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## Home hospice cancer care: Family members' expectations, perceptions and satisfaction with care

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**HOME HOSPICE CANCER CARE: FAMILY MEMBERS' EXPECTATIONS,  
PERCEPTIONS AND SATISFACTION WITH CARE**

by

**Kristina Medigovich RN**

**A Thesis Submitted in Partial Fulfillment of the  
Requirements for the Award of**

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at the Faculty of Health and Human Sciences  
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## USE OF THESIS

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

## ABSTRACT

Increasingly, there is greater expectation by the public, as health consumers, that they will receive care from health professionals which meets their expectations and does not leave them dissatisfied. The stress experienced by families caring for a family member with advanced cancer may be complicated when they are dissatisfied with care received from health care professionals. To further promote family satisfaction it is important therefore for health professionals to understand the theoretical underpinning of family satisfaction with care.

One theoretical explanation of family member satisfaction with advanced cancer care in the palliative care setting, Porter's Discrepancy Theory, was investigated in this study. A descriptive correlational design was used to evaluate family members' expectations of care, perceptions of care, and level of satisfaction with advanced cancer care replicating one arm of Kristjanson's work (1991). Data was collected from 55 family members, who were the principal caregivers for patients with advanced cancer receiving palliative care from a home hospice service in Western Australia. Stratified random sampling was used to select participants for the study based upon the divisional areas of the home hospice service. Four instruments were used to collect data: (1) FAMCARE Scale, (2) F-Care Expectations Scale, (3) F-Care Perceptions Scale, (4) Family Assessment Device: General Functioning Subscale and a short demographic questionnaire. Data analysis included: descriptive statistics to summarise the sample, reliability testing of the instruments, calculation of the discrepancy between expectations and perceptions and testing the extent to which the discrepancy variable predicted care satisfaction using regression analysis. The relationships between

sociodemographic and family care expectations, family care perceptions and family satisfaction with care variables were also examined.

Discrepancy theory explained 29% of the variance in family care satisfaction. When the variables age and family functioning were added to the regression 42% of the variance in family care satisfaction was explained. An alternative model was tested using family care perceptions to explain 54% of the variance in family care satisfaction with home hospice care. Implications for clinical practice and recommendations for further research with regard to further theory testing and investigation of the less satisfied subgroup are suggested.

## DECLARATION

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

Signed: .....

Date: ..... 22nd September 1997

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## CHAPTER 1

### Introduction

A major focus in the monitoring and evaluation of health care standards has been the use of client satisfaction surveys as an important indicator of the quality of care provided by health care professionals. Oberst (1984) suggests that the assessment of care adequacy may be incomplete without the inclusion of outcomes as perceived by clients. Client assessment of quality and satisfaction with care is particularly important in the palliative care setting. The family is regarded as the unit of care in hospice care programs. Family members of cancer patients expect health professionals to provide quality care to the patient, as well as meet their own needs in the areas of information, assistance with care and emotional support (Kristjanson, 1991).

For hospice programs, satisfaction of the patient and the patient's family is a particularly important outcome measure. There is however little theoretical understanding of satisfaction despite its frequent use as an outcome measure. One theoretical explanation of family member satisfaction with advanced cancer care in the palliative care setting as previously tested by Kristjanson (1991) was investigated in this study. Outlined in this chapter are the research problem, the purpose of the study, the research hypothesis followed by the significance of the study.

### Background to the Study

A total of 5,383 new cases of cancer were registered in West Australia (WA) resulting in 2,869 deaths in 1991 (Fitzgerald, Thomson and Thompson, 1994). Most illness occurs within the context of a family and therefore, from these figures alone, it can be estimated that cancer and its demands touch the lives of many West Australians. As the number of aged persons in the population increases there will be an increase in the number of new cancer cases (Hatton, 1987). It is anticipated that most people who



die of cancer will need palliative care and/or terminal care at some stage of the illness trajectory. Currently, in metropolitan Perth just over 70% of people who die with cancer have palliative care services (WA Hospice Palliative Care Association, 1995).

The conventional care of a hospital was the setting for providing terminal cancer care until the development of the modern hospice movement. The hospice movement in West Australia has developed as a number of separate services and a high level of coordination, communication and liaison is undertaken to meet the needs of cancer patients and their families (M Smith, personal communication, June 1996). The services include stand alone inpatient and day care hospice, inpatient hospice with attached home hospice, a home hospice service and consultative hospice services for inpatients within acute private and teaching hospitals and nursing homes.

#### Research Problem

The patient and family is considered to be the primary unit of care by hospice programs and there is a recognition by hospice care providers that cancer affects the whole family (Australian Association For Hospice And Palliative Care Inc.,1994). A home hospice care service enables the patient to remain at home, through providing direct care and by supporting family members as they actively participate in the patient's care.

Cancer represents a crisis in the lives of family members and causes profound and multifaceted disruptions (Sales, Schulz and Biegel, 1992). Further, terminal care places pressures on the family members with physical and emotional demands reaching their peak as the patient's disease progresses to the terminal stage (Sales, 1991). The stress experienced by families has been well documented in the literature. Holing (1986) identified 66 critical events during the terminal phase of the family member's illness. The majority of these events (46) were perceived by family members to be

stressful. A number of stressors have been identified as having a negative impact on family members. These include: stage of illness and prognosis (Wellisch, Fawzy, Landsverk, Pasnau and Woolcott, 1983), demands of caregiving (Casselith, Lusk, Brown and Cross, 1985; Mor, Guadagnoli and Wool, 1987), duration of illness (Oberst, Thomas, Gass, and Ward, 1989; Vachon et al. (1977), site of illness (Cassileth et al. 1985; Wellisch et al. 1983), patient distress (Baider and De-Nour, 1984; Cassileth, Lusk, Brown and Cross, 1985; Houts, Yasko, Kahn, Schelzel, and Marconi, 1986; Mor, Guadagnoli and Wool, 1987). Whilst much of the stress experienced by families is not within the control of health professionals, it is important that they not add to the stress of these individuals by providing care that fails to meet their expectations or leaves them with feelings of dissatisfaction and regret about the quality of care their loved one received (Kristjanson, 1991).

Wright and Dyck (1984) suggest that greater stress may be experienced by families whose care expectations are not met and who negatively evaluate care. Further evidence suggests that care experiences perceived as unsatisfactory or stressful by families may complicate recovery during the grief process (Parkes, 1985). Locker and Dunt (1978) suggest that in long term care the quality of care can become synonymous with the quality of life and therefore satisfaction with care is an important component of life satisfaction.

The measurement of client satisfaction has been encouraged by a growing consumer orientation in health care (Avis, Bond and Arthur, 1995) and evaluating consumer satisfaction with health care services has become a standard component of assessing service delivery (Bouchard, 1993). Measurement of satisfaction also has become increasingly important as a guide to quantifying effectiveness and efficacy and is considered essential in the provision of client centred care (Bond and Thomas, 1992).

Although there is considerable literature related to consumer/product satisfaction and patient satisfaction with health care providers and services, there is very little research undertaken to investigate family satisfaction with care in general. Furthermore, the area of family satisfaction with palliative care has lacked research investigation.

There is, therefore, a need to evaluate health care practices and services using outcome measures such as satisfaction. For hospice programs, satisfaction of the patient and the patient's family is a particularly important outcome measure. There is however little theoretical understanding of satisfaction despite its frequent use as an outcome measure. Most research has focused on sociodemographic correlates of satisfaction. In a seminal article, Locker and Dunt (1978) state that there has been little attention directed towards the development of a well defined socio-psychological theory of satisfaction. Erickson (1995) highlights the remaining and ongoing need for conceptual clarity in client satisfaction research.

Kristjanson (1991) identified and tested four explanatory theories of satisfaction. These were: (1) Vroom's Fulfillment Theory, (2) Porter's Discrepancy Theory, (3) Thibaut and Kelley's Social Comparison Theory and (4) Ajzen and Fishbein's Expectancy-Value Theory. Of the four, Porter's Discrepancy theory best explained the variance in care satisfaction in palliative care. Discrepancy theory therefore offers a theoretical explanation of the relationship between family members' care expectations, care perceptions and satisfaction with care and was tested in this study.

### Purpose

The purpose of this study is to examine the relationship between family members' expectations, perceptions and level of satisfaction with advanced cancer care in the home hospice setting. The relationship amongst these variables will be tested

using Porter's Discrepancy Theory (1961). The application and testing of this theory in the Australian context is the overall purpose of the study.

### Study Objectives

The aim of this research is to:

- (i) Determine the extent to which Porters' Discrepancy Theory (1961) provides a model to understand family care satisfaction in home hospice in WA.
- (ii) Assess the level of family members' care expectations, perceptions and satisfaction with care in the home care setting.
- (iii) Assess the usefulness of the study instruments with English speaking family members of palliative care patients in the home hospice care setting in WA.
- (iv) Determine the extent to which demographic variables and family functioning influence family members' care expectations, perceptions of care and satisfaction with care in the home hospice setting.

