the respondents in this study.

Clumpus and Hill (1999) highlighted the coordination of communication and 
information between different departments and hospitals as a difficulty for families. 
Families want information that is honest, given in a compassionate and timely 
manner and in language that they can understand (Hampe, 1975; Hanson et al., 1997; 
Yates, 1999). Grbich et al. (2000) found that information giving was described on a 
scale from honest and straightforward to incomplete, misleading and uncaring. The 
participants in this study appreciated honest and caring information giving.

Lack of privacy, space and time has been cited by families and nurses as 
contributing to difficulties in access to staff and communication difficulties for 
families and patients in hospitals (Copp, 1993; Bridgeman & Carr, 1997; Dunne & 
Sullivan, 2000).

One important aspect of communication of information to families is 
communication regarding hope. The issue of hope in terminal illness has been the 
subject of research by nurse researchers over the past 10 years. Maintaining hope is a 
guiding principle of Palliative Care nursing and accordingly nurses can have a 
significant influence on fostering or hindering hope in these patients and families 
(Herth & Cutcliffe, 2002). When patients and families can acknowledge that cure is 
no longer possible, staff need to assist them to work through changing their focus 
from dying of a terminal illness to living with a life threatening illness. 

7
Context Setting for Family Information Studies

Much of the work on family communication in advanced cancer care has been conducted in inpatient hospice and hospice home care settings. The communication difficulties that families face in the acute hospital environment have been less well researched.

Families of patients with cancer in hospitals frequently identify poor communication with health professionals as a major difficulty (Bond, 1982a, Hampe, 1975, Wakefield & Ashby, 1993).

Caring for dying cancer patients in an acute hospital ward may be particularly difficult because of the blend of care required within an acute care setting. This includes providing care for patients undergoing active treatment, those with recurrence of cancer and those requiring end-stage care (Irvine, 1993). Attention to the communication needs of advanced cancer patients and their families may be difficult to achieve amidst the demands of a busy ward. Dunne and Sullivan (2000) interviewed eight bereaved families of patients who had died in an acute hospital setting, one to two years post bereavement. All family members described the acute setting as an inappropriate environment for terminal care. They complained of a “rushed and hurried environment, with dying patients being moved around as the need for acute beds dictated.” (p.173). Communication as experienced by the families was identified as one of the four core themes to emerge from the data in this study.

Research conducted on bereaved family members related to the benefits of hospice care when compared to terminal care in an acute hospital demonstrated that the families felt better informed and more supported by hospice staff. Families of hospice patients also reported feeling less anxious than families not receiving hospice care. These findings have been consistently reported over a period of 20 years (Smith & Hill, 1978; Murray-Parkes, 1985; St Aubin Lund, 1986; Wakefield & Ashby, 1993; Scale & Kelly, 1997).

Given that families consistently report better communication with hospice staff than with hospital staff, further research is needed to determine the information needs of the families of patients with advanced cancer in hospitals and the extent to which these needs are met.
Family Care Instruments

A review of the literature revealed various tools to measure the needs of the cancer patients (Fallowfield, Ford & Lewis, 1994; Meredith et al., 1996) and tools to measure the needs of the families of cancer patients.

To ascertain the self-focused and patient-focused needs of families of cancer patients, Wright and Dyck (1984) used semi-structured interviews in addition to a 12-item Likert questionnaire. Other methods included use of an open-ended questionaire as a pilot that was subsequently converted to a Likert scale, to identify family members' perceptions of useful nursing interventions (Welch, 1981). Tringali (1986) also utilised a Likert scale to determine the needs of the families of cancer patients and Hinds (1985) developed a 46-item interview schedule to study the needs of families caring for patients at home. Grbich et al. (2000), administered a questionnaire consisting of closed ended questions to 116 bereaved care givers of cancer patients as part of a study to determine the families' communication and information needs at diagnosis and during treatment of terminal cancer.

The two most relevant tools that were identified in the literature and included specific items for measuring families' satisfaction with information giving and measuring information needs were the FAMCARE Scale (Kristjanson, 1993) and the FIN (Kristjanson, Atwood & Degner, 1995). The FAMCARE Scale was developed to measure family satisfaction with advanced cancer care and was tested in an outpatient oncology department and a home care service. Of the twenty questions on this scale, nine relate specifically to information needs (Kristjanson, 1993). There is no reported literature that documents use of this tool in an acute hospital environment.

The FIN was designed to measure the importance of care needs of families of patients with advanced cancer and the extent to which their needs had been met (Kristjanson et al., 1995). The FIN was based on a 45-item Likert-type scale developed to measure the needs of the families of critical care patients. Further adaptations were made by Tringali (1986), who developed a 53-item Likert scale for use with the families of advanced cancer patients. The FIN was developed using qualitative data obtained from families of Palliative Care patients. It was designed and tested using patients and families from two homecare hospice programmes and a
tertiary care hospice programme. The FIN has been adapted for use with specific groups, for example the FIN-II, was designed to measure the information needs of husbands of women with breast cancer and the extent to which these needs are met (Kilpatrick, Kristjanson & Tataryn, 1998). The FIN-PED was adapted to measure the care needs of the parents of children with cancer and the extent to which these needs are met (Whitely, Kristjanson, Degner, Yanofsky & Mueller, 1999).

The FIN has twenty questions, fifteen of which relate specifically to information needs, but they are not specific to an acute hospital environment. Accordingly, they do not address some of the concerns identified in other studies such as privacy, access to staff, the need for information about hospices and home care services and financial issues (Addington-Hall, 1991; Copp, 1993 & Bridgeman & Carr, 1997). Although this is a useful tool, it is not specific for measuring information needs of families in an acute hospital setting.

**Summary**

The literature describes many needs of the families of patients with advanced cancer. Although information needs of families in different care settings have been identified as a priority in many of these studies, none of the authors have specifically researched the information needs of these families in an acute hospital, and the degree to which these needs have been met. In addition, the majority of this research has been conducted in England and Canada with little published Australian data. In view of the differences between these populations in terms of ethnic composition, healthcare systems and attitudes, it was important to undertake a study in an Australian health care context.

Accordingly, a modified version of the FIN to more precisely measure these needs was developed. This scale was then used to assess the information needs of families of patients with advanced cancer at a 600-bed teaching hospital in Perth, Western Australia and the degree to which these needs were met. The scale was also tested for validity and reliability.
Chapter Three: Conceptual Framework

The purpose of this chapter is to present the conceptual framework underpinning this research. The Family Information Model (FIM), (see Figure 1) is derived from synthesis and refinement of relevant theoretical and clinical literature, integration of empirical findings emerging from an earlier phase of this program of research and the clinical observations of the researcher.

The Theoretical Basis for the Conceptual Framework

The theoretical basis for the development of the FIM has been derived from theories of communication in health care (Northouse & Northouse 1985), literature related to the concept of information needs (Derdjian, 1987) and earlier empirical work that has identified sources of communication difficulties. In addition the Kuyper’s H-E-C model as described by Kristjanson, Tamblyn and Kuypers (1987) (see Figure 2), has been used as a basis for the FIM. This model provides a theory of clinical practice that offers a broad framework for directing health care providers to make explicit their plan of care.

Each of these theoretical sources will be described and applied to the issue of family information needs in the context of acute cancer care.

Health Communication Model

Northouse and Northouse (1985) describe a process of healthcare communication which is a multidimensional, dynamic process affected by many complex variables. This process of health care communication includes three major elements: the participants, the health transactions and the contexts.

The participants in this model are health professionals, the patient and significant others, who, for the purpose of this chapter are referred to as family members. The health transactions in this model refer to the many aspects of communication among health professionals, patients and family members. These
interactions occur at many levels including health professional to health professional, interactions between health professionals and the patient, exchanges between the patient and family members and interactions between health professionals and family members. The model identifies that there are many factors that influence the quality of these transactions, including complex variables such as trust, empathy and control.

The third element of the model is the context in which the communication occurs. This can refer to either the environmental context or the number of people involved in the communication. With respect to the environmental setting, this can include such areas as an acute hospital ward, an outpatient clinic, a nursing home or a hospice. The environment can affect the quality and dynamics of the communication. For example, there is often a lack of privacy in an acute ward in contrast to a hospice or consulting room in a clinic. The number of participants involved in the communication will impact on the interactions that occur.

The development of the FIM is based on the elements of health professional-family communication within the context of the acute hospital environment. Inherent in the FIM is recognition of the many family-related variables that impact on the level of communication between health care professionals and families, as described in the literature review.

Kuypers’ H-E-C Framework

Kuypers’ H-E-C framework (Kristjanson et al, 1987) is the dominant foundation for the FIM. Kuypers believes that health care professionals develop a theoretical understanding of clinical situations. He postulates that application of the theory will assist health care professionals to assess a variety of clinical situations and develop and implement appropriate strategies for care. This framework refers to the domains of Health, Error and Change as a mechanism for helping clinicians when assessing a problem and setting care goals. When a problem is identified the clinician must determine what the ideal is (health), what is preventing the ideal from happening (error) and what needs to take place in order for the ideal to occur (change). The flexibility of this model allows for application of these domains to a variety of clinical contexts and care circumstances. The model provides a framework
for clinicians to employ their specialised knowledge and experience whilst articulating the decisions that they make about how to meet the needs of patients and/or families.

Within the domain of health, the health care professional assesses the ideal health outcome for the patient and or family. This assessment is based on physical and or psychosocial factors and forms the basis for the health professional and family interaction. In the context of the FIM this is an assessment of the information needs of the families of patients with advanced cancer in an acute hospital.

The framework also specifies that the health professional identify sources of error that may be preventing the ideal or health state from occurring. The health professional must assess and identify possible sources of error to determine a range of appropriate interventions. For example, error in this context refers to an assessment of possible barriers that families encounter when trying to receive information within an acute hospital.

Reference to the domain of change involves the process of generating, choosing and implementing interventions in an effort to address sources of error with the aim of achieving health. In the case of the FIM, this process involves identifying, selecting and implementing actions to improve the communication of information to families.

These interventions could include strategies to improve team communication to facilitate clarity of care planning or use of an assessment tool such as the modified FIN, so that health professionals are able to provide the information that families need.

It is essential that the H-E-C model is viewed as a continuous process that involves balanced attention to all three domains of the model. If any domain is used in isolation or over-emphasised, then the outcome of health is less likely to be achieved. The FIM uses the Kuypers’s model as an underpinning framework.
Derdarian's Theory of Informational Needs of Newly Diagnosed Cancer Patients

Integral to the FIM is the application of other theories including aspects of Derdarian's (1987) theoretical framework for the information needs of recently diagnosed cancer patients, which uses theories of coping, appraisal, information seeking and hierarchy of needs. The concepts of appraisal and information seeking are used in the development of the FIM.

The process of appraisal is described in three phases. Firstly assessing the threat, secondly working out the internal and external resources needed to cope with the threat and thirdly a re-appraisal process whereby the threat and resources are re-assessed and a plan of action developed. Information seeking is also identified as a major form of coping with a potentially harmful situation.

Within the context of the FIM these concepts help to explain the processes used by families to determine their need for information, to assist them to cope more effectively with the potentially stressful situation of caring for a dying relative.

In the development of this theory, Derdarian also identifies the variables that influence the information needs of these patients. These include the type of cancer, the stage of the cancer and the nature of the cancer treatment.

In summary, the development of the FIM has been influenced by theories of healthcare communication (Northouse & Northouse, 1985), a theory to assist clinician decision making (Kristjanson et al, 1987) and Derdarian's (1987) theoretical framework for the informational need of recently diagnosed cancer patients.

The Family Information Model

The FIM has been designed as a model to guide the practice of health care professionals in order to ensure that the families of patients with advanced cancer in the acute care context have their information needs met. The Family Information Model integrates aspects of the H-E-C model in the following way (see Figures 1 and 2).
The Problem: The families of patients with advanced cancer in the acute care context need information.

Error: There are barriers to the communication of information to these families.

These barriers can be categorised into patient and family errors, structural errors and team errors.

Patient and family barriers to the effective communication of information include cultural and language issues, a patient or family member who is in denial, family conflict, healthcare professionals who do not know the patient and family and a patient who is experiencing symptom distress (Bridgeman & Carr, 1997; Davis et al., 2003; Kristjanson & Ashcroft, 1994). Issues related to trust in the family/healthcare professional relationship will impact on the effectiveness of communication. Northouse and Northouse (1985, p.45) define trust as “an individual's expectation that he or she can rely on the communication behaviors of others”.

Structural barriers to the communication of information to families are lack of privacy, lack of time, difficulty of access to staff and the mix of patients on an acute care ward (Bridgeman & Carr, 1997; Copp, 1993; Dunne & Sullivan, 2000; Davis et al., 2003).

The team factors that are barriers to the communication of information include poor communication between team members, no defined plan of care, healthcare professionals' lack of knowledge, poor communication skills and dishonest communication (Bridgeman & Carr, 1997; Copp, 1993; Davis et al., 2003; Grbich et al., 2000).

An assessment of the barriers to communication needs to occur for change to take place.

Change: It is necessary to remove the identified barriers to communication to achieve the outcome of health. It is therefore necessary to assess the families' information needs and ensure communication of appropriate information occurs. This assessment can be undertaken using a systematic approach. For example, the FIN is one such instrument that has been developed to measure the needs of family members of patients with advanced cancer.
**Health:** Within this domain, it is considered that a state of health has been achieved when the families of patients with advanced cancer in an acute care setting have their information needs met. This is achieved by the identification of errors and implementation of change to achieve health.
**Health**

*Families of patients with advanced cancer in an acute hospital have their information needs met.*

This results in:
- Satisfaction with care
- Improved coping during the illness and in bereavement
- Improved family communication

**Error**

*Barriers to the communication of information exist.*

This results in:
- Patient/family errors i.e. culture, language, denial, family conflict, lack of information
- Structural errors i.e. privacy, time, access to staff, patient mix
- Team errors i.e. lack of team communication, knowledge, communication skills, dishonest

**Figure 1. Family Information Model**

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Figure 2. The H-E-C Framework
Conclusion

The FIM provides a framework for the assessment of the information needs and improved communication of information to the families of patients with advanced cancer in the acute care setting.

This model has been based predominately on Kuyper's H-E-C model (Kristjanson at al, 1987). The development has also integrated theories of healthcare communication (Northouse & Northouse, 1985) and a theoretical framework for the information needs of recently diagnosed cancer patients (Derdianian, 1987). Empirical findings from an earlier phase of this research have also been integrated into the model (Davis et al., 2003).

The FIM identifies barriers to the communication of information to families and the processes that need to be implemented to ensure families receive the information they need, in order to be able to cope with the care of a family member with advanced cancer.

It is anticipated that this model will provide a framework for future programs of research into the care of families of patients with cancer. The model has potential as the basis for the communication of information to families at different timeframes in the patient's cancer journey.
Chapter Four: Method

This study consisted of three phases and employed descriptive qualitative and quantitative research methods. The target population for the research was the bereaved family members in Phases I and II and the families of patients with advanced cancer in the acute hospital setting in Phase III.

Method Phase I

Phase I consisted of semi-structured interviews conducted with bereaved family members of patients who had been cared for at a 600-bed teaching hospital in Perth, Western Australia.

The purpose of this phase of the study was to elicit from bereaved families the type and quality of information they had received throughout the patient’s hospitalisation during the terminal phase of their illness. Families were also given the opportunity to describe information they had not received, but that they believed would have been beneficial. The aim was to confirm the literature related to the information needs of these families in the acute care environment.

Bereaved families were selected for this phase of the study as they were able to identify the information that had been important to them as well as any additional information that they would like to have received. The benefit of the insight of the bereaved families, as opposed to families who are caring for a patient with advanced cancer, is that it is not often clear what information is needed until after the patient has died (Addington-Hall & McPherson, 2001).