### Research Hypotheses

The principal research hypothesis examines the relationship between the variables Family Care Expectations, Family Care Perceptions and Family Care Satisfaction using Porter's Discrepancy Theory as previously tested by Kristjanson (1991). The greater the discrepancy between family care expectations and family care perceptions, the lower the family's care satisfaction rating. The null hypothesis tested is that there will be no relationship between the constructed discrepancy variable and family care satisfaction.

It is also hypothesised that the variables Family Care Expectations, Family Care Perceptions and Family Care Satisfaction are potentially influenced by family functioning and a number of sociodemographic variables including: marital status, relationship to patient, age, sex, education, work and other commitments, income,

number of months since patient's cancer diagnosis, length of time with home hospice care, frequency of a team member visit and other sources of support. These relationships will be tested in this study.

### Significance of the Study

Increasingly, families are providing care to the person with cancer (Kristjanson, 1991). As participation in the care of cancer patients increases, family members are in a position to observe and evaluate the care received by themselves and the patient. As family members evaluate the care received they may, at times, be dissatisfied with the care provided by health professionals of hospice services. Understanding the elements that contribute to satisfaction with care will enable health professionals to better anticipate and address the expectations and concerns of family members. In turn this will benefit family members by decreasing the levels of stress experienced by them when care expectations are not met and reducing levels of dissatisfaction and regret about the care loved ones received.

Previous research has identified the lack of specific and distinct theoretical formulations in health care satisfaction (LaMonica, Oberst, Madea and Wolf, 1986; Locker and Dunt, 1978). Considerable research has been undertaken investigating patient satisfaction in various health care settings. However, the area of family satisfaction with care has attracted little research attention and family satisfaction with palliative care receiving even less. This study will provide empirical evidence of care expectations, perceptions of care and satisfaction with palliative care and how family members rate their importance. The findings will be clinically useful particularly in planning and providing more personalised family care.

### Definition of Terms

Conceptual definitions for concepts utilised in this study are provided below:

#### Advanced Cancer

Advanced cancer is defined for this study as being Stage III or Stage IV cancer. In the life history of a cancer three significant events are used to indicate the extension of cancer. These are: tumour growth (identifying tumour size and local invasion), spread to regional lymph nodes and manifestation of distant metastases (Beahrs, Henson, Huller and Kennedy, 1992, p. 3 - 5). Whilst development of staging systems for malignancies at various anatomical sites continues, the definitions of Stage III and Stage IV broadly speaking are as defined in the following way.

#### Stage III Cancer

Extensive primary tumour with fixation to a deeper structure, bone invasion, and lymph nodes of a similar nature. The lesion is operable but not resectable, and gross disease remains. Five-year survival rate is low.

#### Stage IV Cancer

The tumour is inoperable with evidence of distant metastases. There is little or no chance for 5-year survival.

(Rubin, cited O'Mary, 1993).

#### Family Care Expectations

The degree to which actions provided by health care providers are believed by the family member to be usual or reasonable (Kristjanson, 1989).

#### Family Care Perceptions

Awareness by the family member of the actions of health care providers (Kristjanson, 1991).

### Family Care Satisfaction

The degree of valuation of distinct dimensions of actions of the health care providers (Ajzen and Fishbein, 1980; Linder-Pelz, 1982a).

### Family Member

The family member is the person identified by the agency and confirmed at interview as the person most involved in the care of the patient. The relationship with the patient can be biological, legal or functional.

The nuclear family has generally been associated with the term 'family' (Leonard, Enzle, McTavish, Cumming and Cumming 1995). This view of the family has usually consisted of mother, father and children. However, this definition is becoming increasingly irrelevant as people structure their primary relationships to include such relationships as blended families, de-facto and other stable relationships. Therefore, the family member definition for this study steers away from the traditional notions of who can be identified as a family member.

### Sociodemographic Correlates of Satisfaction

The demographic and socioeconomic variables which correlate with satisfaction, not necessarily always in the same way (Ware, Davies-Avery and Stewart, 1978).

These may include: age, education, income, marital status, occupation, sex, social class.

### Socio-psychological Determinants of Satisfaction

Factors which antecede the positive or negative evaluations of care (Linder-Pelz, 1982a; Kristjanson, 1991). These may include: expectations, values, entitlements, perceptions, attitudes, evaluations.

### Thesis Organisation

This chapter has provided an introduction to this study including the purpose, objectives and research hypothesis. Chapter 2 discusses the relevant literature relating to family care satisfaction with palliative care and the development of a socio-psychological theory approach to evaluating satisfaction with advanced cancer care. Chapter 3 provides the theoretical and conceptual frameworks. Chapter 4 details the research methods used which includes a description of the design, setting and sample, data collection procedures and data analysis. The ethical considerations of the study are also discussed. Chapter 5 details the results of the study while Chapter 6 discusses and interprets them. Finally, the conclusions and implications of this research with recommendations and suggestions for further research are discussed.



## CHAPTER 2

### Literature Review

Considerable research has been undertaken in the area of consumer satisfaction in health care including both general and specific aspects of care. However, little research has been devoted to investigating family satisfaction, and in particular family satisfaction with advanced cancer care. This review examines the current knowledge of health care satisfaction from a theoretical perspective, and the development of a socio-psychological theory approach to evaluating family satisfaction in palliative care will be discussed.

Whilst the focus of this literature review is family satisfaction with palliative care and developments toward a theory of satisfaction in palliative care, the majority of research into satisfaction with healthcare has centred on patient satisfaction. Therefore, this review will also examine the literature as it relates to the development of a socio-psychological theory to evaluate family and patient satisfaction and the empirical support of the relationship between demographic variables and satisfaction with health care. In addition, methodological and conceptual issues in measuring client satisfaction will be discussed.

#### Family Satisfaction With Palliative Care

Olsen (1970) describes serious illness as a family affair whereby the family and not just the patient has the illness. Likewise the experience of cancer affects the entire family unit. Northouse and Peters-Gorden (1993) describe illness as creating a ripple effect, affecting the family's basic identity and changing the usual functioning of the family unit. The terminal phase of the cancer trajectory is also a particularly stressful time. The requirements of terminal care bring not only anxiety about how to cope with

the situation, but also the strain involved in continuous care of a severely ill person (Sykes, Pearson and Chell, 1992).

Factors surrounding the death of a loved one can have a profound impact on the grief experience of survivors. Steele (1990) found that family members' common responses to the death of a loved one included anger and hostility from the feelings of loss of control, frustration, helplessness over the events surrounding the illness and death and guilt feelings about not having done enough. Kerr (1994) found that respondents' feelings of guilt stemmed from feeling they had not done enough for the patient during the patient's illness. The findings of these studies therefore, underscore the importance of providing care that meets the family's care expectations and leaves it with feelings of satisfaction regarding the quality of care their loved one received.

Substantial research has been undertaken with regard to the family's cancer experience. Major dimensions of this experience include: developmental stage of the family, cancer illness trajectory, family responses to cancer and health care provider behaviours directed at these responses (Kristjanson and Ashcroft, 1994) with little research reported on family satisfaction with care. The research undertaken to identify family satisfaction with palliative care is discussed next. The research has not utilised a theory testing approach as the basis for their study.

Specific health care provider behaviours have been reported as important to families' satisfaction level. Hull (1991) examined caring behaviours of hospice nurses as perceived by family care givers in a home hospice care program to be most useful. Using a qualitative approach with a convenience sample of 10 families, 55 semistructured interviews and participant observations were undertaken. The four most caring behaviours were 24 hour service, effective and sensitive communication, a

nonjudgemental attitude and clinical competence. It is clear that further research is needed to study the relationship between these behaviours and family satisfaction.

A number of studies involving primary care givers have been conducted following the death of patients (Beck-Friis and Strang, 1993; Dawson, 1991; Wakefield and Ashby, 1993). Wakefield and Ashby in South Australia conducted structured interviews with surviving caregivers one year or more after the death of a family member. They examined overall level of satisfaction, and found that those receiving hospice care were more likely to rate the care as excellent and this was significantly higher than those rating the care received from non-hospice providers ( $p = 0.001$ ). Home death respondents ( $n=18$ ) rated the home service as good to excellent. However 22% ( $n=4$ ) rated the General Practitioner service as fair and 11% ( $n=2$ ) rated the Royal District Nursing Service as fair.

The institutional death respondents (who had spent some time with the home service,  $n=52$ ) generally rated the services provided in the home as good to excellent. However, 16% ( $n=8$ ) rated the General Practitioner service as poor to fair, 9% ( $n=4$ ) rated the nursing service as poor to fair and 6% ( $n=3$ ) rated the domiciliary service as poor to fair. Access to services, or delay in initiating assistance was a problem for 17% ( $n=17$ ). Thirty percent ( $n=30$ ) of the total number of respondents wished that they had had more assistance with practical caring tasks as well as respite care.

Although, overall the respondents rated the service provided highly, there was a small number (the proportion was not specified by the authors) who expressed dissatisfaction, and some respondents reported lingering anger and feelings of anxiety one year into the bereavement period. Reasons for these outcomes were given as the way bad news was broken, problems with access to a medical practitioner and lack of practical help. If it were possible to identify potential areas of dissatisfaction through

understanding expectations and perceptions of care, health professionals would be better able to anticipate the needs and concerns of family members. The earlier identification of dissatisfaction, that is prior to bereavement, would allow health professionals to better address expectations, concerns and needs of family members.