Sample

Six to ten bereaved family members of patients who had been cared for at a 600-bed teaching hospital in Perth, Western Australia were invited to participate in
the study. A sample group of six to ten family members was considered to be adequate for this phase of the research, as previous qualitative research indicates that interviewing beyond a small number leads to the generation of no new information and to redundancy in the data (Swanson, 1986). The members of the Palliative Care team at the hospital identified suitable families whose family member had died between three and six months previously. The period between the experience and the recollection is important. The shorter the timeframe, the easier it is for families to recall facts, but this has to be balanced with causing distress to already stressed individuals (Addington-Hall & McPherson, 2001). The researcher and the Palliative Care team felt that the families would not be too early in their bereavement to be distressed by participating, yet they would still be able to recall relevant facts related to the patient’s care and the information that they had received.

**Recruitment**

Suitable families were invited to participate by the Palliative Care social worker. All families who were approached agreed to take part in the study. The researcher contacted these families and agreed on a mutually acceptable time for the interview.

**Setting**

The interviews were conducted in a setting that was convenient and acceptable to the participants. Accordingly, all interviews took place in the homes of the families who participated in this phase of the research.

**Interview Schedule**

Semi-structured interviews were conducted using an interview guide that was developed using the relevant literature and the clinical experience of the researcher.
(Appendix A). The guide consisted of questions related to the information that was received by the families during the patient's hospitalisation, including whether it was enough, what other information the families would like to have received and the source of the information, (i.e. resident doctor, registrar, consultant or nurse). In addition, the guide aimed to explore issues of privacy in information giving, the ease or otherwise of locating staff and whether written information would have been beneficial. The researcher took field notes of the families' responses to the interview guide.

Demographic Data

Participants were provided with an Information Sheet (Appendix B) and asked to complete a Consent Form (Appendix C) and Demographic Data (Appendix D).

The family demographic data consisted of age, gender, relationship of the participant to the patient and whether they lived with the patient. The following categories were also included: the country of birth, whether English was the first language and the level of understanding of English. This data was intended to give an indication of the relationship between an understanding of the English language and the understanding of information related to the patient. In addition, the family member's highest education level achieved was recorded in the demographic data because the literature describes the relationship between level of education and communication issues in cancer care (Kristjanson, Leis, Koop, Carriere & Mueller, 1997).

The participants also completed the 12-item General Functioning subscale of the FAD (Appendix E). The 12-item General Functioning subscale of the FAD is a simple and brief tool that gives an indication of the overall health and functioning of the family (Epstein, Baldwin & Bishop, 1983). The FAD has been tested in a variety of sites, including with families of Palliative Care patients and has demonstrated good reliability and validity (Miller et al, 1994; Kristjanson et al, 1997). The purpose of including the General Functioning subscale of the FAD was to describe the range of families included in the study and determine if the sample represented families that varied according to level of family functioning. It was important to ensure the
families in the sample were representative of all levels of family functioning, as there was a risk of only "good families" being identified by staff as appropriate participants for this study.

The General Functioning subscale of the FAD consists of 12 items that assess problem solving, communication, roles, affective responses, affective involvement and behaviour control (Epstein et al, 1983). Family members rated their agreement or disagreement with each statement based on how well each item described their family functioning. The families had a choice of four responses; Strongly Agree, Agree, Disagree and Strongly Disagree. The General Functioning subscale of the FAD takes approximately five minutes to complete.

To score the General Functioning subscale of the FAD the responses are coded by scoring as follows, 1 (Strongly Agree), 2 (Agree), 3 (Disagree) and 4 (Strongly Disagree). The scores for the items that describe functioning which is unhealthy are then scored by subtracting them from 5. This then enables a Strongly Agree response from an unhealthy item to equate to a Strongly Disagree response to a healthy item on the scale. Consequently, 1 is a healthy response and 4 is an unhealthy response for all items. To calculate a scale score the scores attached to each item are added and then divided by the sum of the number of items that have been answered. Scale scores thus range from 1 (healthy) to 4 (unhealthy).

Families were also asked to provide information about the patient including, age, gender, primary and secondary sites of cancer, date of diagnosis, number of admissions to hospital and the number of family members involved in the care of the patient (Appendix F).

The interviewer had 18 years experience as a Palliative Care nurse and thus was accustomed to interviewing and supporting bereaved families. The researcher had a plan in place for any families who displayed characteristics suggesting they were not coping with their grief. These families would be offered access to Silver Chain Grief Support Service or other forms of support, as deemed appropriate.
Data Analysis

Patient and family demographic data were described using descriptive statistics and the families each designated a FAD score.

Field notes taken during the interview process and the descriptive interview results were described.

Method Phase II

The purpose of Phase II was to modify the FIN based on the descriptive information obtained in Phase I. Specifically it was intended to be modified to more precisely assess the information needs of families of patients with advanced cancer in an acute hospital.

Phase II consisted of two phases. Phase IIa involved testing of the FIN (Appendix G) for clarity and content validity with the families from Phase I and Phase IIb the testing of the modified FIN (Appendix H) for clarity and content validity with a panel of expert health professionals in the acute hospital setting.

Phase IIa

Sample. The families interviewed in Phase I were invited at the end of their interview to provide feedback on the FIN for clarity and content validity. Clarity is the degree to which the questions are worded clearly and unambiguously. Content validity is the degree to which the items of an instrument adequately represent the universe of content (Polit & Hungler, 1995).

Consent to participate in Phase II of the study was obtained from the families when consent was obtained for Phase I (see Appendix C).

Setting. Phase IIa took place in the families’ homes.
**Instruments.** The FiN is a validated tool, designed to measure the importance of care needs of families of patients with advanced cancer and the extent to which these needs have been met. The FiN has been developed using qualitative data obtained from families of Palliative Care patients in Canada. This tool has been designed to measure all family needs, not specifically information needs.

The FiN has 20 statements of need and the families in this study were asked to rate the importance of their needs on a rating of 1 to 5, 1 being *(important)*, 2 *(somewhat important)*, 3 *(average importance)*, 4 *(very important)* and 5 *(extremely important)*. Participants were asked to place the number that matched their response (1 to 5) next each need statement. If the number was rated higher than 1 then they were asked to rate whether the need was “met”, “partly met,” or “unmet”.

**Clarity.** The families were asked to answer Yes/No to the following questions. If they answered no, they were asked to comment.

1. Do you understand what this questionnaire is for?
2. Are the instructions clear?
3. Is each of the statements clear?

**Content Validity.** The families were asked to answer Yes/No to the following questions:

1. Is each statement a suitable item to identify information needs of families? If they answered no they were asked to comment.
2. Are there any items missing from the tool?
3. Does the tool as a whole measure the information needs of families?

**Data Analysis.** To measure clarity each of the “yes” answers to the three questions were collated and given a score out of eight (the number of family members involved in this phase of the study). Percent agreement amongst the
families' responses was used to measure the extent to which the FIN demonstrated clarity.

To measure content validity each of the "yes" answers to the question "is each statement a suitable item to identify information needs of families?" was collated and given a score out of eight. The answers to question three, "does the tool as a whole measure information needs of families?" were also collated. Percent agreement amongst the families' responses was used to measure the extent to which the FIN demonstrated content validity. According to Lynn (1986), a minimum of five experts is required to determine content validity. If there are five or fewer experts then they must all agree on the content validity, but if there are six or more, one or more of the experts can disagree with the others and the tool can still be determined to be content valid. For the purpose of Phase IIa of this study, as there were eight family members, no more than two "no" answers were allowed for this to be assessed as content valid.

**Phase IIb**

**Sample and Setting.** The modified tool was then administered to a panel of six experienced cancer nurses, from the acute hospital environment.

The nurses were asked to assess the modified FIN for clarity and content validity, using the following questions (Appendix I).

**Clarity.** They were asked to answer Yes/No to the following questions. If they answered no, they were asked to comment.

1. Do you understand what this questionnaire is for?
2. Are the instructions clear?
3. Is each of the statements clear?
Content Validity. They were asked to answer Yes/No to the following questions:

1. Is each statement a suitable item to identify information needs of families? If they answered no they were asked to comment.

2. Are there any items missing from the tool?

3. Does the tool as a whole measure the information needs of families?

Data Analysis Phase IIIb. To measure clarity in the modified FIN each of the “yes” answers to the three questions was collated and given a score out of six. Percent agreement amongst the nurses’ responses was used to measure the extent to which the modified FIN demonstrated clarity.

To measure content validity each of the “yes” answers to the question “is each statement a suitable item to identify information needs of families,” was collated and given a score out of six, as was the answer to the question “does the tool as a whole measure the information needs of families?”

Percent agreement amongst the nurses’ responses was used to measure the extent to which the modified FIN demonstrated content validity. According to Lynn (1986), five out of six agreement is adequate. Percent agreement was described under Phase IIa.

Method Phase III

The purpose of Phase III of this research was to administer the modified FIN to the families of patients with advanced cancer in an acute hospital environment, to test the tool for reliability and to describe the information needs of these families and the extent to which they had been met. Phase III was a descriptive pilot study.
Sample and Setting

The modified tool was administered to family members of patients with advanced cancer on an oncology ward and a cancer surgical ward at a 600-bed teaching hospital in Perth, Western Australia until at least 60 completed questionnaires were returned. This sample size was considered to be adequate to gain the clinical information needed for the study. Sixty participants was also deemed adequate for the validity and reliability testing (Peat, 2001). Convenience sampling was used for this phase of the research. Convenience sampling is a form of non-probability sampling and involves the most convenient group of people for a study. Polit and Hungler (1995, p. 223) judge this method of sampling to be the “most likely to be used when the research population consists of people with specific traits who might otherwise be difficult to identify”.

Families of patients with advanced cancer who were inpatients or who had been inpatients in the previous month and were attending the Palliative Care clinic or Radiation Oncology clinic, were identified for the study by the clinical staff on the wards and the Palliative Care team members. A research nurse who was experienced in the care of advanced cancer patients administered the questionnaire to the families. Families who were experiencing distress or who were deemed to be inappropriate for the study for any reason were excluded from the study. Families who spoke no English were also excluded from the study.

For the purpose of reducing distress amongst the families, especially where a family member did not know or would not accept that the patient had advanced cancer, the term “advanced cancer” was removed from the documentation for this phase of the study and replaced with “cancer”.

Instruments

The FAD has been described in Phase I.
The FAMCARE scale (Appendix J) was developed to measure family satisfaction with advanced cancer care. The scale was developed based on qualitative data that identified concepts of family satisfaction with advanced cancer care.

The FAMCARE is a 20-item Likert-type scale that requires the family member to indicate the level of satisfaction with the care that their family member has received or is receiving. The family rates the satisfaction for each item on the scale by circling one of the following: very satisfied (VS), satisfied (S), undecided (U), dissatisfied (D), or very dissatisfied (VD). The scale is scored by giving a numerical score to each of the ratings, i.e 1 (VD), 2 (D), 3 (U), 4 (S) and 5 (VS). The total possible range is from 20 to 100. The tool has previously been tested for validity and reliability (Kristjanson, 1993).

**Demographics**

The families were given an Information Sheet (Appendix K) and asked to complete Family Demographic Data (Appendix L) and Patient Demographic Data (Appendix M).

The family data included age, sex, relationship to the patient, country of birth, first language, level of understanding of English and level of education.

This data was intended to give an indication of the relationship between an understanding of the English language and the understanding of information related to the patient.

The level of education was also included in the demographic data.

The patient data included age, gender and the primary site of the cancer, with the options of breast, lung, prostate, bowel, brain or other, whether there was secondary spread and the date of diagnosis if known. The number of admissions to hospital and outpatient visits was included to give an indication of the amount of information to which these families had potentially been exposed.
Data Collection

A research nurse with experience in the care of advanced cancer patients was employed to collect the data. The modified FIN was administered to the families on the two study wards and the Palliative Care outpatient clinic at time period one (t1) and then the families were asked to fill in a second modified FIN 24 hours later, to be returned in the self addressed stamped envelope (t2) provided with the FIN. To identify the participants in the test -- retest while maintaining confidentiality, participants were given matched coded questionnaires.

Data Analysis

Quantitative research techniques were utilised for this phase of the research. Data analysis was conducted using SPSS for Windows Version 10.

Two sets of research questions were posed: methodological and clinical

Methodological Questions:

1. To what extent does the modified FIN demonstrate internal consistency reliability, as measured by Cronbach’s alpha coefficient (r = >0.80)?

Internal consistency reliability is the extent to which the items in the scale are measuring the same characteristic.

Cronbach’s alpha is a widely used method of determining internal consistency. The normal range of values is between 0.0 and +1.00, a higher value representing a higher degree of internal consistency. A reliability coefficient of above 0.80 is considered to be adequate (Polit and Hungler, 1995).

2. To what extent does the modified FIN demonstrate stability over time as measured by the intraclass correlation coefficient (r = >0.80)?

Stability of the modified FIN was measured using a test-retest with a 24-hour timeframe. The 24-hour timeframe has been used previously (Kilpatrick et al, 1998) and is appropriate for this population, as the information needs of these families are likely to change over a longer timeframe. Stability measures are usually higher for
short time periods for the test-retest. There can be difficulties with measuring stability including participants’ memory of their first responses or they may not be as careful on completing the tool for a second time. The intraclass correlation coefficient is used as an index of correlation between repeated measures of the same method (Bland & Altman, 1990).

3. To what extent does the FAD demonstrate internal consistency reliability, as measured by Cronbach’s alpha coefficient, \( r = 0.80 \) ?

4. To what extent does the FAMCARE scale demonstrate internal consistency reliability, as measured by Cronbach’s alpha coefficient, \( r = 0.80 \) ?

5. What is the association between family satisfaction with care as measured by the FAMCARE and the extent to which information needs are met?

**Clinical Research Questions:**

1. What are the information needs of family members of patients with advanced cancer in an acute hospital, as described during interviews with bereaved family members of patients who had received care at a 600-bed teaching hospital in Perth, Western Australia?

2. What are the self-reported information needs of family members of patients with advanced cancer in an acute hospital, as measured by the modified FIN?

3. To what extent are the information needs of family members of patients with advanced cancer in an acute hospital being met, as measured by the modified FIN?

**Ethics**

Permission to conduct this study was obtained from the Ethics Committee of Edith Cowan University recognising reciprocal arrangements with Sir Charles Gairdner Hospital.
Prospective participants were given an information sheet outlining the study and giving the name of an independent person to contact to obtain further information on the study if needed.

Participants were assured of confidentiality.

The families participating in phase 3 were asked to complete basic information about the patient, therefore eliminating the need to access patient records.

They were informed that participation was voluntary and that they could withdraw from the study at any time. An assurance was given that refusal to participate or withdrawal from the study would in no way affect the care of the patient or the family.

No risks were associated with this research. Some family members may experience mild anxiety as a result of participation in the interview or completion of the questionnaire. The research nurse had experience in caring for the families of patients with advanced cancer and was able to offer support to the participants if needed. Referral to the appropriate staff at Sir Charles Gairdner Hospital or Silver Chain could have been offered to the families if needed for additional support and information. Once data had been collected in each phase of the study, families could have been referred to the appropriate staff for more information if necessary.

The participants were informed that there was no cost to them, but the potential benefits were to improve the care for future families of patients with advanced cancer receiving care at acute hospitals.