Dawson (1991) investigated needs satisfaction with terminal care settings across three sites. The Need Satisfaction Scale consisting of 10 items on a Likert scale was utilised to record the degree to which a need was intensely felt and secondly the degree to which the need was actually fulfilled. The Overall Satisfaction Scale was a single evaluative statement. The sample consisted of 100 bereaved family care givers in Pennsylvania, U.S.A. The findings indicated that overall satisfaction is negatively related to unmet needs ( $r = -0.69$ ). This suggests that need fulfillment was related to satisfaction. However, the limitation of this study was the lack of dimensions of satisfaction with care measured on the satisfaction tool used in the study.

Beck-Friis and Strang (1993) in Sweden asked 87 bereaved next-of-kin (87% were the next-of-kin of the former cancer patients) 6 to 28 months after the death of their relative in a hospital-based home care unit to give written comments on their experiences and complete questionnaires regarding their satisfaction on a number of variables. Total time within the home care program significantly influenced results. Those who were from the home program were more satisfied with the variables 'providing the patient with an atmosphere of security' ( $p = .003$ ) and 'high quality of care and nursing' ( $p = .01$ ). The survey was limited by being conducted retrospectively at some time distant to the actual home care experience relying on the recall abilities of the next-of-kin. Moreover, the study failed to conceptualise satisfaction and no reliability and validity testing was undertaken. As Eriksen (1995) has stated

conceptualisation of the phenomena under study is the first step in instrument development.

Stetz and Hanson (1992) found in their study conducted in the U.S.A, 51% (n=16) of spouse caregivers, when asked to reflect on the care experience, indicated they would have sought out additional resources. Fifty percent also reported the need to receive additional information about how to care for their partner at home.

The timing of these studies suggests that it may have been more useful to conduct them during the period the participants were recipients of the service. Dawson (1991) used one single evaluative statement as a unidimensional measure of the overall satisfaction of family care givers. A number of authors agree, however, that satisfaction is multidimensional (Carr-Hill, 1992; Hall and Dornan, 1990; Kristjanson, 1991), and therefore a satisfaction tool which has only one evaluative statement does not investigate the dimensions of care. Persons may state they are satisfied overall but may not be satisfied with care on particular dimensions of care.

### Theories of Satisfaction

Research into understanding the theoretical structure of satisfaction in health care has been undertaken primarily by investigating patient satisfaction. The research undertaken has not yet presented conclusive support for one particular theoretical explanation. Four competing theories of satisfaction were identified by Kristjanson (1991) following examination of the literature. These are discussed below.

#### Expectancy-Value Theory

According to Avis, Bond, and Arthur (1995) a valid theory of satisfaction has not been developed and therefore the model that underpins research is based upon an assumption that satisfaction, or a positive attitude to care results from the patient's perception that the service has fulfilled his or her expectations. This attitude theory

framework was developed by Ajzen and Fishbein (1980). Evidence regarding expectancy-value theory is conflicting. Kristjanson (1991) found some support for this model of health care satisfaction. Only three per cent of the variance in family member satisfaction was explained by expectancy-value theory. Linder-Pelz (1982b) failed to support the theory but found that eight percent of the variation in satisfaction with physician conduct was accounted for by expectations. Linder-Pelz concluded that expectations had an independent effect on satisfaction. Therefore, there is a lack of empirical evidence to strongly support this theoretical link between expectation, fulfillment and health care satisfaction. Despite this, there continues to be a widely held assumption of a substantial link between satisfaction and the fulfillment of expectations (Williams, 1994).

#### Fulfillment Theory

Family needs fulfillment studies have been undertaken by a number of researchers (Dawson, 1991; Grobe, Ahmann and Ilstrup, 1982; Hampe, 1975; Hileman, Lackey and Hassanein, 1992; Hinds, 1985; Kristjanson, 1991; Skopura and Bohnet, 1982; Tringali, 1986; Wright and Dyck, 1984). Of these, only Dawson and Kristjanson have investigated the relationship between need fulfillment and family care satisfaction. Dawson as discussed in the section headed family satisfaction with palliative care measured satisfaction with care with only one evaluative statement. Kristjanson investigated Fulfillment Theory and found that need fulfillment accounted for 31% of the explained variance in family care satisfaction. The more family care needs were met the more satisfied families were with the care received. Linder-Pelz (1982a, 1982b) also investigated fulfillment theory with patients. However, the findings did not support fulfillment theory.

### Social Comparison Theory

Kristjanson (1991) tested Thibaut and Kelley's Social Comparison Theory (1959). This theory proposes that past experiences are evaluated by the individual and may affect expectations about future similar events. Previous positive evaluations may increase expectations whilst conversely they may be decreased by negative evaluations. Also, the notions of equity and social comparison are important in this theory of satisfaction. Model testing of satisfaction with the three constructs Importance of Family Care Expectations, Family Care Expectations and Family Care Perceptions showed that Importance of Family Care Expectations was not statistically significant in the model. Therefore, the difference between the remaining two constructs (family care expectations and family care perceptions) gave very similar results as that of Discrepancy theory.

### Discrepancy Theory

Discrepancy theory is commonly used to understand job satisfaction (Willcock and Wright, 1991). In the conceptualisation of discrepancy theory in the area of job satisfaction there have been a number of similar interpretations (Katzell 1964; Locke 1969; Porter 1961). Porter (1961) used this discrepancy approach to study perceived need satisfactions of managers. He argued that satisfaction is determined by what one expects to receive rather than by what one wants and that if expectations are greater than perceptions, then there is a deficiency in "need satisfaction". A small number of researchers in the health area have used this discrepancy approach (Fox and Storms, 1981; LaMonica, Oberst, Madea and Wolf, 1986; Linder-Pelz, 1982b; Kristjanson, 1991).

Fox and Storms (1981) conducted a telephone survey of 2592 randomly selected residents in the Baltimore region of the United States of America (USA) to investigate

patient satisfaction with health care. Their results indicated that higher satisfaction scores occurred when there was congruence between expectations and care perceptions rather than when there was incongruence between the expectations and perceptions variables.

Linder-Pelz (1982b) with a convenience sample of 125 clinic attendees at a primary care clinic, tested a model of satisfaction using five hypotheses regarding the social psychological determinants of patient satisfaction based on theories from the job satisfaction research. Her results showed some support for the Discrepancy model (satisfaction was inversely correlated with discrepancy  $p = .02$ ,  $N = 125$ ). She suggested that patients' background beliefs play a more significant role in determining their satisfaction with care than their perceptions of the care received, so much so that patients are likely to express satisfaction independently of the care actually provided. In her study, however, there was only a single item measure for care perceptions. She concluded that satisfaction is a function of the independent contributions of expectations and perceptions.

LaMonica, Oberst, Madea and Wolf (1986) conducted three studies designed to develop and test a tool to measure inpatient satisfaction with nursing care using a discrepancy theory definition of satisfaction consistent with that originally described by Risser in 1975. The Risser Patient Satisfaction Scale is an indirect measure of satisfaction. In this scale satisfaction is inferred from respondents' judgements about the extent to which nursing behaviours occurred. The definition was not operationalised but rather implied; thus expectations were not clearly measured and an indirect approach was used to measure satisfaction. In this approach patients were asked to indicate to what extent care behaviours had occurred representing perceptions



of care rather than satisfaction with care. The tool however, did receive good internal consistency results as evidenced by alpha coefficients (.92 and .95).

Kristjanson (1991) identified that determining sociodemographic correlates of satisfaction had been the focus of previous research rather than emphasis on developing a socio-psychological theory. Kristjanson defines socio-psychological theories as explaining “perceptions, evaluations, and comparisons which antecede positive or negative evaluations” (p 15). A theory testing approach was used by Kristjanson (1991) to study family member satisfaction with advanced cancer care. Four alternate theories of satisfaction were tested. These were : (1) Vroom’s Fulfillment Theory, (2) Porter’s Discrepancy Theory, (3) Thibaut and Kelley’s Social Comparison Theory and (4) Ajzen and Fishbein’s Expectancy Value Theory. Five instruments were used to collect data: FAMCARE Scale, F-Care Needs Scale, F-Care Expectations Scale, F-Care Perceptions Scale and a short demographic scale. This study was conducted with a Canadian population of 109 family members of patients with advanced cancer receiving care from two urban hospice care programs involving an inpatient palliative care unit and two home hospice care services. Porter’s Discrepancy Theory was found to best explain the variation in satisfaction accounting for 68% of the variance. Awareness of the care provided was the best indicator of satisfaction, family care perceptions being identified as the strongest predictor of satisfaction. Also, 20% of the study sample rated care satisfaction on the lower end of the distribution.

At present Porter’s Discrepancy Theory as operationalised for palliative care by Kristjanson (1991), provides the most developed theoretical work in the area. In regard to the four theories tested, Discrepancy theory was the most credible explaining 68% of the variance in care satisfaction in a Canadian population.

### Sociodemographic Correlates of Satisfaction

Sociodemographic variables have been identified in the literature as having a relationship to satisfaction with health care (Fox and Storms, 1981; Hall and Dornan, 1990; Kristjanson, 1986; 1991). These variables include age of patient, age of family member, education level, religious affiliation, gender and relationship to patient. Fox and Storms (1981) argue that whilst establishing firm relationships between sociodemographic characteristics and satisfaction is problematic, variables which some studies have shown to be related include age, where the elderly tend to record greater levels of satisfaction and gender with women being more satisfied than men. Fox and Storms reported also that those with less education are more satisfied than the more educated, females more satisfied than men and those with less income more satisfied than those with higher incomes. Other variables have been found significant in some research. Kristjanson (1991) identified marital status as increasing the explained variance in satisfaction.

Ware, Davies-Avery and Stewart (1978) identified in their review of the literature that the relationship between sociodemographic variables and patient satisfaction was inconsistent. Income was both negatively and positively related to patient satisfaction. Two of four studies reviewed by Ware et al. found no significant relationship between marital status and satisfaction: of the other two studies, singles were less satisfied than those who were married in one, marrieds were less satisfied than singles in the other.

These findings suggest that further examination of the sociodemographic variables may help to provide additional information with regard to their relationship to expectations, perceptions and satisfaction. Secondly, examination of these variables may help to increase the explanatory power of Discrepancy theory.

### Conceptual and Methodological Issues In The Measurement of Satisfaction

Studies of satisfaction with care must be methodologically sound and have adequate conceptual and theoretical basis. The literature in relation to conceptual and methodological considerations reveals interesting and important issues. Lack of precision in defining a concept can lead to measurement problems resulting in suspect research findings (Eriksen, 1995). There is no agreed definition of the concept of patient satisfaction and it has been conceptualised in innumerable ways in different studies. Although there has been extensive use of patient satisfaction as an outcome measure, conceptual diversity is evident even in studies which have the same objectives (Avis, Bond and Arthur, 1995; Bond and Thomas, 1992). Weak study design, lack of conceptual clarity in both dependent and independent variables are cited (Bond and Thomas, 1992; Kristjanson, 1991; Thompson and Sunol, 1995) as reasons for consistently disparate findings.

Methodological considerations regarding timing of questionnaires in patient opinion surveys have been investigated. French (1981) recommends that surveys be undertaken as close to events as possible and suggests that memory may well play a part in opinion surveys. Westbrook (1993) found that patients were more critical when completing satisfaction surveys while in hospital. Further, Westbrook also goes on to state that despite methods used, the vast majority of patients are loathe to criticise any aspect of their care and tend to say they are satisfied. This, however, may not be true for family members. It may be concluded therefore that surveys might more usefully be undertaken whilst hospice care is current for family members and patients. In addition Pelletier (1985) identifies that high positive ratings are not unusual and therefore results below this level including neutral responses, may well be signs of discomfort and should be viewed as significant. An additional issue is that satisfaction is a

multidimensional concept (Oberst, 1984; Ware, Davies-Avery and Stewart, 1978), yet research continues to be undertaken using one item (unidimensional) satisfaction scales (Dawes, 1991).

### Summary

To summarise, whilst sociodemographic correlates have been the focus of satisfaction research up to recent times, a theory testing approach has been postulated to provide a better explanation of satisfaction. Wakefield and Ashby (1993) have revealed that although overall, patients and their families are satisfied with their care, a small number are dissatisfied and that this dissatisfaction may linger after the death of the patient. Problems in measuring satisfaction have been raised in the literature identifying timing of administration of questionnaires and respondents' reluctance to be critical. An investigation of the theoretical approach taken by Kristjanson (1991) to further understand the elements of satisfaction in a home hospice care setting would now be useful to test the theory's applicability to family member satisfaction with palliative care in an Australian population. Understanding the elements that contribute to satisfaction will enable health professionals to better anticipate and address the expectations and concerns of family members. The findings will be clinically useful particularly in planning and providing more personalised family care.

## CHAPTER 3

### Theoretical and Conceptual Frameworks

This chapter describes the theory underpinning the study of which there are two main components: the theoretical work of Porter (1961) and the conceptual framework specifically formulated for this study. There are three assumptions about satisfaction on which the theoretical and conceptual frameworks rest. These assumptions were identified by Kristjanson (1991) and are appropriate for this study. They are: 1) Satisfaction is an attitude, 2) Satisfaction occurs within a context of social and psychological factors which include interpersonal and intrapersonal factors, and 3) Satisfaction involves an evaluative process.

#### Theoretical Framework

In the conceptualisation of discrepancy theory in the area of job satisfaction there have been a number of similar interpretations (Katzell 1964; Locke 1969; Porter 1961). Porter's Discrepancy Theory (1961) was tested by Kristjanson (1991) and provides the framework for this study. Porter (1961) used a discrepancy approach to study perceived need satisfactions of managers. He argued that satisfaction is determined by: a) how much of the characteristic is present and b) how much of a characteristic one thinks should be present. In testing the need satisfaction of managers he suggested that if b) is greater than a) then there is a deficiency in "need fulfilment." This discrepancy approach between expectations (what the managers thought should be present) and perceptions (what the managers thought was present) therefore identified those less satisfied.

Discrepancy theory is used to test relationships between the concepts family care perceptions, family care expectations and family care satisfaction with palliative care. Family satisfaction with care is said to be some function of the discrepancy between

family care expectations and family care perceptions (Kristjanson, 1991). The value of testing discrepancy theory lies in the area of health care satisfaction, as ratings of care reported by some researchers are generally high. Kristjanson suggests a possible reason for these high ratings could well be that health care consumers use lower expectations as a standard against which perceptions of care are evaluated.

### Conceptual Framework

The conceptual framework that guides this study is diagrammatically represented in Figure 1. This conceptual framework has been designed to offer an explanation for the relationships under study based on previous research as a guide to analysis. Family Care Satisfaction is hypothesised to be some function of the discrepancy between Family Care Expectations and Family Care Perceptions. The constructed variable (PDIFF) denotes the discrepancy between Family Care Expectations and Family Care Perceptions.

Some of the sociodemographic variables under study (age, marital status, education, income, sex, relationship to patient) as discussed in the literature review have previously been identified as having a relationship to satisfaction with health care (Fox and Storms, 1981; Hall and Dornan, 1991; Kristjanson, 1991) and are examined in this study to assess whether there are relationships between these variables and the concepts Family Care Expectations, Family Care Perceptions and Family Care Satisfaction with palliative care.

The variables of work and family commitments, number of months since diagnosis, length of time with hospice, frequency of care visits, family functioning and other sources of support were identified by expert palliative care clinicians as being variables which may influence satisfaction with care. These variables are examined to assess their impact on the concepts family care expectations, family care perceptions

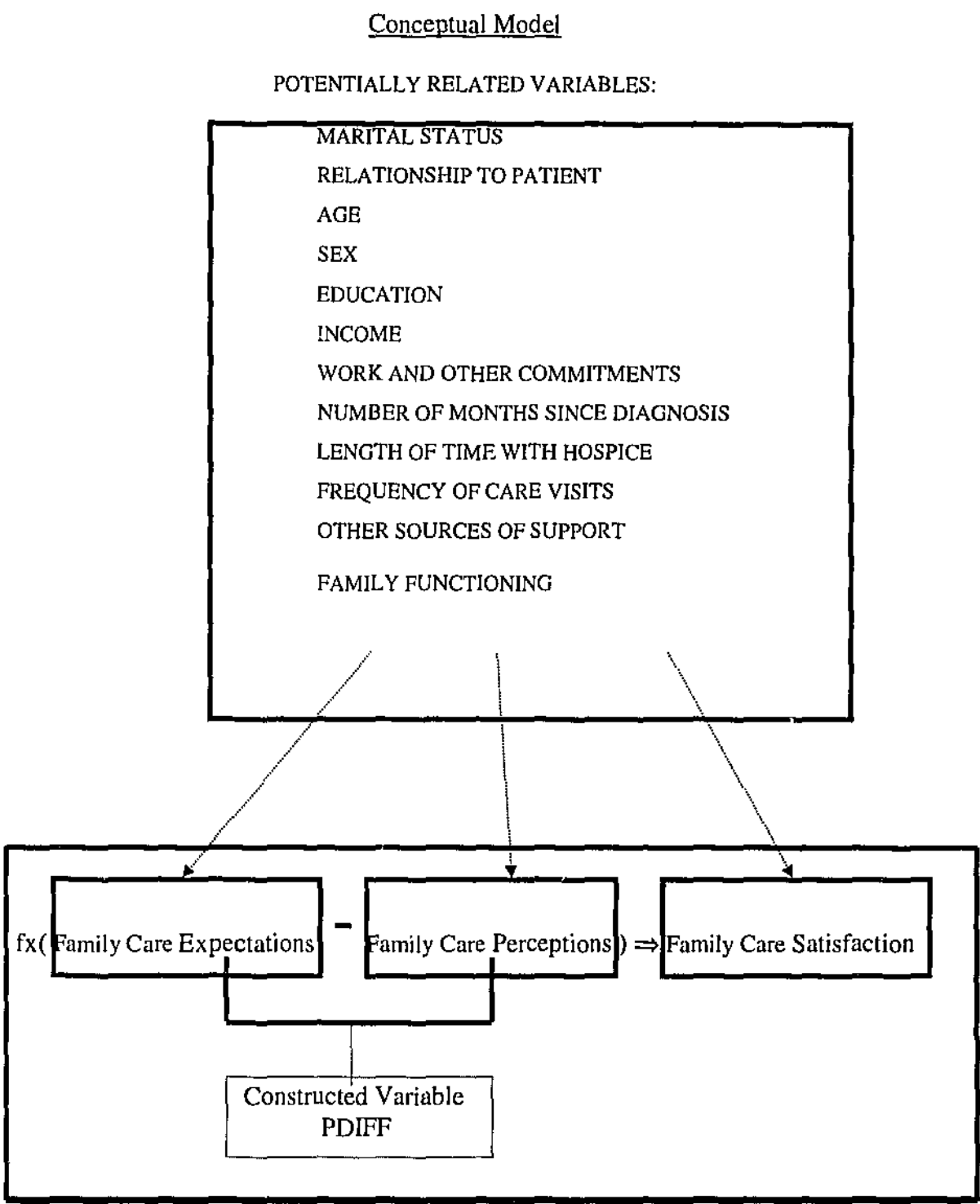


Figure 1. Diagrammatic representation of conceptual model.