The principal investigator, the two supervisors and research assistant had access to the research records, which were stored in locked filing cabinets in the department of nursing at the hospital where this study was undertaken. Computer files used for data entry were protected by a password known only to the researcher. Signed consent forms and lists of participants are kept in separate files in a locked filing cabinet separate from the raw data. No names were used when collecting data or entering it onto the computer, each participant was allocated a code number and all data was entered under these code numbers. The raw data will be destroyed by shredding five years after the completion of the study. Computer databases will be deleted and computer discs will be erased.
Chapter Five: Results

Results Phase I

Family Demographic Data

Of the eight family members interviewed, three were from the same family. The family members ranged in age from 32 to 81 years, with a mean age of 61 years. There were four male and four female, consisting of two sons, three wives, two husbands and one daughter in law. Six (75%) lived with the patient.

Four (50%) were born in Australia, three (37.5%) were born in England and one (12.5%) was born in Holland. Seven (87%) had English as their first language and one reported Dutch as her first language, but stated that her understanding of English was very good.

The level of education achieved was as follows: less than high school four (50%), trade or TAFE two (25%) and two (25%) had degrees. The family members were between 4 and 6 months from bereavement, with a mean of 5.5 months and a median of 6 months.

The adjusted mean scores for the General Functioning subscale of the FAD for these families ranged from 1 to 1.91, with a mean score of 1.5 and a median score of 1.58. These scores for the General Functioning subscale of the FAD indicate that there was a limited range of families and family functioning within this group of families and that the families represented had a high level of family functioning.

Patient Demographic Data

There were six patients represented, as there were three family members from the same family interviewed. The patients ranged in age from 70 to 80 years with a mean age of 74 years. There were three male and three female patients.

The diagnoses consisted of breast cancer with bone and pulmonary metastases, cholangiocarcinoma, cancer of the parotid gland with widespread lymph
node involvement, prostate cancer with bone and liver metastases, lung cancer and bladder cancer with lymph node involvement. The time from diagnosis to death ranged from six months to seven years, with a mean time of 2.9 years and a median of 1.5 years.

Three (50%) of the patients had had only one admission to hospital and the remaining three (50%) had multiple admissions. There was one family member involved in the care of the patient in three (50%) of cases, two (33%) had three family members involved and one (16%) had more than three family members involved in the care of the patient.

**Interview Results**

This section describes the main discussion points that emerged during the interviews with the bereaved family members. These have been reported under the headings of prognosis, disease and treatment, information about caring for the patient, the source of the information and issues about the manner in which the information was communicated. The three family members from the same family reported significantly different experiences from each other and accordingly their experiences are represented as individual family members.

**Prognosis**

All of the family members interviewed wanted accurate and timely information about prognosis. Three family members felt that the information they received regarding prognosis was appropriate and timely and had no significant issues about this aspect of the information sharing. One family member described in detail the many multi-disciplinary family meetings that took place, in which all questions related to prognosis were answered.

Three family members were not happy with the information provided to them about the prognosis of their family member. One participant described his mother
who had breast cancer: she had been told that she had 12 months to live, but she was extremely tired and stated that she wanted to die. She was admitted to the acute hospital environment for “rehabilitation”. During this admission to hospital, the medical team determined that the patient was terminal, but the son was not informed for several days that his mother was terminal, and was encouraging her to get out of bed and eat, as he considered that she was in hospital for rehabilitation. The weekend before this patient died, she was extremely distressed, experiencing pain and restlessness. As this was the weekend, the specialist teams were not available and the son said that even though he had the phone number of the specialist involved in the patient’s care, he did not call him because he felt that he “may need him at a later time.” The son stated that he had received extremely poor communication from the junior medical team on duty over the weekend, saying, “if only they told me what was happening.” He stated that he believed that the nurses knew that the patient’s condition was terminal as after her death they told him that they had felt powerless to intervene in her care over the weekend. The son now feels an immense amount of guilt about his mother’s last weekend. If he had been aware of her poor prognosis he would have allowed her to rest, would not have forced her to eat and would have made the call to the specialist in order to improve the standard of her symptom control.

Another family member knew that his wife was terminal, but was not told that her death was imminent on the night that she died and was therefore not given an opportunity to stay with her. This situation arose due to poor communication between members of the team caring for the patient. The nursing staff asked him to remain at the hospital until he had spoken to the doctor caring for the patient. He spoke to the registrar who gave him no additional information about the patient’s condition and thus he went home. The next day after his wife had died, he learned from the nurses that it was the resident who had wanted to speak to him to tell him of the imminent death of his wife, and to suggest he stay with her for the night. The impact of this poor communication between the staff and subsequently the husband has had a lasting negative impact on him. He had always promised his wife that he would remain with her when she died.

The third family who described issues of poor communication regarding prognosis stated that the patient was told that he was “all clear” approximately six
weeks before his death. Three weeks later, he was told he had several months, and died two weeks after this date. Although the family was unaware of the poor prognosis of the patient, they had considered that the patient may have known his prognosis and not told them in order to protect them, or did not understand the information he was given. His son stated that “it comes down to what he was told or what he understood.” The family was still extremely upset about the inaccurate information that they were given about the prognosis of the patient.

Disease and Treatment

All family members interviewed stated that information about the disease was extremely important to them.

Only one family member felt that adequate information about the disease had been given. One participant did not know the name of his wife’s cancer until he read the death certificate. Another participant was shown a video related to cancer. She found this very useful. The most useful piece of information she gleaned from the video was that cancer was not contagious. This was of extreme significance to her as her daughter had died of cancer eight years previously, and she had not understood at that time that cancer was not contagious and therefore had had minimal physical contact with her daughter, even though she was her primary carer.

Information about the disease, the side effects of treatment and medications were extremely important to all families interviewed. One patient had severe lymphoedema as a side effect of a second course of radiotherapy and the family was angry about not being told of the chances of this occurring. They stated that if they had been given this information, knowing that the prognosis was poor, they would not have agreed to the treatment.

One participant described how her husband had surgery six times in a few months, and stated that if they had known the extent of the surgery and the fact that the outcome was not going to be a cure, they would not have agreed to the surgery.
The families all agreed that they were keen to receive information about changes in treatment and the rationale for these to occur. All family members described the importance of information about the medications that the patients were receiving, the reason for the medications, their possible side effects and the rationale for adjustments to medications. One participant stated that he had received very good information about medication from the team, but made comments such as “she became drowsy once the morphine pump was started, as ‘...we all wanted her to die’”, while he felt that he had adequate information, he had not understood the role of the morphine pump. Similarly with the removal of intravenous hydration from a terminal patient, the husband stated that he felt that the staff were removing the hydration because “they wanted her to die.” His daughter-in-law who was a nurse then explained the rationale for the removal of the fluids. He was very happy with this decision once he fully understood it.

All family members commented on the importance of information related to opioids such as morphine and all described the usefulness of information related to terminal illness and opioid addiction.

One family member described the importance to him of being informed by the nurses that his wife was aware, despite being very drowsy. He wished that he had received this information earlier, as when he started involving his wife in conversation she would smile and respond in small ways.

**Information about Caring for the Patient**

Three families discussed the fact that they needed to be informed about how to care for the patient, both in hospital and after discharge. Staff did not volunteer this information and families found it difficult to pin the staff down to obtain the facts that they needed.

Information about financial assistance was a gap identified by one participant who stated that she only discovered after her husband died that she would have been entitled to this assistance.
The Source of the Information

All family members stated that medical staff gave the majority of information they received in relation to the disease, prognosis, treatments and medications. On further questioning, all families stated that resident medical officers had given significant information to them. However the families felt that these junior doctors were often not able to give the level of detail and information that the families wanted and needed.

Two families described the final admission to hospital for their family members when they were forced to wait in the Emergency Department for 12 hours before a bed became available. They described the frustration of having to repeat information in the Emergency Department to nurses as well as to Emergency Department doctors and doctors from the specialty team before the patients were admitted.

Three families described the difficulties that they had understanding the roles of different teams providing care to their patient. The three families commented that they felt that the communication between these teams was often very poor and that the teams all gave conflicting information to the patient and to the family. One family member stated that four teams visited her husband on the day of his death.

All family members described the role of the nurses in relation to information giving. The nurses gave a great deal of information on the nursing care that the patients were receiving. All families praised the nurses for the way in which they kept the families informed about procedures and the essential care that was being given.

Nurses were also credited with keeping the families informed about medications. In particular, the actions, side effects and reasons for change being made to medication orders.

All families stated that the nurses were responsible for giving information related to nursing care, medications and other issues such as how to provide care at home. The families felt that giving information on issues such as disease and prognosis was not the role of the nursing staff.
Several participants discussed at length their perception that the nurses often had the information that they needed, but were not in a position to disclose this information to the families.

**Issues Related to the Manner in which Information was Communicated**

Of the eight family members interviewed, only one was satisfied with the way in which the information was given to her and other members of her family. All other family members, while they were happy with the majority of information they received, described instances of poor communication, and the impact that this had on them. One family member described the way in which the news of his wife’s cancer was broken to them. The doctor entered the room grinning so that they thought that the news was good. The doctor stated “Oh well, you’ve got cancer. It’s in your blood.” The patient and her husband were stunned and the patient then asked, “Am I going to die?” The doctor replied “Oh yes”.

Two families described poor communication processes when being asked to sign the Not for Resuscitation form. In both cases a junior medical officer that neither family had met before approached them to discuss this issue and the important communication took place at the nurses’ station which is a very public venue. One family member was so distressed by the way in which these doctors described the issues surrounding resuscitation and the fact that the patient would not receive care in the Intensive Care Unit, that she decided to discuss this with her husband herself and not accept the doctor’s offer of doing so.

Most families felt that they wanted honest communication from all members of the team including medical, nursing and allied health staff.

Privacy was extremely important to all family members interviewed. The family members stated that communication and information sharing was easier when they were in a single room or given access to an area where a private conversation was possible. The families stated that these areas were difficult to find in an acute hospital.

All families interviewed felt it was important that information was given to them in terms that were understandable to them. Only one of the family members
interviewed had no complaints about the technical level at which the information was imparted. One family member who was blind said that all information given to her was too technical and that she understood very little of it. One family member observed that the level at which the information was given to him was directly related to how he dressed. When he attended the hospital on the weekend in his casual clothes, he was treated very differently to when he attended the hospital during the week in his business suit.

All families interviewed stated that they were often confused about which member of the team was the most appropriate to provide them with the information that they needed. In addition they all stated that they would like something in writing with the name and contact numbers of the appropriate medical staff member for them to contact.

There was difficulty for families visiting on weekends and in the evenings, as the team caring for the patient was usually not available.

All participants stated that they found any written information given to them was extremely helpful particularly in relation to disease, treatments, side effects of treatments, medications and side effects of medications and diet.

Summary

The information gained from the semi-structured interviews with bereaved family members confirmed the literature in relation to the information needed by families. Families wanted accurate information about prognosis, disease, treatments and assistance available to them. They wanted this information to be communicated in a caring manner with attention to privacy.
Results Phase IIa

Review of the FIN for Clarity and Content Validity

At the completion of the semi-structured interviews the families were asked to review the FIN for clarity and content validity. They were required to answer the following questions.

Clarity.

Question 1: Do you understand what this questionnaire is for?

Six of the eight participants answered in the affirmative. The two who gave a negative answer, needed further explanation as to the purpose of the FIN and stated that the explanation for the purpose of the FIN could be worded more clearly.

Question 2: Are the instructions clear?

Five of the seven (The eighth participant was visually impaired and unable to comment on the instructions) felt that the instructions were clear, and two stated that a different layout and format would be easier to follow.

Question 3: Do you understand each of the statements of need?

Eight out of 8 family members understood the statements of need.

The results are summarised in Table 1

41
Table 1

Results of Phase IIa Clarity of the F/N

<table>
<thead>
<tr>
<th>Questions</th>
<th>Number who answered yes: n=</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Do you understand what this questionnaire is for?</td>
<td>6</td>
<td>75</td>
</tr>
<tr>
<td>2. Are the instructions clear?</td>
<td>5 of 7</td>
<td>71</td>
</tr>
<tr>
<td>3. Do you understand each of the statement of need?</td>
<td>8</td>
<td>100</td>
</tr>
</tbody>
</table>

**Content Validity.** The families were asked the question: “For each statement of need, is this a suitable item to identify the information needs of families of cancer patients in an acute hospital?” They were also asked, “Does the tool as a whole measure the information needs of families?”

To measure content validity each of the “yes” answers to the above questions were collated and given a score out of 8. Percent agreement amongst the families’ responses was used to measure the extent to which the FIN demonstrated content validity. According to Lynn (1986), five out of six agreement is adequate.
<table>
<thead>
<tr>
<th>I need to:</th>
<th>Number who felt this to be a suitable item: n=</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Have my questions answered honestly</td>
<td>6</td>
<td>75</td>
</tr>
<tr>
<td>2. Know specific facts concerning the patient's prognosis</td>
<td>8</td>
<td>100</td>
</tr>
<tr>
<td>3. Feel that the health professionals care about the patient</td>
<td>6</td>
<td>75</td>
</tr>
<tr>
<td>4. Be informed of changes in the patient's condition</td>
<td>8</td>
<td>100</td>
</tr>
<tr>
<td>5. Know exactly what is being done for the patient</td>
<td>8</td>
<td>100</td>
</tr>
<tr>
<td>6. Know what treatment the patient is receiving</td>
<td>8</td>
<td>100</td>
</tr>
<tr>
<td>7. Have explanations given in terms that are understandable</td>
<td>8</td>
<td>100</td>
</tr>
<tr>
<td>8. Be told about treatment plans while they are being made</td>
<td>8</td>
<td>100</td>
</tr>
<tr>
<td>9. Feel there is hope</td>
<td>6</td>
<td>75</td>
</tr>
<tr>
<td>10. Be assured the best possible care is being given to the patient</td>
<td>7</td>
<td>87.5</td>
</tr>
<tr>
<td>11. Know what symptoms the treatment or disease can cause</td>
<td>8</td>
<td>100</td>
</tr>
<tr>
<td>12. Know when to expect symptoms to occur</td>
<td>8</td>
<td>100</td>
</tr>
<tr>
<td>13. Know the probable outcome of the patient's illness</td>
<td>8</td>
<td>100</td>
</tr>
<tr>
<td>14. Know why things are being done for the patient</td>
<td>8</td>
<td>100</td>
</tr>
<tr>
<td>15. Know the names of health professionals involved in the patient's care</td>
<td>8</td>
<td>100</td>
</tr>
<tr>
<td></td>
<td>Description</td>
<td>Count</td>
</tr>
<tr>
<td>---</td>
<td>-----------------------------------------------------------------------------</td>
<td>-------</td>
</tr>
<tr>
<td>16.</td>
<td>Have information about what to do for the patient at home</td>
<td>8</td>
</tr>
<tr>
<td>17.</td>
<td>Feel accepted by the health professionals</td>
<td>7</td>
</tr>
<tr>
<td>18.</td>
<td>Help with the patient's care</td>
<td>7</td>
</tr>
<tr>
<td>19.</td>
<td>Have someone be concerned with my health</td>
<td>7</td>
</tr>
<tr>
<td>20.</td>
<td>Be told about people who could help with problems</td>
<td>8</td>
</tr>
</tbody>
</table>

The following describes the comments made by the family members about each item in the FIN.

**Item 1: Have my questions answered honestly**

Two participants felt that this item was open to misinterpretation. One stated "the item has too much scope, who and what is it directed at? Is it about the disease or has my husband eaten breakfast?"

A second participant felt that it was not an appropriate question. "If I answer no to this item, then there is no point in completing the remainder of the questionnaire!"

The remainder of the participants conveyed passionately their desire for and expectation of honest information from the staff.