————→ proposed/ hypothesised relationships

fx = function of

and family care satisfaction with palliative care.

The usual family functioning of families is described as being changed by serious illness (Northouse and Peters - Gordon, 1993; Olsen, 1970). This study will also measure the family members' perceptions of how the family works together on essential tasks and will determine the relationships between family functioning and family care expectations, family care perceptions and family care satisfaction with palliative care.



## CHAPTER 4

### Method

This chapter presents the research process used to investigate the research hypothesis. The design, sample and setting, and the data collection procedure are described. The instruments used are presented and the reliability and validity of the instruments are discussed. This chapter also includes details of data analysis and the ethical considerations concerned with undertaking this study.

#### Design

The study utilised a descriptive correlational design, and used structured questionnaires to access data at one point in time. The dependent or outcome variable was satisfaction with care. The predictor variables of family care expectations and family care perceptions were the antecedent factors. The confounder variable, family functioning, was measured and demographic data obtained.

#### Sample

The participants in this study were family members of patients with advanced cancer currently receiving care and assistance from the Silver Chain Hospice Care Service (HCS). A stratified sample (a stratum being one of the eight HCS areas) of 55 family members representing 55 family units was obtained using the list of clients with the HCS.

#### Selection of Participants

The HCS undertook the selection of participants. The respective team leaders reviewed a list of all patients for each of the eight metropolitan areas of the HCS. The inclusion criteria utilised by the team leaders was that the patient had a diagnosis of advanced cancer, had been admitted to the home care program for at least four days, was not expected to die within the next four days and the age of the family member was

at least 18 years. Including only those who were in the programme for at least four days ensured that only those who had received services from the HCS were included and therefore able to make a judgment about the services. Excluding the family members of patients who were likely to die within the next four days meant that the researcher would be less likely to intrude on families at this time or less likely to be contacting families after the patient had died as this might have been interpreted as the researcher lacking sensitivity to the priorities of the family.

For ease of data collection, the eight metropolitan areas of the HCS, depending on their proximity to each other, were divided into three groups. Further selection of participants was then undertaken from each area within the first group before proceeding to the second group of areas leaving the third group to last. This was done at weekly intervals so that the interval between initial contact with the family members and data collection was reduced, thus lessening the possibility that family members would be excluded from the study if the patient had died in the interval period.

The names remaining on the list were then subject to random selection where 25 names were selected from each area in each group in the first and second groups using the computerised format available in the software program Statistical Package for the Social Sciences (SPSS). A letter of introduction (Appendix A) and an accompanying permission to release name and phone number form (Appendix B) was sent by the HCS to the principal carers of the patients who had met the inclusion criteria thus far. The permission form was then returned directly to the researcher if the family member wished to be contacted by the researcher regarding participation in the study.

Only 21 family members were available in one area in the first group. Also, two names were not included following random selection and prior to mailing because of unexpected deaths. The response rate was low for the first and second groups (see

Table 4.1). In view of time constraints with regard to allocated research time and the impending satisfaction survey by the HCS, all those who met the inclusion criteria in the list of possible participants for the third group were included. Subsequently this area received a greater number of letters of introduction than the other two groups (see Table 4.1). Comparison of the randomly selected groups (first and second) with the convenience group (third) on the main demographic characteristics of age, education, income and sex using t-test and chi-squared analysis revealed that the group was homogenous on these characteristics. This means that the change in sampling technique to ensure adequate numbers for analysis did not affect the representativeness of the sample.

Table. 4 1

Summary of Introductory Letters Sent, Response Rates and Number of Participants

Group	Number Of Introductory Letters	Number Of Responses	Number Included	Participation Rate (%)
First Group	69	23	16	23
Second Group	49	21	16	33
Third Group	88	31	23	26
Totals	206	75	55	100

### Setting

The principal family member's home was the setting for this study. This usually was the patient's home but not necessarily in all cases. The participant and researcher sat at a table. The questionnaire was thus completed more comfortably than if seated in a lounge chair. Details of the home hospice service used in this study can be found in Appendix C.

### Instrumentation

Four instruments were used to collect the data for this study; FAMCARE Scale (Appendix D), F-Care Perceptions Scale (Appendix E), F-Care Expectations Scale (Appendix F), Family Assessment Device: General Functioning Scale (Appendix G), as well as a short demographic questionnaire (Appendix H). A total of 82 items were included in the instruments and demographic questionnaire.

#### FAMCARE Scale

The 20 item FAMCARE Scale was developed by Kristjanson based upon earlier research (n=30, 1986; n=210, 1989) and was designed to quantify the concept of satisfaction with advanced cancer care. A separate study of 109 family members reported an internal consistency estimate as measured by Cronbach's standardized alpha coefficient of .95 (Kristjanson, 1991). The scale achieved internal consistency estimates as measured by Cronbach's standardized alpha coefficient of .93 at both initial and retest times, a test-retest correlation of .91 and estimates of criterion validity using the McCusker scale of .79 and .77 (Kristjanson, 1993).

#### F-Care Perception Scale

Family members' care perceptions were measured using the 21 item F-Care Perceptions Scale developed from research by Kristjanson (1986, 1989). This instrument measures a family member's awareness of the health care provider

behaviours directed toward the patient and themselves. Previous results indicate internal consistency estimate of .88 and .89 (Kristjanson, 1989) and .90 using Cronbach's alpha coefficient (Kristjanson, 1991). Stability over time was assessed using Pearson's correlation coefficient and a value of .82 obtained (1991).

#### F-Care Expectations Scale

The F-Care Expectations Scale has 16 items and measures the concept care expectations which are the actions by health professionals that family members believe are usual or reasonable. This instrument was developed from prior qualitative research where family members of cancer patients identified what they considered to be important indicators of quality care by Kristjanson (1986), and adaptation of some items from the study undertaken by Linder-Pelz (1982a). The instrument was also checked for validity content and clarity with six family survivors of cancer patients and found to exhibit clarity and minimal redundancy (1991). Previous results indicate an internal consistency estimate of .91 using Cronbach's alpha coefficient (Kristjanson, 1991).

#### Family Information

The family information questionnaire was based on one previously developed by Kristjanson (1992, Appendix H). Demographic and relationship information was collected about the family member which included their marital status, age, sex, education completed, relationship to patient, income, ancestry and religion. As well, the number of months since cancer diagnosis of the patient was obtained. These variables were previously investigated by Kristjanson (1991) to describe the characteristics of the Canadian population and were utilised in Australia with the addition of: frequency of team member visits; length of time with Home Hospice care, work/or other commitments and other sources of support.

### Family Assessment Device: General Functioning Subscale

Family functioning was assessed using the General Functioning Subscale of the Family Assessment Device with the permission of the author (Appendix I contains the letters giving permission for use of instruments not in the public domain). The Family Assessment Device (FAD) is a 60 item self-report scale, based on the McMaster Model of Family Functioning, which operationalises the six family functioning dimensions of: problem solving, communication, roles, affective involvement, affective responsiveness and behaviour control. The General Functioning Subscale consisting of 12 items can be used independently from the other scales as an overall measure, has an age 12 readability level (Sawin and Harrigan, 1994) and is a single index representing overall functioning. The FAD has demonstrated adequate reliability and validity (Epstein, Baldwin and Bishop, 1983; Kabacoff, Miller and Bishop et al., 1990; Miller, Epstein, Bishop and Keitner, 1985; Miller, Kabacoff, Epstein et al., 1994). The General Functioning Subscale has previously demonstrated adequate reliability (Byles, Byrne, Boyle and Offord, 1988). Results from an unpublished study indicate an internal consistency estimate of .86 using Cronbach's alpha coefficient in a Hospice care population (Kristjanson, Leis, Koop, Carriere and Mueller, under review).

### Procedure

#### Obtaining Consent

The family members interested in participating in the study returned their signed 'permission to release name and phone number' form directly to the researcher in the pre-addressed stamped envelope provided. The researcher then made contact over the phone and confirmed the person's ability to read and write English and explained the research. It was also confirmed that the family member was the person most involved in the care of the patient. Sample selection criteria included that if more than one

person was identified, the spouse would be the participant. If the spouse was not one of the two identified, the relative closest in age to the patient was the participant (Kristjanson, 1991). If the family member wished to participate in the study an appointment was made for the researcher to attend at the participant's home. If the family member did not wish to participate after listening to the explanation then he/she was free to decline. Twenty of the respondents to the introductory letter did not participate in the study (see Table 4.1 for response and participation rates). The reasons for non-participation are summarised in Table 4.2.

At the appointed time, in the participant's home, the information sheet (Appendix J) was given to the participants to read and any questions were answered by the researcher. The consent form (Appendix K) was then given to the participant to read and sign. Any questions or queries were answered at the time by the researcher.

#### Data Collection

Data collection was undertaken by the researcher during the period 24 August to 25 September 1996. Once the family member had signed the consent form the five questionnaires were completed. These were administered in exactly the same order to the participants, having been stapled together in booklet form (Appendix L). On average, data collection took 40 minutes, some participants taking longer if they had questions regarding the questionnaires.

One commonly asked question was which doctor was the questionnaire referring to as some patients were currently under the care of a number of doctors. These included medical specialists, general practitioners and home hospice doctors. To maintain consistency participants were asked to use the doctor currently most involved in the patients' care as their frame of reference.

Table 4.2

Frequency Distribution of Reasons for Non-participation by Respondents To

Introductory Letter

Reason	Number
1. Refusal following explanation of study	4
2. Patient has died	4
3. Patient too ill	3
4. Researcher unable to contact respondent	3
5. Too busy	2
6. Poor English	1
7 Family member ill	1
8.Wasn't primary caregiver	1
9. Primary caregiver had died	1
<b>Total</b>	<b>20</b>

Ethical Considerations

Approval from the Edith Cowan University's Higher Degrees Committee and the HCS was obtained before participant selection and data collection was undertaken. A written consent (Appendix K) was read and signed by participants assuring their rights and confidentiality of data collected. They were informed that their questionnaires would be coded by a nonidentifying number only and data entered into the computer under that number. Participants were also assured that participation or nonparticipation in the study would in no way affect the care that their relative/loved one received (Appendices A, J, K). The participants were advised that a summary



report of grouped data would be available to the HCS and that results from the research would be published in professional nursing journals.

### Data Analysis

The data analysis included descriptive statistics to summarise the sample in terms of demographic characteristics. Internal consistency reliability testing of the instruments was assessed by using Cronbach's alpha coefficient. The relationships between family care expectations, family care perceptions and family care satisfaction were identified using Pearson's Product-Moment Coefficient. The extent to which the discrepancy between expectations and perceptions explained the variance in family satisfaction with palliative care was undertaken using regression analysis. Hierarchical regression analysis was undertaken to examine the extent to which family care satisfaction with palliative care was explained by the discrepancy variable and sociodemographic variables. Finally, as a consequence of the findings of testing discrepancy theory, post hoc analysis was conducted using regression analysis to determine an alternative model of family care satisfaction more suited to this sample. Significant characteristics of the less satisfied subgroup identified were also identified.

### Method of Scoring

#### F-Care Expectations Scale.

The possible score range for each item on the F-Care Expectations Scale was one to five. Participants were asked to indicate how important the listed expectations were by indicating (1) Not Important, (2) Somewhat Important, (3) Average Important, (4) Very Important or (5) Extremely Important. The participants' response became the score for the item. Each item in the instrument was then summed to give a total score of the whole instrument for each participant.

### F-Care Perceptions Scale.

Response options for the F-Care Perceptions Scale were labelled Strongly Agree(SA), through to Strongly Disagree (SD) indicating degree of agreement along a Likert scale. The possible score range was five to one with Strongly Agree being a score of five and Strongly Disagree being one. The scoring scale on data entry was reversed for the statements negatively phrased (items 3,4,5,10,15,16). As a result, for these items, a score of five represented a 'strongly disagree' with a negatively worded statement eg. the patient lacks trust and confidence in the doctor (L. Kristjanson, personal communication, September, 1996). A score of one represented a 'strongly agree' response, an 'uncertain' response was unchanged in score value. Agree became a score of four and Disagree a score of two. Each item score in the instrument was then summed to give a score for the whole instrument for each participant.

### FAMCARE Scale.

The possible score range for each item on the FAMCARE Scale was one to five. Response options were labelled Very Satisfied (VS) through to Very Dissatisfied(VD) indicating degree of satisfaction along a Likert scale. Each item in the instrument was then summed to give a score for the whole instrument for each participant.

### Family Assessment Device: General Functioning Subscale.

The Family Assessment Device: General Functioning Subscale was scored according to Miller's (1982) scoring instructions. Low scores in items one to six represented healthy functioning and high scores represented unhealthy functioning. High scores in items seven to twelve represented healthy functioning and low scores unhealthy functioning. Scores for items seven to twelve were reversed so that an overall low score for the instrument represented healthy functioning. The mean of the twelve items was the score used for the instrument.

### Total Number of Commitments.

The number of commitments the participants had was calculated, using the following scoring method: Not currently working = 0, Part time work = 1, Full time work = 2, each preschool child = 1, each school age child = 1, each dependent adult/elderly adult = 1. Other commitments reported by participants included volunteering and childcare and these were each given a score of one. These were then summed to give a total score for each participant.

### Total Number of Other Sources of Support.

Each source of support was added together to give a total for each participant.

### Construction of the Discrepancy Variable

PDIFF was a constructed variable representing the discrepancy between expectations of care and perceptions of care based on Porter's Discrepancy Theory as operationalised by Kristjanson (1991). This was achieved mathematically using the following formula:

$$\text{PDIFF} = \begin{array}{c} \text{total score of F-Care} \\ \text{Expectations Scale} \end{array} - \begin{array}{c} \text{total score of F-Care} \\ \text{Perceptions Scale} \end{array}$$

### Statistical Assumptions Underlying the Use of Regression Analysis

An overview of the process undertaken in testing regression analysis assumptions for this study is described in general here. The results of testing specific regression equations are reported in chapter 5.

Regression analyses allow an assessment of the relationship between one dependent variable and several independent variables and the result is an equation that represents the best prediction of a dependent variable from several continuous or

dichotomous independent variables (Tabachnik and Fidell, 1989). The assumptions underlying the use of multiple regression are examined in relation to data from this study. Coakes and Steed (1996) list these assumptions as being: (1) adequate ratio of cases to independent variables, (2) no outliers, (3) absence of multicollinearity and singularity, (4) presence of normality, linearity, homoscedasticity and independence of residuals. A further two assumptions are listed by Verran and Ferkitch (1987). These being: (5) the residual mean is zero and (6) the residual variance is equal at all points of the predicted dependent variable.

#### Ratio of Cases to Independent Variables.

Whilst the number of cases needed depends upon the type of regression model to be used, the minimum requirement is to have five times more cases than independent variables (Tabachnik and Fidell, 1989). This assumption was not violated as hierarchical regression was used allowing for up to ten independent variables to be included in the regression analysis with a sample size of 55 participants.

#### Outliers.

Multivariate outliers were sought using Mahalanobis distance for the regression analyses undertaken in this study (outliers sought were those outside 3 standard deviations). The distance of a case from the centroid created by the remaining cases is known as the Mahalanobis distance (Tabachnik and Fidell, 1989). The critical level value of chi-square for the number of independent variables, at the alpha level of .001 was checked. A large Mahalanobis distance identifies a case as having extreme values on one or more of the independent variables. If a large Mahalanobis distance was detected a decision would need to be made to either delete the case from the data set or to change the outlier variable value so that the case no longer had as much impact (Tabachnik and Fidell, 1989).

### Multicollinearity and Singularity.

Multicollinearity and singularity is assessed by examining the correlational matrices demonstrating the relationship between variables. With highly correlated variables the analysis would be in jeopardy because of instability of regression coefficients (Tabachnik and Fidell, 1989). Therefore, the correlational matrices were examined to screen the variables for multicollinearity and singularity. Table 5.12 in chapter 5 shows the generated correlational matrix comparing variables of interest. The correlational matrix for the remaining variables under examination can be found in Appendix M.

### Normality, Linearity, Homoscedasticity and Independence of Residuals.

Examination of residuals scatterplots provide a test of assumptions of normality, linearity and homoscedasticity between predicted scores of the dependent variable and errors of prediction.

Normality. Tabachnik and Fidell (1989) state that normal probability plots and detrended expected normal probability plots are a more helpful graphical device than frequency histograms for assessing normality. Normal distributions in the probability plot are expected to show the points for all the cases falling along the diagonal with "... some minor deviations due to random processes" being acceptable.

Linearity. For a finding consistent with linearity, scatterplots of residuals against predicted values should reveal no clear relationship between the residuals and the predicted values (Coakes and Steed, 1996).

Homoscedasticity. This is assessed by examining a scatterplot of standardised residuals versus predicted dependent variable. The scatterplot is rectangular in appearance when homoscedasticity is present.

Independence of Residuals. Tabachnik and Fidell (1989) state that errors of prediction are assumed to be independent of one another and that independence may be violated when one residual value depends on the value of another eg time or distance. These variables were not relevant to this study.