**Item 2: Know specific facts concerning the patient's prognosis**

While all felt this item should remain, one commented that the timing of this information is very important. "I wanted this information early in the piece when there was several years to go, not when my husband was very sick." As stated in the previous section, those families who did not have accurate or timely information regarding the prognosis of the patient, had experienced many consequences of this, including sadness and guilt.
**Item 3: Feel that the health professionals care about the patient**

Two of the families stated that while they did feel it was important to know that the health professionals cared about the patient, they did not see this as an information need and that it could therefore be excluded from the tool.

The remainder of the participants said that it was important for them to feel that the staff cared about the patient and accordingly several families felt that this enabled them to cope better with the situation.

**Item 4: Be informed of changes in the patient's condition**

All families wanted this item to be included in the tool. Many family members stated that while they often could see that the condition of the patients had changed, when no information on this was forthcoming from staff, this caused a great deal of anxiety for them.

**Item 5: Know exactly what is being done for the patient**

All participants stated that they wanted this item to be included in the tool. One family member commented that “Staff seem to assume that we know what is going on. How we are supposed to know when no one tells us is beyond me! Some teams are better than others at giving this information and you can always rely on the nurses to fill you in. But we mostly have to ask.”

**Item 6: Know what treatment the patient is receiving**

All participants stated that this was an important item for this tool.

**Item 7: Have explanations given in terms that are understandable**

All family members interviewed stated that this was a very relevant item with regard to their information needs. Several commented on the fact that at various meetings, interviews and conversations with medical and nursing staff information had been given that they had not understood well.
**Item 8: Be told about treatment plans while they are being made**

All families interviewed wanted to be told about treatment plans while they were being made. They felt that this gave them the opportunity to help the patient in decision-making and have full information about the rationale for treatment decisions.

**Item 9: Feel there is hope**

There was a great deal of discussion regarding the issue of hope and whether it should be an item in this questionnaire.

Some initially felt that as they knew that the patient was dying, there was no point in discussing hope. “It is a very difficult one to answer”, another stated “I only want to feel there is hope if it is true.” Another stated “if there is no hope I want to know that.”

There was discussion regarding the importance of putting hope into the context of the patient’s condition and while the hope may not be for a cure, it may be for more realistic aims, such as being able to go home, or good pain control.

Two of the eight family members stated that this item should not be included, as it was a difficult issue to rate on the scale and would not provide valid information, while the other six wanted the item included due to its perceived importance.

**Item 10: Be assured the best possible care is being given to the patient**

One participant felt that this item could be excluded from the tool, as it did not precisely measure information needs. The remaining seven participants felt that the item was important and should be included as it was essential information for them to possess.

**Item 11: Know what symptoms the treatment or disease can cause**

All participants were insistent that this item was included in the tool. Many gave examples of the consequences of not being informed of the symptoms that the
treatment or disease could cause, including decisions that they regretted. An example of this was outlined by one family member in relation to the side effects of repeat radiotherapy treatment that the patient had received, concluding that with forewarning of the possibility of these side effects, the patient would probably not have agreed to the treatment.

**Item 12: Know when to expect symptoms to occur**

All participants stated that this was an important information need.

**Item 13: Know the probable outcome of the patient’s illness**

All participants stated that this was an important information need. Several family members comments on the similarity with item 2, but wanted both items to be included as they felt that they were relevant for different times in the disease journey.

**Item 14: Know why things are being done for the patient**

All participants stated that this item was an important item for inclusion in the tool. They discussed this particularly in relation to day-to-day care on the ward. This included such things as routine nursing care to tests that were being undertaken.

**Item 15: Know the names of health professionals involved in the patient's care**

All family members felt that this item should be included in the tool. They all commented on the large numbers of teams involved in the care of the patient and the difficulty of knowing the identity and role of each team member in relation to the patient’s care.
**Item 16:** Have information about what to do for the patient at home

All participants felt that this item needed to be included in the tool. All families had at some stage taken the patient home from hospital and felt that while they were given some information, it was never adequate.

**Item 17:** Feel accepted by the health professionals

One of the families did not feel that the need to feel accepted by the health professionals fitted into this tool as an information need. The remaining participants stated that this was an essential aspect of the nurse (and other health professionals) and family communication.

**Item 18:** Help with the patient’s care

One of the eight families stated that the need to help with the patient’s care was not an information need and thus did not need to be included in this tool. Several other family members described the importance to them of having the skills and permission from the staff to assist with the patient’s care and how this assisted them to cope with the difficult situation in the hospital. These family members felt strongly that this should be included in the tool.

**Item 19:** Have someone be concerned with my health

One of the participants stated that while they did need to have someone concerned for their health, they did not regard this as an information need and therefore did not consider it belonged as an item in this tool.

**Item 20:** Be told about people who could help with problems

All participants stated that this item should be included in the tool. The majority of the families had accessed assistance from services such as social work, Silver Chain, and occupational therapy. These families all stated that they would have benefited from earlier referral to these services.
All family members agreed that the tool as a whole measured the information needs of families and none of the family members identified items that were missing from the tool. The issue of privacy was discussed as a possible item for the tool with all families, but while all felt that privacy was very important to them in relation to their information needs, they did not feel that it belonged as an item on this tool.

The FIN was then modified based on the feedback from the families. (See Appendix H).

The modifications included the following changes.

The instructions for the FIN were adjusted and simplified based on the feedback from the families in Phase I. In addition, a change in the layout of the FIN was incorporated, based on the modifications made to the FIN-PED (Whitely, 1999), to include Part A and Part B. Part A being “the importance of needs” and Part B “the degree to which the need was met. In Part A, the families were previously asked to rate the importance of needs with a number from 1 to 5, 1 (important), 2 (somewhat important), 3 (average importance) 4 (very important) and 5 (extremely important). They were asked to place the number 1-5 next to the statement of need. If the number was rated higher than 1 then they were asked to rate whether the need was “met”, “partly met” or “unmet”.

In the modified tool, Part A has the statement “How important is this need to you now?” The families are then asked to rate the importance as “not at all, a little, somewhat, very much, and extremely,” by circling the numbers 0 to 4, 0 (not at all) through to 5 (extremely). In Part B the families were asked to rate “how well has this need been met for you?” The statements for part B were “not a need, not met at all, partly met, well met, completely met,” and the families rated this by circling the numbers 0 to 4, 0 representing (not a need) through to 4 representing (completely met).
Results Phase IIb

In Phase IIb, six experienced cancer nurses from the acute hospital environment were asked to assess the modified FIN for clarity and content validity. The average age of the nurses was 40.8 years, with a range of 30 to 54 years. Two nurses (33.3%) had less than five years experience in cancer nursing and four (66.6%) had greater than five years experience in cancer nursing.

In order to assess for clarity, the participants were asked the following questions:

**Question 1:** Do you understand what this questionnaire is for?

**Question 2:** Are the instructions clear?

**Question 3:** Do you understand each of the statements of need?

Table 3

**Results of Phase IIb Clarity of the Modified FIN**

<table>
<thead>
<tr>
<th>Questions</th>
<th>Number who answered yes: n=</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Do you understand what this questionnaire is for?</td>
<td>6</td>
<td>100</td>
</tr>
<tr>
<td>Are the instructions clear?</td>
<td>6</td>
<td>100</td>
</tr>
<tr>
<td>Do you understand each of the statement of need?</td>
<td>6</td>
<td>100</td>
</tr>
</tbody>
</table>

In order to assess for content validity the participants were asked the question: for each statement of need, "is this a suitable item to identify the information needs of families of cancer patients in an acute hospital?"

If they answered no to any question they were asked to provide comment.
They were also asked to identify if there was anything missing from the questionnaire and "does the tool as a whole measure the information needs of families?"

Table 4

**Results Phase IIb Content Validity of the Modified FIN**

<table>
<thead>
<tr>
<th>I need to:</th>
<th>Number who felt this to be a suitable item: n=</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Have my questions answered honestly</td>
<td>6</td>
<td>100</td>
</tr>
<tr>
<td>2. Know specific facts concerning the patient's prognosis</td>
<td>6</td>
<td>100</td>
</tr>
<tr>
<td>3. Feel that the health professionals care about the patient</td>
<td>6</td>
<td>100</td>
</tr>
<tr>
<td>4. Be informed of changes in the patient's condition</td>
<td>6</td>
<td>100</td>
</tr>
<tr>
<td>5. Know exactly what is being done for the patient</td>
<td>6</td>
<td>100</td>
</tr>
<tr>
<td>6. Know what treatment the patient is receiving</td>
<td>6</td>
<td>100</td>
</tr>
<tr>
<td>7. Have explanations given in terms that are understandable</td>
<td>6</td>
<td>100</td>
</tr>
<tr>
<td>8. Be told about treatment plans while they are being made</td>
<td>6</td>
<td>100</td>
</tr>
<tr>
<td>9. Feel there is hope</td>
<td>6</td>
<td>100</td>
</tr>
<tr>
<td>10. Be assured the best possible care is being given to the patient</td>
<td>6</td>
<td>100</td>
</tr>
<tr>
<td>11. Know what symptoms the treatment or disease can cause</td>
<td>6</td>
<td>100</td>
</tr>
<tr>
<td>12. Know when to expect symptoms to occur</td>
<td>6</td>
<td>100</td>
</tr>
<tr>
<td>13. Know the probable outcome of the patient's illness</td>
<td>6</td>
<td>100</td>
</tr>
</tbody>
</table>
14. Know why things are being done for the patient 6 100
15. Know the names of health professionals involved in the patient's care 6 100
16. Have information about what to do for the patient at home 6 100
17. Feel accepted by the health professionals 5 83.3
18. Help with the patient's care 5 83.3
19. Have someone be concerned with my health 5 83.3
20. Be told about people who could help with problems 6 100

Comments were made for the following items:

**Item 9: Feel there is hope**

While the participant felt that this item should be included in the tool, the comment was made that it may be difficult for some families to rate.

**Items 17 and 18: Feel accepted by the health professionals/ Help with the patient’s care**

One participant stated, “these don’t fit with the other statements, as information needs.”

**Item 19: Have someone be concerned with my health**

One participant stated that this item was “irrelevant-how does health status of family members affect their information needs?”

None of the participants identified items that were missing from the tool and all agreed that the tool as a whole was suitable to measure the information needs of families.

As described earlier Lynn (1986), states that a minimum of five experts is required to determine content validity.
No more than two experts assessed any aspect of the tool as not belonging to the tool, therefore confirming the content validity of the tool.

**Results Phase III**

The main aim of this phase of the study was to test the modified FIN for reliability and validity and to gain useful clinical information regarding the priority information needs of this group of families and the extent to which these needs have been met.

From June 2002 to January 2003 61 families of patients with advanced cancer who were inpatients or attending the Palliative Care clinic at large teaching hospital in Perth, Western Australia, agreed to participate in the study.

**Patient Demographics**

The following data describes the demographic characteristics of the patients in the sample. The demographic data for 60 patients was obtained. One family did not report information related to the patient. There were 34 (56.7%) male and 26 (43.3%) female patients. The mean age was 61.05 years with a standard deviation of 15.81 and a range of 6 to 82 years. Information from the family of the child was included as the child was receiving specific treatment only available at this hospital.

The primary tumour site was lung 14 (23.3%), breast eight (13.3%), prostate seven (11.7%), bowel five (8.2%), brain three (5.0%) and other 23 (38.3%). The other category was grouped to include lymphomas five, head and neck five, leukaemias three, multiple myeloma two, melanoma two, pancreas one, bladder one and spine one. Secondary spread was present in 45 (80.4%) of patients. There were five missing cases from this data.

The number of years since diagnosis ranged from 0 to 15 years, with a mean of 2.9 years, median of 1.43 years and a standard deviation of 3.54 years. Sixty one percent of the patients had one year or less since diagnosis. There were six missing cases from this data.
Figure 3. Frequency Histogram: Years since Diagnosis

The numbers of admissions of the patient to hospital were identified and were as follows, one patient (1.7%) had no admissions, 14 patients (23.7%) had one admission, 30 patients (50.8%) had two to five admissions and 14 patients (23.7%) had more than five admissions. There were two missing cases from this data.

Eight patients (13.3%) had zero outpatient visits, 13 (21.7%) had one to five outpatient visits and 39 (63.9%) had more than five outpatient visits. There was one missing case from this data.

This data indicates that this group of patients had had significant contact with the hospital both as inpatients and through outpatient visits.

Twenty eight (46.7%) of the patients had one family member involved in their care, 28 (46.7%) had one to five family members involved and four (6.7%) had more than five family members involved in their care.
**Family Demographics**

The following data describes the demographic characteristics of the families in the sample.

There were 43 female (70.5%) and 18 male (29.5%). The mean age was 54.62 years with a standard deviation of 15.52 and range of 20 to 81 years.

The most common relationship of each respondent to the patient was wife 22 (36.1%), followed by husband 12 (21.1%), daughter nine (15.8%), partner three (5.3%) son, mother and sister three each (5.3%) and brother and father one each (1.8%). Forty-six of the family members in the sample (76.2%) lived with the patient.

Forty (65.6%), were born in Australia with 18 (29.5%) born in the UK, two (3.3%) born in Europe and one (1.6%) born in South America. English was the first language for 59 (96.7%) and 100% stated that their English was good.

More than half of the family members, 34 (55.7%), had completed high school, while six (9.8%) had completed less than high school, seven (11.5%) had completed a trade or TAFE, 11 (18%) had a diploma or degree and three (4.9%) a higher degree.

**FAD Results**

The mean score for the General Functioning subscale of the FAD, which measures the overall health and functioning of the family, was 1.81 with a standard deviation of 0.53, a median of 1.81 and a range of 1.00 to 3.58. These scores indicate that on average, the families in the sample were healthy in terms of general functioning, but there was a range of levels of family functioning represented in the sample.

Table 5 indicates the mean scores for each item in the General Functioning subscale of the FAD. The mean scores ranged from 1.46 (Item 2: in times of crisis we turn to each other for support) to 2.27 (Item 3: we cannot talk to each other about the sadness we feel). These scores indicate that the families generally were able to
gain support from each other, but they were not as healthy in terms of being able to talk to each other about their feelings. There were two to four missing cases on each item of this data.

**Table 5**

**Mean FAD Scores and Standard Deviation for Each Item**

<table>
<thead>
<tr>
<th>Domain</th>
<th>Mean Score</th>
<th>S.D.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Planning family activities is difficult because we misunderstand each other</td>
<td>2.10</td>
<td>1.00</td>
</tr>
<tr>
<td>In times of crisis we can turn to each other for support</td>
<td>1.46</td>
<td>0.65</td>
</tr>
<tr>
<td>We cannot talk to each other about the sadness we feel</td>
<td>2.27</td>
<td>0.98</td>
</tr>
<tr>
<td>Individuals are accepted for what they are</td>
<td>1.71</td>
<td>0.70</td>
</tr>
<tr>
<td>We avoid discussing our fears and concerns</td>
<td>2.15</td>
<td>0.88</td>
</tr>
<tr>
<td>We can express feelings to each other</td>
<td>1.76</td>
<td>0.68</td>
</tr>
<tr>
<td>There are lots of bad feelings in the family</td>
<td>1.60</td>
<td>0.72</td>
</tr>
<tr>
<td>We feel accepted for what we are</td>
<td>1.75</td>
<td>0.80</td>
</tr>
<tr>
<td>Making decisions is a problem for our family</td>
<td>1.80</td>
<td>0.78</td>
</tr>
<tr>
<td>We are able to make decisions about how to solve problems</td>
<td>1.73</td>
<td>0.61</td>
</tr>
<tr>
<td>We don’t get along well together</td>
<td>1.71</td>
<td>0.79</td>
</tr>
<tr>
<td>We confide in each other</td>
<td>1.76</td>
<td>0.68</td>
</tr>
</tbody>
</table>
The General Functioning Subscale of the FAD was assessed for internal consistency reliability using Cronbach's alpha coefficient. Cronbach's alpha is a widely used method of determining internal consistency. The normal range of values is between 0.0 and +1.00, the higher the value the higher the degree of internal consistency.