Zero Mean of Residuals.

The mean of the residuals for each regression analysis is zero and is assessed by examining the stated mean generated during the regression procedure.

Variance Equality.

The residual variance is equal at all points of the predicted dependent variable. A scatterplot of standardised residuals and predicted dependent variable will demonstrate a random and equal scatter of residuals about the zero line of the residuals if there is no violation of the assumption (Verran and Ferketich, 1987).

## CHAPTER 5

### Results

This chapter presents the results of the study. Firstly the sample will be described, followed by the psychometric properties of the instruments. The final section includes the results of theory testing followed by post hoc analysis. An alpha level of .05 significance was set for use throughout data analysis and exact p, r, t, rho values have been presented. All other findings have been rounded off to two decimal points. Descriptive results are presented as summaries and tables. Data were analysed using the software program Statistical Package for the Social Sciences (SPSS for Windows, Release 6.0).

#### Demographic Characteristics of the Sample

The participants in this sample were the family members of 55 patients with advanced cancer receiving home hospice care. The participant was the family member most involved in the patient's care in each family. During the study period, 206 family members were contacted as possible participants for the study. Of this group, 55 family members met the inclusion criteria and agreed to participate for a response rate of 26.70% (see Table 4.2 and 4.3 in chapter 4 for details).

The mean age of the participants was 60.87 years (SD = 11.65) with the median being 61 years. The majority (80%) were over 50 years of age, with age range 36 to 87 years. The mean age for the males was 66.58 years, and for women 56.45 years.

Female participants represented 56.36% of the sample.

The remainder of the demographic data is presented in the order appearing in the Family Information Questionnaire.

Marital Status

The marital status of the participants is shown in Table 5.1. The majority were married with those divorced, never married, widowed and in de-facto relationships representing 12.73% of the sample population.

Table 5.1

Marital Status

<b>Marital Status</b>	<b><u>N</u></b>	<b>%</b>
Married	48	87.27
Never Married	3	5.45
De-facto	2	3.64
Divorced	1	1.82
Widowed	1	1.82
<b>(<u>N</u> = 55)</b>		

Relationship to Patient

As shown in Table 5.2 the majority of the participants were the spouse of the person with cancer. The 10.91% of participants included in the “other” category described their relationship to the patient as that of daughter-in-law, niece, friend, partner or step-daughter.



Table 5.2

Relationship to Patient

<b>Relationship to Patient</b>	<b><u>N</u></b>	<b>%</b>
Spouse	41	74.55
Other	6	10.91
Daughter	4	7.27
Mother	3	5.45
Son	1	1.82
<b>(<u>N</u> = 55)</b>		

Highest Level of Education

Educational achievement is shown in Table 5.3. The majority (52.70%) indicated that their highest level of education was primary school or 'some or all junior high school'.

Some of junior high school here means that some participants may have completed one or two years of high school as opposed to the full three years of junior high school.

Sixty per cent had no post-school qualifications. This is representative of the West Australian population (Australian Bureau of Statistics, 1991), where 60 % have no post-schooling qualifications.

Table 5. 3

Highest Level of Education

Highest Level of Education	<u>N</u>	%
Some or all Junior High School	24	43.64
TAFE/Trade/Diploma	10	18.18
University Degree	6	10.91
Primary School	5	9.10
Tertiary Entrance Exam	4	7.27
College of Advanced Education	4	7.27
Post Graduate Studies	2	3.63
(N = 55)		

Occupation

Table 5.4 and 5.5 identifies occupational categories of the participants and whether they were currently working in paid employment. A majority of the participants were retired and therefore not working whilst some were on leave from their employment (7.2%) to care for the person with cancer. Those who stated they were on leave from their work were a subgroup of those not currently working but identified themselves as belonging to an occupational grouping other than retired.

Table 5.4

Occupation

<b>Occupation</b>	<b><u>N</u></b>	<b>%</b>
Retired	31	56.36
Professional	11	20.00
Full-time Homemaker	5	9.09
Clerical	5	9.09
Skilled Trade	1	1.82
Labourer/Unskilled	1	1.82
Management	1	1.82
<b>(<u>N</u> = 55)</b>		

Table 5.5

Currently Working

<b>Currently Working</b>	<b><u>N</u></b>	<b>%</b>
No	40	72.72
Full time	10	18.18
Part time	5	9.10
<b>(<u>N</u> = 55)</b>		

### Work and Other Commitments

As shown on Table 5.6, the majority of the sample had no additional commitments above caring for the person with cancer. Twenty nine per cent had one or two commitments whilst 14.54% had 3 or more additional commitments. The type of commitments and method of scoring these commitments have been previously described in chapter 4.

Table 5.6

### Work and Other Commitments

<b>Total Number of Commitments</b>	<b><u>N</u></b>	<b>%*</b>
0	31	56.36
1	8	14.54
2	8	14.54
3	2	3.64
4	3	5.45
5	2	3.64
6	1	1.82
( <u>N</u> = 55)	.	

Note:\* Percentage does not equal 100 due to rounding

### Income

Family members reported their income as shown in Table 5.7. Australian Bureau of Statistics (1991) reports that those with an individual annual income below \$12,000 represent 43.85% of the West Australian population. Therefore, the lowest income group is over represented in the study sample.

Table 5.7

### Family Member Income

<b>Income</b>	<b><u>N</u></b>	<b>%</b>
<\$10,000	29	52.72
\$10,000 - \$20,000	8	14.54
\$20,001 - \$30,000	7	12.73
\$30,001 - \$40,000	3	5.45
\$40,001 - \$50,000	2	3.64
\$50,001 - \$60,000	2	3.64
over \$60,000	2	3.64
missing data	2	3.64
<b>(<u>N</u> = 55)</b>		

Ancestry

Table 5.8 represents 13 reported ethnic affiliations. The 13 affiliations are reported in three groups. Firstly British Isles, which includes those who indicated they were of British, English, Scottish, Welsh and Irish descent. Included in this group were those who identified themselves as Australian of Anglo-Saxon descent. Secondly Australian, which includes all those who designated their ancestry as Australian. The third group identified here as European were all those who indicated their ancestry as being European, Czech, German, Greek, Spanish, Hungarian and Dutch. There were no participants of Asian or Aboriginal /Torres Strait Islander descent in the sample.

Table 5.8

Ancestry

Ancestry	<u>N</u>	%
British Isles	37	67.27
Australian	11	20.00
European	7	12.73
(N = 55)		

Religion

The religious affiliation of the sample is summarised in Table 5.9. The ‘other’ group identifies the following religions: Uniting Church, Presbyterian, Pentecostal, Lutheran, Non Denominational Christian, Greek Orthodox, Methodist and Jehovah’s Witness.

Table 5.9

Religion

<b>Religion</b>	<b><u>N</u></b>	<b>%</b>
Anglican	23	41.82
Other	17	30.91
Catholic	12	21.82
None	3	5.45
<b>(<u>N</u> = 55)</b>		

Number of Months Since Cancer Diagnosis

The mean number of months since cancer diagnosis was 53.9 (SD = 58.62). The median and mode were 24 months. Seventy four percent of the participants had known of the cancer diagnosis for ten months, 54% for 24 months and 25% for 78 months.

Length of Time (Weeks) with Home Hospice Care.

The sample produced a skewed distribution for the time ranged from 3 to 216 weeks (M=25.04, SD = 31.75). The median was 17 weeks and mode 4 weeks. Seventy five per cent of the sample had been with the Hospice at least 8 weeks, 53.7% at least 17 weeks and 24.6% at least 26 weeks. Seven per cent of the sample population had been with the Hospice 52 weeks.

Frequency of Team Member Visit Each Month

Number of visits by team members each month ranged from 2 to 180 (M=19.10, SD = 29.70). The median number of visits was eight and the mode four. Seventy five per cent of the sample population received at least four visits per month, 50% eight visits and 25% at least 30 visits per month. Each visit represents a staff contact with the

family. Some visits to families entailed more than one staff member and therefore each staff contact was counted as a visit.

#### Other Sources of Support

Most of the participants (74.54%) (as shown in Table 5.10) had one or two sources of support other than the HCS. These were usually friends and/or family. Eighty per cent of the participants indicated that friends were a source of support. Eighty per cent (although not necessarily exactly those indicating friends as a source of support) indicated that family members were a source of support. Additional sources of support included local support groups, Senior Citizens Association, Cancer Foundation, Cancer Support Service, Social worker from the Hospital of previous attendance, Silver Chain Counsellor, Minister of Religion, church members and the day hospice.

Table 5.10

#### Other Sources of Support

<b>Total Number of Other Sources of Support</b>	<b><u>N</u></b>	<b>%*</b>
2	26	47.27
1	15	27.27
3	10	18.14
0	1	1.82
4	1	1.82
5	1	1.82
6	1	1.82

(N = 55)

---

Note:\* Percentage does not equal 100 due to rounding



In summary, the typical family member in this sample was a married, 60 year old female with all or some junior high school completed; she was now retired and on a low income. This individual was usually the spouse of the person with cancer and was of anglo/saxon/celtic descent with a Christian religious affiliation. The cancer diagnosis had been known for 53.9 months (4.5 years) and professional help and support had been provided by the HCS for 17 weeks. A team member visited the home on eight occasions each month. The family member had no further commitments other than the caring for the person with cancer and the sources of support in the main came from family and friends. The extent to which the study sample may be regarded as representative of the principal family member caregiver in the HCS client group is unable to be determined. Demographic data to the extent that was collected with this study is not recorded by the HCS and therefore no comparison could be done on demographic data to determine the extent to which the study population was similar to the client population of the HCS.