The General Functioning subscale of the FAD demonstrated an internal consistency rating of 0.85 as measured by Cronbach's alpha coefficient, which was greater than the preset criterion of 0.80. (Polit and Hungler, 1995).

**FAMCARE Scale**

The mean score for the FAMCARE scale, which measured the families' satisfaction with advanced cancer care, was 79.25, with a range of 44 to 100 and standard deviation of 11. This is a high score, which indicated that the families were generally satisfied with the care that they received.

The two highest rating items describing the families’ satisfaction with care were: item 1: “the patient’s pain relief” and item 2: “the way tests and treatments were performed.” The two lowest scoring items were item 19: “information given about the patient’s tests” and item 20: “family conferences held to discuss the patient’s illness.”

Table 6 illustrates the mean scores in descending order of mean satisfaction, for each statement on the scale.
### Table 6

**Mean Scores and Standard Deviation for the FAMCARE Scale Items in Descending Order of Mean Satisfaction**

<table>
<thead>
<tr>
<th>Statement of satisfaction. How satisfied are you with:</th>
<th>Mean Score</th>
<th>S.D.</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. The patient’s pain relief</td>
<td>4.45</td>
<td>0.67</td>
</tr>
<tr>
<td>2. The way tests and treatments are performed</td>
<td>4.38</td>
<td>0.76</td>
</tr>
<tr>
<td>3. Coordination of care</td>
<td>4.26</td>
<td>0.80</td>
</tr>
<tr>
<td>4. Doctor’s attention to patient’s description of symptoms</td>
<td>4.20</td>
<td>0.87</td>
</tr>
<tr>
<td>5. Availability of nurses to the family</td>
<td>4.18</td>
<td>0.83</td>
</tr>
<tr>
<td>6. How thoroughly the doctor assesses the patient’s symptoms</td>
<td>4.18</td>
<td>0.74</td>
</tr>
<tr>
<td>7. The way tests and treatments are followed up by the doctor</td>
<td>4.14</td>
<td>0.71</td>
</tr>
<tr>
<td>8. Referrals to specialists</td>
<td>4.13</td>
<td>0.85</td>
</tr>
<tr>
<td>9. Answers from health professionals</td>
<td>4.08</td>
<td>0.94</td>
</tr>
<tr>
<td>10. Availability of the doctor to the patient</td>
<td>4.05</td>
<td>0.87</td>
</tr>
<tr>
<td>11. Time required to make a diagnosis</td>
<td>4.04</td>
<td>0.86</td>
</tr>
<tr>
<td>12. Speed with which symptoms are treated</td>
<td>3.98</td>
<td>1.02</td>
</tr>
<tr>
<td>13. Information given about how to manage the patient’s pain</td>
<td>3.95</td>
<td>0.93</td>
</tr>
<tr>
<td>14. Information provided about the patient’s prognosis</td>
<td>3.83</td>
<td>0.89</td>
</tr>
<tr>
<td>15. Availability of doctors to the family</td>
<td>3.82</td>
<td>1.08</td>
</tr>
<tr>
<td>16. Information about side effects</td>
<td>3.70</td>
<td>1.11</td>
</tr>
<tr>
<td>17. The way the family is included in treatment and care decisions</td>
<td>3.67</td>
<td>1.13</td>
</tr>
<tr>
<td>18. Availability of a hospital bed</td>
<td>3.65</td>
<td>1.35</td>
</tr>
<tr>
<td>19. Information given about the patient’s tests</td>
<td>3.47</td>
<td>1.16</td>
</tr>
<tr>
<td>20. Family conferences held to discuss the patient’s illness</td>
<td>3.27</td>
<td>1.25</td>
</tr>
</tbody>
</table>
The FAMCARE scale demonstrated an internal consistency rating of 0.93, as measured by Cronbach's alpha coefficient, which was greater than the preset criterion of 0.80.

Nunnally (1978), recommends that 50% of items meet the item-to-total correlation of 0.40 to 0.70, with items greater than 0.70 representing redundant information and items less than 0.40 representing items that do not fit within the scale. Thirteen of the 20 items (65%) in the FAMCARE scale met the preset criterion of 50% item-to-total correlation between 0.40 and 0.70. Those items which exceeded the preset criterion, are documented in Table 7.

**Table 7**

<table>
<thead>
<tr>
<th>Item number</th>
<th>Satisfaction Statement</th>
<th>Item-Total Correlation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Item 2</td>
<td>Information provided about the patient's prognosis</td>
<td>0.72</td>
</tr>
<tr>
<td>Item 7</td>
<td>Availability of a hospital bed</td>
<td>0.74</td>
</tr>
<tr>
<td>Item 10</td>
<td>The way tests and treatments are performed</td>
<td>0.75</td>
</tr>
<tr>
<td>Item 11</td>
<td>Availability of doctors to the family</td>
<td>0.75</td>
</tr>
<tr>
<td>Item 13</td>
<td>Coordination of care</td>
<td>0.72</td>
</tr>
<tr>
<td>Item 17</td>
<td>Information given about the patient's tests</td>
<td>0.75</td>
</tr>
<tr>
<td>Item 20</td>
<td>Availability of the doctor to the patient</td>
<td>0.73</td>
</tr>
</tbody>
</table>

As none of these items greatly exceeded the preset criterion they should all remain as items in the tool.

**Internal Consistency of the Modified FIN**

Analysis of the modified FIN was based upon the data obtained at time one (t1) because the t1 data was first time it was completed.
The modified FIN was assessed for internal consistency reliability using Cronbach’s alpha coefficient. The FIN Part A achieved an alpha of 0.91 and the FIN Part B achieved an alpha of 0.92, both exceeding the preset criterion of 0.80 and therefore satisfying the criterion for reliability. Seventeen of the twenty items (85%) in the FIN part A met the preset criterion of 50% item-to-total correlation between 0.40 and 0.70. Item 19 “have someone be concerned with my health” attained an item-to-total correlation of 0.30 suggesting that this item may be less consistent with other items in the scale. Other needs in the FIN Part A which exceeded 0.70 were need 7 “have explanations given in terms that are understandable” with a score of 0.74 and need 18 “help with the patient’s care” with a score of 0.72.

In the FIN Part B eighteen (90%) of the items met the preset criterion of 50% item-to-total correlation between 0.40 and 0.70. Item 9 “feel there is hope” measured 0.35 and item 11 “know what symptoms the treatment or disease can cause” measured 0.74.

None of these scores vary greatly from the preset criterion.

**Stability of the Modified FIN**

Stability of the modified FIN was measured using intraclass correlation coefficient (ICC), using test-retest with a 24-hour timeframe. The 24-hour timeframe has been used previously (Kilpatrick et al, 1998) and is appropriate for this population, as the information needs of these families are likely to change over a longer timeframe. Stability measures are usually higher for short time periods for the test-retest. The ICC is used as an index of correlation between repeated measures of the same method (Bland & Altman, 1990). The return rate for the test retest was 49 of 61 (80%). The preset criterion for the test-retest was ICC = 0.80.

The FIN demonstrated an ICC of 0.91 for Part A and 0.91 for Part B. Since both of these results exceeded the preset criterion of 0.80, these results indicate that the modified FIN demonstrated stability over time.
Association Between the FAD Scores and Needs Met

The association between FAD scores and percentage of needs met was measured using Pearson's Correlation Coefficient. The correlation was $r = 0.247$ ($p=0.739$) which does not demonstrate a relationship between these two variables.

Association Between the FAMCARE Scores and Needs Met

Previous research had reported that family members who had fewer needs met were less satisfied with care (Kristjanson et al, 1997). This hypothesis was tested using Pearson’s Correlation Coefficient. The results indicated a strong negative correlation between the percentage of needs met and family care satisfaction.

The correlation was $r = -0.719$ ($p=0.000$), demonstrating a strong negative relationship between the two variables, indicating that families who had fewer unmet needs were more satisfied with care.

The Importance of Needs and the Extent to which they are Met

The modified FIN consisted of two subscales, Part A, in which the families were asked to provide a rating for each need showing “how important is this need for you now?” and Part B in which the families were asked to provide a rating for each need showing “how well has this need been met for you?”

These two subscales were scored separately.

Each rating on the FIN Part A, importance of needs, was scored as follows: 0 (not at all), 1 (a little), 2 (somewhat), 3 (very much) and 4 (extremely).

Each rating in Part B, needs met, was scored as 0 (not a need), 1 (not met at all), 2 (partly met), 3 (well met) and 4 (completely met).

A mean score for each need in Part A and Part B was determined.

The total mean score for the FIN Part A was 71.10 with a median of 73.00 and standard deviation of 8.54. This score is from a possible score of 80, indicating
that the families involved in this study had a high number of needs. There were 4 missing cases from this data.

The total mean score of the FIN Part B was 57.94 with a median of 58.00 and standard deviation of 11.76. This score is from a possible score of 80 and thus this is a low score for the number of needs met. This score cannot be taken in isolation from the importance of needs, but given that the mean score for Part A was so high this score for Part B indicated that many families with high needs had not had these needs met.

The number of needs and their frequency were calculated by counting the number of families who had rated a need as greater than or equal to 2 in Part A of the FIN. Table 8 lists the number of needs, their frequency and percent. The list starts at fifteen as no one had less than 15 (from a possible 20) needs. This table shows that 82% of the families (n=57 with 4 missing cases) had 19 or 20 needs.

In order to determine the percentage of unmet needs, the following process was adopted. The number of needs rated as important (2 or more) was divided by the number of unmet needs (not met at all or partly met) and multiplied by 100. An overall mean percentage of unmet needs was calculated. This was 29.10%.
Table 8

Frequency Distribution of Number of Needs and Percent

<table>
<thead>
<tr>
<th>Number of Needs</th>
<th>Frequency</th>
<th>Percent</th>
</tr>
</thead>
<tbody>
<tr>
<td>15</td>
<td>1</td>
<td>1.8</td>
</tr>
<tr>
<td>16</td>
<td>2</td>
<td>3.5</td>
</tr>
<tr>
<td>17</td>
<td>4</td>
<td>7.0</td>
</tr>
<tr>
<td>18</td>
<td>4</td>
<td>7.0</td>
</tr>
<tr>
<td>19</td>
<td>10</td>
<td>17.5</td>
</tr>
<tr>
<td>20</td>
<td>36</td>
<td>63.2</td>
</tr>
<tr>
<td><strong>Total</strong></td>
<td><strong>57</strong></td>
<td><strong>100</strong></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Missing cases</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Total</strong></td>
<td><strong>61</strong></td>
<td></td>
</tr>
</tbody>
</table>

As demonstrated in Table 9 the mean scores of importance ranged from 2.53 to 3.79 from a possible score of 4.00. The first 16 items had mean scores over 3.50 demonstrating that the families rated the importance of all these needs as high. The standard deviations ranged from 0.48 for the items “feel that the health professional care about the patient” and “be assured that the best possible care is being given to the patient” to 1.30 for the item “have someone be concerned for my health.”

The five highest ranked needs were: 1) “know the probable outcome of the patient’s illness” 2) “feel that the health professionals care about the patient,” 3) “be assured the best possible care is being given to the patient,” 4) “have my questions answered honestly” and 5) “know what symptoms the treatment or disease can cause.”

The five lowest ranked items were: 16) “know the names of health professionals involved in the patient’s care,” 17) “help with the patient’s care,” 18) “feel accepted by the health professionals,” 19) “be told about people who can help with problems” and 20) “have someone be concerned with my health.”
Table 9

Mean Scores and Standard Deviation of Importance of Needs in Descending Order and Mean Scores and Standard Deviation of Needs Met

<table>
<thead>
<tr>
<th>Need Statement</th>
<th>Mean Importance</th>
<th>SD</th>
<th>Mean Needs Met</th>
<th>SD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Know the probable outcome of the patient’s illness</td>
<td>3.79</td>
<td>0.56</td>
<td>2.95</td>
<td>0.87</td>
</tr>
<tr>
<td>Feel that the health professionals care about the patient</td>
<td>3.74</td>
<td>0.48</td>
<td>3.46</td>
<td>0.70</td>
</tr>
<tr>
<td>Be assured the best possible care is being given to the patient</td>
<td>3.74</td>
<td>0.48</td>
<td>3.27</td>
<td>0.73</td>
</tr>
<tr>
<td>Have my questions answered honestly</td>
<td>3.72</td>
<td>0.49</td>
<td>3.08</td>
<td>0.80</td>
</tr>
<tr>
<td>Know what symptoms the treatment or disease can cause</td>
<td>3.72</td>
<td>0.56</td>
<td>2.88</td>
<td>0.95</td>
</tr>
<tr>
<td>Have explanations given in terms that are understandable</td>
<td>3.70</td>
<td>0.50</td>
<td>3.10</td>
<td>0.80</td>
</tr>
<tr>
<td>Know exactly what to do for the patient</td>
<td>3.69</td>
<td>0.53</td>
<td>3.02</td>
<td>0.91</td>
</tr>
<tr>
<td>Know specific facts concerning the patient’s prognosis</td>
<td>3.67</td>
<td>0.54</td>
<td>2.97</td>
<td>0.88</td>
</tr>
<tr>
<td>Know why things are being done for the patient</td>
<td>3.67</td>
<td>0.55</td>
<td>3.04</td>
<td>0.73</td>
</tr>
<tr>
<td>Be informed of changes in the patient’s condition</td>
<td>3.66</td>
<td>0.54</td>
<td>2.95</td>
<td>0.84</td>
</tr>
<tr>
<td>Feel there is hope</td>
<td>3.66</td>
<td>0.70</td>
<td>2.78</td>
<td>1.03</td>
</tr>
<tr>
<td>Know what treatment the patient is receiving</td>
<td>3.64</td>
<td>0.61</td>
<td>3.10</td>
<td>0.90</td>
</tr>
</tbody>
</table>
Table 10 represents the difference between the mean importance score and the score for the mean needs met. This is important data as it represents the major problem areas for unmet needs within the study. The highest-ranking item was “have information about what to do for the patient at home” (mean difference 1.06), followed by “know when to expect symptoms to occur,” “feel that there is hope,” “know the probable outcome of the patient’s illness” and “know what symptoms the treatment or disease can cause.” The five lowest scores in Table 10 were items related to the general care of the patient and family. The lowest score (mean difference 0.28) was “feel that the health professionals care about the patient,” which was the second highest ranking need for these families as illustrated in Table 9.
<table>
<thead>
<tr>
<th>Need Statement</th>
<th>Mean Importance</th>
<th>Mean Needs Met</th>
<th>Difference Between Mean Importance and Mean Needs Met</th>
</tr>
</thead>
<tbody>
<tr>
<td>Have information about what to do for the patient at home</td>
<td>3.58</td>
<td>2.52</td>
<td>1.06</td>
</tr>
<tr>
<td>Know when to expect symptoms to occur</td>
<td>3.60</td>
<td>2.58</td>
<td>1.02</td>
</tr>
<tr>
<td>Feel there is hope</td>
<td>3.66</td>
<td>2.78</td>
<td>0.88</td>
</tr>
<tr>
<td>Know the probable outcome of the patient’s illness</td>
<td>3.79</td>
<td>2.95</td>
<td>0.84</td>
</tr>
<tr>
<td>Know what symptoms the treatment or disease can cause</td>
<td>3.72</td>
<td>2.88</td>
<td>0.84</td>
</tr>
<tr>
<td>Help with the patient’s care</td>
<td>3.43</td>
<td>2.65</td>
<td>0.78</td>
</tr>
<tr>
<td>Be told about people who could help with problems</td>
<td>3.16</td>
<td>2.42</td>
<td>0.74</td>
</tr>
<tr>
<td>Be informed of changes in the patient’s condition</td>
<td>3.66</td>
<td>2.95</td>
<td>0.71</td>
</tr>
<tr>
<td>Know specific facts concerning the patient’s prognosis</td>
<td>3.67</td>
<td>2.97</td>
<td>0.70</td>
</tr>
<tr>
<td>Know exactly what to do for the patient</td>
<td>3.69</td>
<td>3.02</td>
<td>0.67</td>
</tr>
<tr>
<td>Have my questions answered honestly</td>
<td>3.72</td>
<td>3.08</td>
<td>0.64</td>
</tr>
<tr>
<td>Know why things are being done for the patient</td>
<td>3.67</td>
<td>3.04</td>
<td>0.63</td>
</tr>
<tr>
<td>Have explanations given in terms that are understandable</td>
<td>3.70</td>
<td>3.10</td>
<td>0.60</td>
</tr>
<tr>
<td>Be told about changes in treatment plans while they are being made</td>
<td>3.54</td>
<td>2.95</td>
<td>0.59</td>
</tr>
<tr>
<td>Perception</td>
<td>Mean</td>
<td>SD</td>
<td>Reliability Coefficient</td>
</tr>
<tr>
<td>------------------------------------------------</td>
<td>------</td>
<td>-----</td>
<td>-------------------------</td>
</tr>
<tr>
<td>Know what treatment the patient is receiving</td>
<td>3.64</td>
<td>3.10</td>
<td>0.54</td>
</tr>
<tr>
<td>Be assured the best possible care is being</td>
<td>3.74</td>
<td>3.27</td>
<td>0.47</td>
</tr>
<tr>
<td>given to the patient</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Feel accepted by the health professionals</td>
<td>3.40</td>
<td>3.00</td>
<td>0.40</td>
</tr>
<tr>
<td>Know the names of the health</td>
<td>3.51</td>
<td>3.20</td>
<td>0.31</td>
</tr>
<tr>
<td>professionals involved in the patient's care</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Have someone be concerned with my health</td>
<td>2.53</td>
<td>2.23</td>
<td>0.30</td>
</tr>
<tr>
<td>Feel that the health professionals care</td>
<td>3.74</td>
<td>3.46</td>
<td>0.28</td>
</tr>
<tr>
<td>about the patient</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**Association of Key Variables According To Characteristics of the Sample**

Demographic data were tested for an association with the FAD, FAMCARE and FIN Part A and Part B.

Family gender was tested using a T-test.

Family age was correlated using Pearson’s Correlation Coefficient.

Levels of education, number of hospital admissions and number of outpatient appointments were tested using ANOVA.

There was no significant association with any of this data.

The relationship to patient demographic was also analysed as spouse (n=37) and “other” (n=20) using t-test, to determine if there was any significant relationship between the spouse and the FAD, FAMCARE and FIN Part A and FIN Part B. There also was no significant association with this data.

The time since diagnosis demographic was divided into the categories of one year or less (n=19-20) and greater than one year (n=27-31). The mean scores for these categories were tested with the FIN Part A using an independent samples T-Test. The difference in means of two items of the FIN Part A were significant: item
18 (p=0.029) “help with the patient’s care” and item 19 (p=0.020) “have someone be concerned with my health.” The means for item 18 were 3.68 for one year or less and 3.11 for greater than one year, demonstrating that helping with the patient’s care was significantly less important to the families where the patient had been diagnosed for greater than one year. The means for item 19 were 2.89 for one year or less and 1.96 for greater than one year again demonstrating that this item was significantly less important to the families where the patient’s diagnosis was greater than one year.

**Summary**

In summary the results demonstrated that the modified FIN was a valid and reliable tool for measuring the information needs of the families of advanced cancer patients in an acute hospital.

The results also indicated that these families had many needs and that 29.10% of these needs were unmet. There was a strong negative correlation between the families’ satisfaction with the care that the patient is receiving and the extent to which the families’ needs are met, indicating that those families that were more satisfied with care had fewer unmet needs.
Chapter Six: Discussion and Conclusion

Discussion

The purpose of this study was to modify and test a tool to measure the information needs of the families of advanced cancer patients in the acute hospital environment. In addition, the study aimed to obtain important clinical information on the self-reported information needs of this population and the extent to which these needs had been met. The conceptual framework underpinning this research was the Family Information Model (FIM) that was derived from synthesis and refinement of relevant literature. This model provides a framework for the assessment of the information needs and improved communication of information to the families of patients with advanced cancer in the acute care setting.

The discussion chapter will include a summary of the key findings of the research and relate these to the conceptual framework and relevant literature. Methodological issues will be discussed; implications for clinical practice and further research recommendations will be made.

Interpretation of the Findings

The Conceptual Framework, the FIM, has been utilised as the framework to discuss the interpretation of findings as illustrated in Figure 4.

The FIM is based on a framework of problem identification, error, change and health. In this study the problem was identified as family information needs in the acute care setting. The framework allows for the identification of barriers to the communication of information to families (error), the processes that need to be implemented (change) to ensure that families receive the information that they need to be able to cope with the care of a family member with advanced cancer (health).

The discussion will be outlined under the FIM headings of problem, error, change and health.
Health: 70% of families had their needs met. Families who had their information needs met were more satisfied with care.

Error: Information needs are important and not met: Nearly 30% of family information needs were unmet.

The 5 highest unmet needs were:
- Have information about what to do for the patient at home
- Know when to expect symptoms to occur
- Feel there is hope
- Know the probable outcome of the patient’s illness
- Know what symptoms the treatment or disease can cause

Families with more unmet needs are less satisfied with care.

Problem: The families of patients in the acute care setting need information:
- Families had a high rating of information needs.
- The mean importance of needs was 71.1 (from a possible score of 80.0).

The 5 highest needs were:
- Know the probable outcome of the patient’s illness
- Feel that the health professionals care about the patient
- Be assured that the best possible care is being given to the patient
- Have my questions answered honestly
- Know what symptoms the disease or treatment can cause

Change: Implications for clinical practice:
- Use of a tool such as the modified FIN to assess information needs and extent to which they are met.
- Education of staff in the information needed and communication skills
- Empowerment of nurses to provide timely information
- Provide written information
- Provide privacy

Figure 4. Study Findings using the Family Information Model
Problem: The Families of Patients with Advanced Cancer in the Acute Care Setting Need Information

The literature clearly identifies that the families of patients with advanced cancer require information about many aspects of the patient's disease, treatment and care options. They want this information to be given in a caring manner. There is sparse literature regarding the information needs of these families in the acute hospital environment. The acute setting is busy and stressful, with many categories of staff and specialist teams involved in the patient's care and where a large amount of significant information exchange takes place between these health professionals and families. The literature describes better communication with families of terminally ill patients by staff in hospices than by staff in acute hospitals (Seale & Kelly, 1997).

The families in this study rated many needs as important in Part A of the FIN. As described earlier the FIN Part A has 20 items and the families were asked to rate "how important is this need to you now?" using ratings from 0 (not at all) to 4 (extremely). As identified in Table 8 no family had less than 15 needs and 36 families identified 20 needs. The mean score for the importance of need subscale in Part A ranged from 2.53-3.79 out of a possible score of 4.00, 4.00 being the highest importance. Sixteen of the items had mean scores of above 3.50, again demonstrating that these families had many needs which they rated as important.

The highest-ranking need with a mean score of 3.79 was to "know the probable outcome of the patient's illness." The related item "know specific facts concerning the patient's prognosis" was also of high importance with a mean score of 3.76. These ratings are consistent with the interviews conducted in Phase 1 where all families stated that they wanted accurate and timely information about the outcome of the patient's illness and prognosis. These families described vividly the consequences for them of not having accurate information about the outcome of the illness. One family member was still experiencing guilt six months after the death of his mother as he felt he would have treated her differently in her last days if he had known how short her prognosis was. Another family member stated that she and her husband would have made different treatment choices if they had been given accurate information about the probable outcome of the illness. The families in Phase
I also reported that the majority of the information had been given to them by junior medical staff, many of whom did not have the knowledge or communication skills to convey difficult information about the outcome of the patient’s illness. Many researchers have reported families’ need for information about prognosis (Kristjanson & Ashcroft, 1994; Hanson et al., 1997; Yates, 1999). Hanson et al. (1997) conducted a study involving interviews with 461 bereaved family members of older patients, many of whom had died of cancer. In this study the family members recommended better communication in relation to prognosis so that they were able to say goodbye to their loved ones.

The second and third highest ranked needs with a mean of 3.74 were to “feel that the health professionals care about the patient” and “be assured that the best possible care is being given to the patient.” This reinforces the importance of families feeling satisfied with the care that the patient receives. It is well documented that families who are less satisfied with care cope less well in bereavement (Steele, 1990; Yancey et al, 1990; Kristjanson et al, 1996). The families in this study were generally satisfied with the care that the patient was receiving as evidenced by the high mean total FAMCARE score of 79.25 from a possible score of 100.

Honesty ranked fourth with a mean score of 3.72. This is consistent with the family interviews in Phase 1 and also the literature that describes the families’ needs for honest communication. (Hampc, 1975; Hanson et al., 1997; Yates, 1999, Grbich et al., 2000). Grbich et al. (2000, p.349) reported that “all caregivers appreciated clear honest information which took into account the individual needs of both caregiver and patient and was presented in a caring manner.” Honesty in communication is indeed a difficult concept to measure. How do we define the difference between information that is dishonest and information that is given by health professionals in good faith but is inaccurate?

Error: There are Barriers to the Communication of Information to Families of Advanced Cancer Patients in the Acute Care Setting

Using the FIM as the framework, error involved the identification of barriers to communication. This section describes the results of the FIN Part B, which
measured the extent to which the needs had been met. 29.10% of identified needs were unmet for the population in this study. This is important clinical information in relation to the care of these families, as previous research had reported that family members who had fewer needs met were less satisfied with care (Kristjanson et al., 1997). This hypothesis, that families with less unmet needs would be more satisfied with care, was tested using Pearson's Correlation Coefficient. The results indicated a strong negative correlation between the percentage of needs met and family care satisfaction, indicating that families who had fewer unmet needs were more satisfied with care.

The data in Table 10 presents the difference between mean importance and mean needs met in descending order. This is important data as it represents the major problem areas for unmet needs within the study and thus provides the opportunity for identification of targeted strategies to ensure that these needs are met.

The highest-ranking item was having information about what to do for the patient at home, which had rated number 14 in the order of needs. This is an area that often poses difficulties in the acute hospital environment due to the potentially complex nature of the care required by advanced cancer patients at home and the lack of knowledge of health professionals in the acute care environment of these care needs. Several studies of similar groups of families have described the families’ need for information about care giving skills and home care services (Tringali, 1986; Addington-Hall, 1991; Adam, 2000). Adam, who interviewed 12 carers of Palliative Care patients in an acute hospital, identified that there was a significant lack of information about discharge planning for these families.

Two items which ranked highly in this table relate to symptom management, knowing when to expect symptoms to occur and what symptoms the disease or treatment can cause. These were issues for all the families in Phase 1 of the study who described the issues raised by inadequate information about symptoms and side effects and the fact that this lack of information had resulted in decisions about treatment that the bereaved family members now regretted. When they felt that they had been given good information about symptoms and side effects they were very grateful for the information. Many studies have also identified the need for this group of families to have information about symptoms of the disease in addition to the side effects of the disease and treatment (Hull, 1989; Addington-Hall, 1991; Wakefield &
Ashby, 1993; Grbich et al., 2000). The introduction of specialist Palliative Care teams into acute hospitals has improved the symptom management of this group of patients (Seale & Kelly, 1997). Unfortunately, not all acute settings have these teams and not all patients have access to this expertise where the teams do exist. Thus this data provides a strong argument for ensuring that access to specialist symptom management is integral to the care of these patients. Research has also identified that poor symptom management can be a threat to hope in the terminally ill patient (Herth & Cutcliffe, 2002).

The third highest ranked item for unmet need was to feel there is hope. This item caused much discussion with the families in Phase I, where two family members felt that this did not belong in the tool as a measure of information needs. The fact that the families in Phase III rated the need to feel that there is hope as important (mean 3.66) and not well met (mean 2.78) is of significance. Hope is an under-utilised and under researched area in Palliative Care but to feel there is hope is clearly a need for this group of families. Hope is an underpinning principle of Palliative Care, but perhaps is better utilised and understood in the hospice setting than in the acute care environment, which is not a specialist Palliative Care setting and where many of the health care professionals have no training in Palliative Care. There is a need for further analysis of the role of hope in terminal illness as well as strategies for education of health care professionals in the effective utilisation of this construct to assist these patients and their families.

Further validation of the communication and information difficulties that these families experience in the acute setting is demonstrated in the analysis of the FAMCARE scale. The FAMCARE scale measured the families’ satisfaction with advanced cancer care. Of the eight lowest satisfaction scores (all with mean scores of less than 4.0 from a possible score of 5.0), six related directly to information. Many of these items related directly to items that had received high scores, such as the highest ranking item “the patient’s pain relief” had a mean score of 4.45 while “information given about how to manage the patient’s pain” was ranked 13 out of 20 items with a mean score of 3.95. Also “the way tests and treatments are performed” was the second highest ranking item with a mean score of 4.38 while the item “information about the patient’s tests” ranked 19th with a mean of 3.47. These variations indicate that while the families were more satisfied with the clinical and
technical care that the patient received, they were less satisfied with the information and communication aspects of the patient’s care. The lowest satisfaction score was “family conferences held to discuss the patient’s illness.” The mean score for this item was 3.27 (from a possible score of 5.0). In a hospice setting family conferences with these families would be routine and well managed whereas in the acute hospital environment family conferences are often not offered to families or perhaps not managed well if they do indeed take place. Hence this has been identified as an issue for the families in this study.

Demographic data were tested for correlation with the FAD, FAMCARE and FIN Part A and Part B using a T-test for family gender, Pearson’s Correlation Coefficient for family member age and ANOVA for level of education, number of hospital admissions and number of outpatient appointments. The relationship to patient demographic was also analysed as spouse (n=37) and “other” (n=20) using t-test, to determine if there was any significant relationship between the spouse and the FAD, FAMCARE and FIN Part A and FIN Part B.

There was no significant correlation with any of this data.

This lack of association is not consistent with the literature. Kristjanson et al. (1997) found a strong relationship between the FAD and the family member’s age, with older family members’ (>51 years) reporting better family functioning than the younger family members (<51 years). In this study Kristjanson also found that family functioning as measured by the FAD was related to the education level of the family members, with those members with a college education reporting a lower level of family functioning than family members who had a high school education level or less. The sample in the Kristjanson study included family members of patients in Palliative Care Units, Hospice Home Care settings and Inpatient Medical units in three provinces in Canada. In a study to assess the validity and reliability of the FAMCARE scale Kristjanson (1993) found an association between family members’ level of education and their satisfaction with the care that the patient was receiving. Those with a college education or higher were more satisfied with care than those with less than a college education. The sample for this study was from an outpatient oncology setting and a home health care service in Canada. The difference between the findings in the Canadian studies and the current study may be explained by the sample setting. The current study sample reported here included family members of
patients with advanced cancer in an acute hospital setting. It may be that the intensity and complexity of this setting influences the information needs and satisfaction with care to such a degree that associations which other studies have found are negated in these circumstances.

The only association with the demographics was time since diagnosis and the FIN Part A. The time since diagnosis variable was divided into the categories of one year or less (n=19-20) and greater than one year (n=27-31). The mean scores for these two categories were tested with the FIN Part A using an independent samples T-Test. The difference in means of two items of the FIN Part A were significant: item 18 (p=0.029) "help with the patient’s care" and item 19 (p=0.020) "have someone be concerned with my health." The means for item 18 were 3.68 for one year or less and 3.11 for greater than one year, demonstrating that helping with the patient’s care was significantly less important to the families where the patient had been diagnosed for greater than one year. The means for item 19 were 2.89 for one year or less and 1.96 for greater than one year again demonstrating that this item was significantly less important to the families where the patient’s diagnosis was greater than one year. This analysis of this demographic was considered to be important as there is little literature on the needs of these families over time. It was surprising that these were the only two items which demonstrated any association with the importance of needs, and both of these findings offer little useful information in terms of clinical practice.

**Change: Remove the Identified Barriers to Communication to Achieve Health**

This section will discuss the implications of the findings of this study to clinical practice. It is postulated that changes to clinical practice to improve the information needs of these families will achieve the domain of health as identified in the FIM.

The literature has identified that caring for dying cancer patients in an acute hospital ward may be particularly difficult because of the blend of care required within this setting. Since attention to the communication needs of the families of these patients may be difficult to achieve amidst the demands of a busy ward,
families of patients with cancer in hospitals frequently identify poor communication with health professionals as a major difficulty (Bond, 1982a; Hampe, 1975; Irvine, 1993; Wakefield & Ashby, 1993). In a study by Dunne and Sullivan (2000) bereaved family members described the acute setting as an inappropriate environment for terminal care. They complained of a “rushed and hurried environment, with dying patients being moved around as the need for acute beds dictated” (p173).

Families of hospice patients also reported better communication with staff and feeling less anxious than families receiving care in an acute hospital. These findings have been consistent over a period of 20 years (Smith & Hill, 1978; Murray-Parkes, 1985; St Aubin & Lund, 1986; Wakefield & Ashby, 1993; Seale & Kelly, 1997).

A validated useful and straightforward clinical tool such as the modified FIN could be used by health care professionals to better assess the information needs of the families of patients with advanced cancer in the acute hospital setting. Health care professionals who are better able to assess families’ needs would then be able to respond more appropriately and precisely to assist these families.

Great benefit could be derived from education of health care professionals in the art of communication as well as the information needed by this group of families. In support of this recommendation the literature has identified that families want information that is honest, given in a compassionate and timely manner and in language that they can understand (Hampe, 1975; Hanson, 1997; Yates, 1999; Grbich et al., 2000). A recommendation from Grbich et al. (2000) included the need for education for health professionals relating to the importance of communication skills and styles and identifying the needs of advanced cancer patients and their families. This is also confirmed by the concerns of families in Phase I who described distressing incidents of information being communicated in an uncaring manner by staff. These families vividly described the effects on them personally of the poor communication skills of these staff members.

This issue could also be addressed by ensuring that senior rather than junior members of the medical team communicate information that is sensitive. The families in Phase I consistently reported that junior medical staff had imparted a certain amount of significant information to them.
Ensuring privacy for the communication of sensitive information is very important in any setting, but especially so in the acute care setting amidst the chaos of a busy ward. Privacy in this situation assists the health care professionals to better deliver difficult information. The importance of privacy is very prominent in the literature (Copp, 1993; Bridgeman & Carr, 1997; Dunne & Sullivan, 2000). Privacy was also extremely important to all family members interviewed in Phase I. The family members stated that communication and information sharing was easier when they were in a single room or given access to an area where a private conversation was possible. The families stated that these areas were difficult to find in an acute hospital. Several family members described discussions about “Not for Resuscitation” orders taking place at the nurses’ station and the distress that this lack of privacy caused them.

The families in Phase I discussed their perception that the nurses appeared to know more, especially about prognosis, than they were often able to impart to the families. This issue has also been reported in various studies which identify the difficulties that nurses encounter when caring for this population of patients and families (Bridgeman & Carr, 1997; Davis et al., 2003). Nurses are often in an invidious position in terms of communication with families when they are privy to important information which the doctors have not yet communicated to the patient and families. Education will address this to a certain degree but nurses need to be empowered to intervene with families when they feel that the information that families are receiving is inaccurate, inadequate or not timely.

Written information for families and patients might be a useful augmentation to communication from health professionals, to assist these families to obtain relevant information. This could include information about the disease, treatments, side effects of disease and treatments, services available to these families both in the hospital and the community and other sources of information such as cancer organisations. All of the families in Phase I stated that written information would have been helpful for them and the literature also documents that these families want written information (Adam, 2000; Grbic et al., 2000).

Education of health professionals should include training in the fostering of hope in terminally ill patients and their families.
Health: Families have their Information Needs Met

It is considered that a state of health has been achieved when the families of patients with advanced cancer in an acute care setting have their information needs met. The identification of errors and the implementation of changes in clinical practice discussed previously will assist in the achievement of this state of health.

A typical family member in Phase III of this study was an approximately 55 year old female, wife of the patient, who was born in Australia and had completed high school. The families in this study were healthy in terms of general functioning as measured by the General Functioning Subscale of the FAD, which measures the overall health and functioning of the family. The mean score for the General Functioning subscale of the FAD for the families in Phase 3 was 1.81, with a standard deviation of 0.53, a median of 1.81 and a range of 1.00 to 3.58. The lowest score (healthiest) was for the item describing their ability to be able to turn to each other for support in times of crisis.

These families were generally satisfied with the care that the patient had received as measured by the FAMCARE Scale, with a total mean score of 79.25, range of 44-100 and standard deviation of 11. These scores are lower than those reported by Kristjanson (1993) whose sample recorded scores of 85.37, range of 61-100 and standard deviation of 9.65. Kristjanson’s data collection had taken place in the homes of the families and in an outpatient clinic. This difference in the data reinforces the concept that this group of patients and families does not receive optimum care in the acute hospital environment. Previous research had reported that family members who had fewer needs met were less satisfied with care (Kristjanson et al, 1997). This study also demonstrated this association as the results indicated a strong negative correlation (r=-0.719, p=0.000) between the percentage of needs met and family care satisfaction, indicating that families who had fewer unmet needs were more satisfied with care. This is a very important finding of this study and will be a powerful argument for the implementation of strategies to improve the information given to these families in the acute care setting.

While it has been reported that approximately 30% of these families’ needs were unmet, this also means that 70% of needs were met. According to Table 10 which reports the difference between the “mean importance” and “mean needs met”
scores, the five lowest ranked items in this data set, that is the range in which the needs were more likely to have been met, were related to the general care of the patient and the family. These included “be assured that the best possible care is being given to the patient,” “feel accepted by the health professionals,” “know the names of the health professionals involved in the patient’s care,” “have someone be concerned with my health” and “feel that the health professionals care about the patient.” This indicated that while the health professionals may not necessarily have had the specific and specialised skills needed to provide adequate information to these families, they demonstrated care for them and the patients. This result further reinforces the need to educate health professionals in the skills required to appropriately care for patients with advanced cancer and communicate with their families. In addition the use of a tool such as the modified FIN would be of great assistance to the staff in the acute care setting to better assess and meet the information needs of these families.

**Validity and Reliability of the Modified FIN: Methodological Implications**

The modified FIN was found to be a valid and reliable tool to measure the information needs of the families of advanced cancer patients in the acute care setting, as measured by percent agreement among participants, Cronbach’s Alpha and the Intraclass Correlation Coefficient. The FAD and FAMCARE scales also demonstrated high internal consistency ratings as measured by Cronbach’s alpha. These results will now be discussed in more detail.

The modified FIN was tested for validity and reliability with bereaved family members, expert nurses and the families of current inpatients with advanced cancer at a large teaching hospital in Perth, Western Australia.

Phase 1 of this study involved semi-structured interviews with bereaved family members of patients who had died at the study hospital. The purpose of these interviews was to elicit from the bereaved families the type and quality of information they had received throughout the patient’s hospitalisation during the terminal phase of their illness. Families were also given the opportunity to describe information they had not received but that they believed would have been beneficial.

80
The aim was to confirm the literature and the clinical experience of the researcher related to the information needs of these families in the acute care environment. The families had been bereaved for three to six months. This was considered an important aspect of the study as with the benefit of hindsight these bereaved families were clearly able to identify information that they had not received, that they would have liked or needed to have received. The results of Phase III of this study are consistent with the needs and issues identified by the families in Phase I.

The families in Phases IIA described some difficulty with the layout and instructions of the FIN. Accordingly the FIN was modified as described in the results and found to be clear and easy to read by the panel of expert nurses in Phase IIb.

Percent agreement from the families’ and nurses’ responses was used to measure the extent to which the FIN demonstrated content validity. Lynn (1986) describes two steps in the quantification of content validity. These are the determination by experts that each item is content valid and the determination that the tool as a whole is content valid. According to Lynn, a minimum of five experts (and no more than 10) is required to determine content validity. If there are five or less experts then they must all agree on the content validity, but if there is six or more, one or more of the experts can disagree with the others and the tool can still be determined to be content valid. For the purpose of Phases IIA and IIb of this study, there were eight family members and six nurses therefore no more than two "no" answers were allowed for this to be assessed as content valid.

The use of bereaved families in Phase IIA and expert nurses in Phase IIb to test for clarity and content validity, while unusual, was determined appropriate by the researcher as it brought richer insights incorporating both perspectives.

The modified layout of the FIN incorporated Part A and Part B with anchors for each section for the scale, which can be circled. Clinically this layout allows the tool to be much more useful as the results are very visual, which is vital in the busy environment of the acute care setting with many staff involved in the care of the patient and family. If a family member rates a need as 5 (extremely important) and the extent to which the need is met as 1 (not met at all), the health professionals can see this at a glance and implement strategies to ensure that the need is met.
The Modified FIN was found to be a very reliable tool as measured by Cronbach's alpha. The FIN Part A achieved an alpha of 0.91 and the FIN Part B achieved an alpha of 0.92. As the FIN had been modified it was difficult to relate these results to other research.

Seventeen of the twenty items (85%) in the FIN part A met the preset criterion of 50% item-to-total correlation between 0.40 and 0.70. In Phase 2a seven items were identified by some family members as unsuitable to measure information needs. Three of these items “feel accepted by the health professionals”, “help with the patient’s care”, “have someone be concerned with my health” were also identified by one of the expert nurses in Phase 2b as not being a suitable item for this tool. Two of these same items in FIN Part A were outside the preset item-to-total correlation of 0.40 and 0.70. The item “help with the patient’s care” measured 0.72, suggesting that this item may be redundant and “have someone be concerned with my health” measured 0.30, suggesting that this item does not fit within the scale. Interestingly, “help with the patient’s care” had a mean importance on 3.43 and a mean needs met of 2.65, indicating that it was identified as an important need for the families and it was a need that was not well met.

Item 19 “have someone be concerned with my health” attained an item-to-total correlation of 0.30, suggesting that this item may be less consistent with other items in the scale. Other needs in the FIN Part A which exceeded 0.70 were need 7 “have explanations given in terms that are understandable”, with a score of 0.74, and need 18 “help with the patient’s care”, with a score of 0.72.

In the FIN Part B eighteen (90%) of the items met the preset criterion of 50% item-to-total correlation between 0.40 and 0.70. Item 9 “feel there is hope” measured 0.35, and item 11 “know what symptoms the treatment or disease can cause” measured 0.74.

As none of these items in Part A and Part B varied greatly from the preset criterion and there was no significant variation in the alpha if the items were deleted, they were deemed appropriate to remain as part of the tool.

The modified FIN was found to be stable over time, in test-retest, as measured by the Intraclass Correlation Coefficient. The results were \( r=0.91 \) for the FIN Part A and \( r=0.91 \) for the FIN Part B. The return rate for the test-retest was 80%,
which demonstrates a strong commitment of these families to contribute to the study. The intraclass correlation coefficient was used to analyse the test-retest, as it is an index of correlation between repeated measures of the same method (Bland & Altman, 1990). The timeframe for the test-retest was 24 hours. The 24-hour timeframe has been used previously (Kilpatrick et al., 1998) and is appropriate for this population, as the information needs of these families are likely to change over a longer timeframe. Stability measures are usually higher for short time periods for the test-retest. There can be difficulties with measuring stability, including participants’ memory of their first responses, which may be a particular problem with the 24 hour timeframe, or the care taken by families may not be as great when completing the tool for a second time. One issue for consideration with the test-test is that of the stability of the tool over time against the stability of the needs over time.

Table 11 provides a summary of the reliability results for the modified FIN, the FAMCARE and the FAD.

The General Functioning subscale of the FAD and the FAMCARE scale were also tested for internal consistency using Cronbach’s alpha coefficient. The alphas for these scales both exceeded the preset criterion of 0.80, the FAD achieving an alpha of 0.85 and the FAMCARE achieving an alpha of 0.93. In previous studies (Kristjanson, 1993; Kristjanson et al., 1997) which tested the reliability of these scales, the FAMCARE achieved an alpha of 0.90 and the FAD an alpha of 0.93.

Previous research which describes the use of the FIN, FAMCARE and FAD (Kristjanson, 1993; Kristjanson et al., 1997) has been conducted in hospital outpatients, hospice and home care settings in North America. The reliability results from this study are extremely valuable as they demonstrate that these are reliable tools for the families of advanced cancer patients in the acute care setting in Australia.
Table 11

**Reliability of FAD, FAMCARE and Modified FIN**

<table>
<thead>
<tr>
<th>Tool</th>
<th>Mean Score</th>
<th>S.D.</th>
<th>Cronbach’s Alpha</th>
<th>Intraclass Correlation Coefficient</th>
</tr>
</thead>
<tbody>
<tr>
<td>FAD</td>
<td>1.81</td>
<td>0.53</td>
<td>0.85</td>
<td>N/A</td>
</tr>
<tr>
<td>FAMCARE</td>
<td>79.25</td>
<td>11</td>
<td>0.93</td>
<td>N/A</td>
</tr>
<tr>
<td>FIN Part A</td>
<td>71.10</td>
<td>8.54</td>
<td>0.91</td>
<td>0.91</td>
</tr>
<tr>
<td>FIN Part B</td>
<td>57.94</td>
<td>11.76</td>
<td>0.92</td>
<td>0.91</td>
</tr>
</tbody>
</table>

**Implications for Future Research**

The following recommendations for future research are made based on the findings of this study.

Firstly, an intervention study should be conducted focussing on the use of the modified FIN as a tool for this population of families in the acute care setting.

Secondly, an intervention study should be undertaken focussing on education for health professionals in identifying and meeting the information needs of these families.

Thirdly, future research using this tool may include a longitudinal study to identify the change in the information needs of these families and extent to which these needs are met over time.

Fourthly, this tool may be tested for reliability and validity with the families of cancer patients at any stage of the illness, not only advanced cancer patients as in this study. This could also include testing of the instrument with families from different cultural backgrounds.
Finally, as there has been no other published research utilising this tool in the adult cancer population in Australia a study could be undertaken to test the tool in the Australian inpatient and home care hospice population.

**Limitations**

A number of limitations of this study have been identified.

The small sample size in Phase 1 and the three family members from the one family may have limited the range of experiences observed. Despite this limitation the three family members all reported vastly different perceptions of their experiences.

Another possible limitation was that this research was based on a convenience sample and thus the results may not be easily generalised to the broader population.

During Phase III of this study a small number of families declined to participate because at the time they were under stress or in crisis. This may have lead to families that participated being a somewhat less heterogeneous population.

**Conclusion**

The results of this research have the potential to provide valuable assistance to staff caring for the families of advanced cancer patients in the acute care setting.

The families of patients with advanced cancer describe the need for information as an important need. A significant amount of information is provided to these families while the patient is an inpatient in the acute care setting. In spite of this there has been little published literature on the information needs of these families within this setting.

This study involved the modification of the FIN, which was found to be a valid and reliable tool for these families in an Australian acute cancer care context.
The families in this study rated many information needs as important, with a mean score of 71.10 (from a possible score of 80), for the importance of need. The highest mean was for the statement "know the probable outcome of the patient's illness." While these families rated these needs as important, nearly 30% of these needs were unmet by the staff in this setting.

This research provides health care professionals with a wealth of data demonstrating which information needs are important to these families, in addition to the information needs that are not being consistently met. The modified FIN could prove to be an invaluable tool to assist these staff to more precisely meet the information needs of these families. As identified in this research the families who have their information needs met are more likely to be satisfied with care, which in turn could have a significant impact on their ability to cope during bereavement.
References


confronting patients, health professionals and family members. _Journal of Psychosocial Oncology_, 5, 17-46.


Appendix A

Interview Guide Phase I

1. When your family member was a patient at SCGH what information did you receive from the staff? (E.g. information about the disease, treatment, drugs, prognosis, goal of care.)
2. Was it enough?
3. What other information would you liked to have received?
4. Who gave you most of this information? (E.g. nurse, Dr (specialist or JMO) other)
5. How was the information given to you? (E.g. compassion, honest, skills, privacy)
6. How important was privacy to you when receiving information?
7. Did you have any difficulty locating the staff to answer your questions?
8. Would written information have been helpful to you?
9. Review of the FIN
Appendix B

Information Sheet Phase I

My name is Sue Davis and I am doing a Masters in Nursing at Edith Cowan University.

As part of my studies I am conducting research in order to find out more about the information needs of the families of patients with cancer at Sir Charles Gairdner Hospital.

I am inviting you to take part in this study.

If you agree to take part I would like the opportunity to interview you to get an idea of the usefulness of the information you received while your family member was a patient at SCGH. I would also like to find out if there were any information that you didn't receive at SCGH that you feel would have been of assistance to you. I will also ask you to comment on a questionnaire that is being developed to help staff and families identify families' information needs.

The interview will take about an hour and I will come to your home or meet you at a convenient location.

Your participation is voluntary and you may withdraw at any time.

The Edith Cowan University Ethics Committee has approved this research.

If you would be willing to take part in this research, please phone Sue Davis at home on 9381 9075 or mobile 0404891023.

If you have any concerns about the project and would like to talk to an independent person, you may contact Di Twigg, Executive Director of Nursing Services, Sir Charles Gairdner Hospital. PH:9346 2684

Thank you, Sue Davis.
Appendix C

Consent Form Phases I and II    ID:___

I have read the information concerning the project "The Information Needs of the Families of Patients with Advanced Cancer in an Acute Hospital" and any questions I have asked have been answered to my satisfaction.

I agree to participate in this research, realising I may withdraw at any time.

I agree that the research data gathered for this study may be published provided I am not identifiable.

Participant Name __________________________

Participant Signature ______________________ Date ___

Name of Witness to Participant Signature __________________________

Witness Signature ______________________ Date ___

Name of Investigator __________________________

Signature of Investigator ______________________ Date ___

Edith Cowan University Ethics Committee has given ethics approval for the conduct of this project.
Appendix D

Family Demographic Data Phase I       ID:__

1. What is your age?

2. Sex
   Male  □  Female  □

3. Relationship to Patient?  (eg Husband, wife, son, friend)

4. Country of Birth

5. Is English your first language?  Yes  □  No  □

6. If you answered no to question 6, what is your level of understanding of English?

   Good  □  Adequate  □  Little  □

7. What level of education have you reached?

   Less than high school  □
   High school  □
   Trade or TAFE  □
   Diploma / Degree  □
   Higher degree  □
Appendix E

McMaster Family Assessment Device   ID:__

This is a list of statements about how families function. Please tick ✓ the Strongly Agree, Agree, Disagree or Strongly Disagree box next to each statement, that best describes how your family relates to each other.

<table>
<thead>
<tr>
<th>General Functioning</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>Planning family activities is difficult because we misunderstand each other.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In times of crisis we can turn to each other for support.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>We cannot talk to each other about the sadness we feel.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Individuals are accepted for what they are.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>We avoid discussing our fears and concerns.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>We can express feelings to each other.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>There are lots of bad feelings in the family.</td>
<td></td>
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</tr>
<tr>
<td>We feel accepted for what we are.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Making decisions is a problem for our family.</td>
<td></td>
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</tr>
<tr>
<td>We are able to make decisions about how to solve problems.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>We don’t get along well together.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>We confide in each other.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix F

Patient Demographic Data Phase I  ID:___

1. Age ________
2. Sex  Male □  Female □
3. Primary Diagnosis __________________________
4. Secondary Involvement ______________________
5. Date of Diagnosis ___________________________
6. Number of admissions to hospital ___________
7. Number of family members involved in the care of the patient
   __________________
Appendix G

Family Inventory of Needs (FIN)

Instructions: The next set of questions is about the needs of family members of cancer patients. Please show how important the following needs are for you as a family member:

(1) Not Important, (2) Somewhat Important, (3) Average Importance, (4) Very Important and (5) Extremely Important

If the need was important to you (2 or higher), check off in the column beside to show if the need has been met, partly met, or not met.

<table>
<thead>
<tr>
<th>I need to:</th>
<th>Ratings from 1-5</th>
<th>Met</th>
<th>Partly met</th>
<th>Unmet</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Have my questions answered honestly</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Know specific facts concerning the patient's prognosis</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Feel that the health professionals care about the patient</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. Be informed of changes in the patient's condition</td>
<td></td>
<td></td>
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</tr>
<tr>
<td>5. Know exactly what is being done for the patient</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Know what treatment the patient is receiving</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td>7. Have explanations given in terms that are understandable</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. Be told about treatment plans while they are being made</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>9. Feel there is hope</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Be assured the best possible care is being given to the patient</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Know what symptoms the treatment or disease can cause</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>12. Know when to expect symptoms to occur</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

If you rated an item higher than 1, tick if met, partly met, or unmet.
<p>| | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>13.</td>
<td>Know the probable outcome of the patient's illness</td>
</tr>
<tr>
<td>14.</td>
<td>Know why things are being done for the patient</td>
</tr>
<tr>
<td>15.</td>
<td>Know the names of health professionals involved in the patient's care</td>
</tr>
<tr>
<td>16.</td>
<td>Have information about what to do for the patient at home</td>
</tr>
<tr>
<td>17.</td>
<td>Feel accepted by the health professionals</td>
</tr>
<tr>
<td>18.</td>
<td>Help with the patient's care</td>
</tr>
<tr>
<td>19.</td>
<td>Have someone be concerned with my health</td>
</tr>
<tr>
<td>20.</td>
<td>Be told about people who could help with problems</td>
</tr>
</tbody>
</table>
Appendix H

Modified Family Inventory of Needs (FIN)

Below is a list of needs identified by some families. For each item, there are two sections. You are asked to give a rating for each need. Please indicate by circling just one number in both parts A & B.

<table>
<thead>
<tr>
<th>I need to:</th>
<th>Part A</th>
<th>Part B</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>How important is this need to you now?</td>
<td>How well has this need been met for you?</td>
</tr>
<tr>
<td></td>
<td>Not at all</td>
<td>A little</td>
</tr>
<tr>
<td>1 Have my questions answered honestly</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>2 Know specific facts concerning the patient’s prognosis</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td>3 Feel that the health professionals care about the patient</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>4 Be informed of changes in the patient’s condition</td>
<td>5 Know exactly what is being done for the patient</td>
</tr>
<tr>
<td>---</td>
<td>--------------------------------------------------</td>
<td>--------------------------------------------------</td>
</tr>
<tr>
<td></td>
<td>0 1 2 3 4</td>
<td>0 1 2 3 4</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Part A How important is this need to you now?</th>
<th>Part B How well has this need been met for you?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Not at all</td>
<td>A little</td>
</tr>
<tr>
<td>8</td>
<td>Be told about changes in treatment plans while they are being made</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>9</td>
<td>Feel there is hope</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>10</td>
<td>Be assured the best possible care is being given to the patient</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td>11</td>
<td>Know what symptoms the treatment or disease can cause</td>
<td>0 1 2 3 4</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>---</td>
<td>-----------------------------------------------------------------</td>
<td>---</td>
</tr>
<tr>
<td>12</td>
<td>Know when to expect symptoms to occur</td>
<td>0</td>
</tr>
<tr>
<td>13</td>
<td>Know the probable outcome of the patient’s illness</td>
<td>0</td>
</tr>
<tr>
<td>14</td>
<td>Know why things are done for the patient</td>
<td>0</td>
</tr>
<tr>
<td>15</td>
<td>Know the names of the health professionals involved in the patient’s care</td>
<td>0</td>
</tr>
<tr>
<td>16</td>
<td>Have information about what to do for the patient at home</td>
<td>0</td>
</tr>
<tr>
<td>17</td>
<td>Feel accepted by the health professionals</td>
<td>0</td>
</tr>
<tr>
<td>18</td>
<td>Help with the patient’s care</td>
<td>0</td>
</tr>
<tr>
<td>19</td>
<td>Have someone be concerned with my health</td>
<td>0</td>
</tr>
<tr>
<td>20</td>
<td>Be told about people who could help with problems</td>
<td>0</td>
</tr>
</tbody>
</table>
Appendix I

Assessment of Clarity and Content Validity for Revised Family Inventory of Needs (FIN)

Age: ________

Profession: ____________________________

Number of years caring for cancer patients:

Nil □
1-5 □
>5 □

Clarity

1. Do you understand what this questionnaire is for? Y/N
2. Are the instructions clear? Y/N
3. Is each statement clear? Y/N

Comments

Content Validity

For each statement answer the question, is this a suitable item to identify the information needs of families of cancer patients in an acute hospital? If you answer "no", please comment.

1. Y/N comment
2. Y/N comment
3. Y/N comment
4. Y/N comment
5. Y/N comment
6. Y/N comment
7. Y/N comment
8. Y/N comment
9. Y/N comment
10. Y/N comment
<table>
<thead>
<tr>
<th></th>
<th>Y/N</th>
<th>Comment</th>
</tr>
</thead>
<tbody>
<tr>
<td>11</td>
<td>Y/N</td>
<td>Comment</td>
</tr>
<tr>
<td>12</td>
<td>Y/N</td>
<td>Comment</td>
</tr>
<tr>
<td>13</td>
<td>Y/N</td>
<td>Comment</td>
</tr>
<tr>
<td>14</td>
<td>Y/N</td>
<td>Comment</td>
</tr>
<tr>
<td>15</td>
<td>Y/N</td>
<td>Comment</td>
</tr>
<tr>
<td>16</td>
<td>Y/N</td>
<td>Comment</td>
</tr>
<tr>
<td>17</td>
<td>Y/N</td>
<td>Comment</td>
</tr>
<tr>
<td>18</td>
<td>Y/N</td>
<td>Comment</td>
</tr>
<tr>
<td>19</td>
<td>Y/N</td>
<td>Comment</td>
</tr>
<tr>
<td>20</td>
<td>Y/N</td>
<td>Comment</td>
</tr>
</tbody>
</table>

Is there anything missing from this questionnaire?

Appendix J

FAMCARE Scale

Instructions: Think about the care that your family member has received. Please answer the following questions indicating how satisfied you are with the care received: Very satisfied (VS), Satisfied (S), Undecided (U), Dissatisfied (D), or Very Dissatisfied (VD). Please circle the letters that best match your experience.

How satisfied are you with:

1. The patient’s pain relief
2. The way tests and treatments are performed
3. Coordination of care
4. Doctor’s attention to patient’s description of symptoms
5. Availability of nurses to the family
6. How thoroughly the doctor assesses the patient’s symptoms
7. The way tests and treatments are followed up by the doctor
8. Referrals to specialists
9. Answers from health professionals
10. Availability of the doctor to the patient
11. Time required to make a diagnosis
12. Speed with which symptoms are treated
13. Information given about how to manage the patient’s pain
14. Information provided about the patient’s prognosis
15. Availability of doctors to the family
16. Information about side effects
17. The way the family is included in treatment and care decisions
<table>
<thead>
<tr>
<th></th>
<th></th>
<th>VS</th>
<th>S</th>
<th>U</th>
<th>D</th>
<th>VD</th>
</tr>
</thead>
<tbody>
<tr>
<td>18. Availability of a hospital bed</td>
<td></td>
<td>VS</td>
<td>S</td>
<td>U</td>
<td>D</td>
<td>VD</td>
</tr>
<tr>
<td>19. Information given about the patient’s tests</td>
<td></td>
<td>VS</td>
<td>S</td>
<td>U</td>
<td>D</td>
<td>VD</td>
</tr>
<tr>
<td>20. Family conferences held to discuss the patient’s illness</td>
<td></td>
<td>VS</td>
<td>S</td>
<td>U</td>
<td>D</td>
<td>VD</td>
</tr>
</tbody>
</table>
Appendix K

Information Sheet Phase III

The Information Needs of the Families of Cancer Patients in an Acute Hospital

My name is Sue Davis and I am doing a Masters in Nursing at Edith Cowan University.

As part of my studies I am conducting research to find out more about the information needs of the families of patients with cancer at Sir Charles Gairdner Hospital. My research involves the development of a questionnaire about the information that families need and whether families are receiving this information. I hope that this questionnaire will help staff to better understand the information that families need from staff.

I am inviting you to take part in this study.

If you agree to take part I will need you to complete the following forms:

- Form 1: The Family Inventory of Needs (FIN) Questionnaire
- Form 2: A second FIN questionnaire (green), will need to be completed 24 hours after the first questionnaire and returned in the envelope provided
- Form 3: The FAMCARE scale, that provides information about your satisfaction with the care that the patient is receiving
- Form 4: A brief questionnaire that provides information about your family
- Form 5: A brief form with information about you
- Form 6: A brief form with information about the patient’s illness

These are anonymous questionnaires.
By completing the questionnaires you are consenting to take part in this research.
Your participation is voluntary and you may withdraw at any time.
If you decide not to participate it will in no way affect the care you or the patient receive.
No information that you provide for this study will be shared with the staff caring for the patient.

The Edith Cowan University Ethics Committee has approved this research.
If you wish to discuss any aspect of this research, please phone Sue Davis
at Sir Charles Gairdner Hospital on 9346 4396, or Mobile 0404891023.
If you have any concerns about the project and would like to talk to an independent person, you may contact:
Professor Linda Kristjanson
Edith Cowan University
9273 8595

Thank you for your assistance,

Sue Davis
Appendix L

Family Demographic Data Phase III  ID:__

1. What is your age? __________

2. Sex  Male  □  Female  □

3. Relationship to Patient?  (eg Husband, wife, son, friend)
   _______________________________________________________

4. Do you live with the patient? Yes  □  No  □

5. Country of Birth  ________________________________

6. Is English your first language?  Yes  □  No  □

7. If you answered no to question 6, what is your level of understanding of English?
   Good  □  Adequate  □  Little  □

8. What level of education have you reached?
   Less than high school □
   High school □
   Trade or TAFE □
   Diploma / Degree □
   Higher degree □
Appendix M

Patient Demographic Data Phase III

ID: __

1. Age of patient __________

2. Sex
   Male □
   Female □

3. Primary Site of Cancer:
   Breast □
   Lung □
   Prostate □
   Bowel □
   Brain □
   Other □ (please specify) ______________________

4. Secondary Spread
   Yes □
   No □

5. Date of Diagnosis (if known) ______________________

6. Number of admissions to hospital
   1 □
   2 – 5 □
   More than 5 □

7. Number of Outpatient Visits
   Nil □
   1-5 □
   More than 5 □

8. Number of family members involved in the care of the patient
   1 □
   2 – 5 □
   More than □