#### Psychometric Properties of the Instruments

Psychometric properties of the scales are reported here for the completed data of this study ( $n = 55$ ). All scales evidenced internal consistency reliabilities above the .80 standard recommended by Nunnally (1978). Factor analysis to assess internal construct validity of the scales was not undertaken in this study. This was previously established by Kristjanson (1991) and the small sample size of this study would preclude robust factor analysis being achieved.

#### F-Care Expectations Scale

The potential range of scores for the 16 - item F-Care Expectations Scale (with a 5 - point scale) was 16 - 80. Total actual scores ranged from 51 to 80 with a mean score of 72.96 ( $SD = 6.31$ ), and a median score of 74. The overall mean of items was 4.56

with all individual item means above 4.2 indicating that most participants scored the instrument at the higher end of the scale indicating high expectations of care. The scale achieved an internal consistency estimate as measured by Cronbach's standardised alpha coefficient of .88.

The lowest scoring item on the F-Care Expectations Scale was 'the doctor will listen to what the family thinks is important'. The item mean was 4.2 ( $SD = .85$ ). This statement reflected that this was the least important family member expectation on average in this sample.

#### F-Care Perceptions Scale

The potential range of scores for the 21 - item F-Care Perceptions Scale (with a 5 point scale) was 21 - 105. Total actual scores ranged from 75 to 105 with a mean score of 89.13 ( $SD = 8.5$ ) and a median score of 89. The overall mean of items was 4.24 with all individual items above 3.44. Three mean of items were below 4.00, whilst the remaining 18 were above 4.20. The scale achieved an internal consistency estimate as measured by Cronbach's standardised alpha coefficient of .79.

One item "there was a delay in making the diagnosis" was deleted from the scale (following discussion with the author) with resultant improvement in Cronbach's alpha coefficient to .80. This statement reflected an aspect of care that occurred earlier in the illness trajectory and therefore was probably not appropriate here.

The remaining results reflect the 20 - item scale. Total actual scores ranged from 75 to 100 with a mean score of 85.58 ( $SD = 7.99$ ) and a median score of 85. The possible score range for each item was 1 to 5 with the overall mean of items 4.28, minimum 3.44 and maximum 4.55 indicating that most participants tended to score the instrument at the higher end of the scale indicating high perceptions of care.

The lowest scoring item on the F-Care Perceptions Scale was 'the doctor has arranged a family conference to discuss the patient's illness'. This item had a mean item score of 3.44 ( $SD = 1.32$ ). This statement reflected that not at any point in the illness trajectory had a family conference been arranged or any other arrangement undertaken that the family member thought was just as adequate.

#### FAMCARE Scale

The potential range of scores for the 20 - item FAMCARE Scale was 20 - 100. Total actual scores ranged from 71 to 100 with a mean score of 88.53  $SD = 8.20$  and a median score of 90. The possible score range for each item was 1 to 5 with the overall mean of items being 4.43, minimum 3.85, maximum 4.8 and with 19 of 20 items having means greater than 4.0. Overall, this indicates that most participants scored at the higher end of the scale reflecting relatively high levels of satisfaction. The scale achieved an internal consistency estimate as measured by Cronbach's standardised alpha coefficient of .88.

The lowest scoring item on the FAMCARE Scale was 'How satisfied are you with family conferences held to discuss the patient's illness'. This item had a mean of 3.85 ( $SD = 1.13$ ).

#### Family Assessment Device (FAD): General Functioning Subscale

The possible score range for each item of the FAD: General Functioning Subscale was 1 to 4 with 1 reflecting healthy functioning and 4 reflecting unhealthy functioning. The overall item mean was 1.58, minimum 1.33, maximum 2.02. Total actual mean scores ranged from 1.00 to 2.67 with a mean and median score of 1.58 ( $SD = .44$ ). Only nine (16.36%) participants reported an overall mean score of greater than 2.0 (representing unhealthy functioning). The internal consistency estimate was .87 using Cronbach's alpha coefficient.

The two lowest scoring items on the FAD: General Functioning Subscale were: 'we cannot talk about the sadness we feel' ( $\underline{M} = 1.82$ ,  $\underline{SD} = .82$ ), 'we avoid discussing our fears and concerns' ( $\underline{M} = 2.02$ ,  $\underline{SD} = .85$ ). The mean for the second item was greater than the score 2 representing unhealthy functioning for the overall mean of the instrument.

#### Examination of Correlation Between F-Care Perceptions Scale and FAMCARE Scale

Factor analysis to assess internal construct validity of the scales was not undertaken because of small sample size. However, a high correlation between the Family Care Perceptions variable and the Family Care Satisfaction variable can be identified by Pearson's Product-Moment Correlation Coefficient ( $r(55) = .74$ ,  $p = .000$ ). To assess the distinction between these two scales correlational analysis was computed on the matched items of each instrument (Appendix N). Two of the item pairs achieved a correlation greater than .65. This criterion is recommended by Gordon (1968) as the value representing multicollinearity. These were items related to information about side effects and availability of hospital beds. Two further item pairs achieved correlations between .5 and .65, the remainder below .5. These results indicate that overall participants did distinguish care perceptions from care satisfaction and also a response set was not operating.

#### Relationship Between the Discrepancy Variable and Family Care Satisfaction

Pearson's Product-Moment Correlation Coefficient is a test of linear association between two variables (Burns and Grove, 1993). It provides information on the nature of a linear relationship (the sign indicating the direction of the relationship) and the magnitude of the linear relationship (the absolute value of the coefficient indicating the strength of the relationship). The Pearson Product-Moment Coefficient ( $r$ ) ranges in

value from -1.00 (perfect negative or inverse relationship) through 0.00 (absence of a linear relationship) to +1.00 (perfect positive linear relationship) (Aitken, 1991).

Pearson's Product-Moment Correlation was calculated to detect any relationship between the constructed Discrepancy variable (Family Care Expectations - Family Care Perceptions) and Family Care Satisfaction. The null hypothesis tested was that there would be no association between the Discrepancy variable and Family Care Satisfaction. The correlation coefficient  $r$  calculated for the Discrepancy variable and the Family Care Satisfaction variable in this study was  $r(55) = -.55$ ,  $p = .000$ . A two tailed test of significance for the calculation was used because there was no evidence to support a directional hypothesis being tested. Therefore, the null hypothesis was rejected. It was concluded that there was a significant negative linear relationship between the Discrepancy variable and the Family Care Satisfaction variable. The magnitude of the slope represented a moderate correlation between the two variables.

#### Relationships Between Major Variables of Interest

Pearson's Product-Moment Coefficients were calculated to detect any relationships between independent variables of interest, and the dependent variable and independent variables. The null hypotheses tested were that there would be no association between any two of these variables. A two-tailed test of significance was used for the calculations as there were no directional hypotheses. The results are shown in Table 5.11. Whilst all variables tested showed a relationship between variables, a number were not statistically significant.

A significant, moderately strong relationship was found between the Family Care Expectations variable and the Discrepancy variable. Also, there was a significant highly correlated relationship between the Family Care Perceptions variable and the Discrepancy variable. The Discrepancy variable is derived from the Family Care

Perceptions variable and the Family Care Expectations variable, so this was not unexpected. The Family Care Perceptions variable was found also to be highly correlated with the Family Care Satisfaction variable, while the Family Care Expectations variable was not significantly correlated with the Family Care Satisfaction variable. The correlations of the variables of age and family functioning with family care expectations, perceptions and satisfaction are reported in the sociodemographic section of this chapter.

The relationship between the Discrepancy variable and Family Care Expectations variable suggests that as the F-Care Expectations Scale score increased, so did the Discrepancy variable score. The Discrepancy variable's relationship to the Family Care Perceptions indicates that as the F-Care Perceptions Scale score decreased so did the Discrepancy variable score. Therefore, a large discrepancy may possibly be dependent on high expectations and low perceptions in this sample.

Table 5.11

Pearson's Correlation Coefficients for Major Variables of Interest

<b>Variables of Interest</b>	<b>Family Care Expectations</b>	<b>Discrepancy (Expectations-Perceptions)</b>	<b>Family Care Perceptions</b>	<b>Family Care Satisfaction</b>	<b>Family Functioning</b>
<b>Family Care Expectations</b>	1.00	.55 (p = .000)	.17 (NS)	.11 (NS)	-.21 (NS)
<b>Discrepancy (Expectations-Perceptions)</b>		1.00	-.75 (p = .000)	-.55 (p = .000)	.14 (NS)
<b>Family Care Perceptions</b>			1.00	.74 (p = .000)	-.33 (p = .015)
<b>Family Care Satisfaction</b>				1.00	-.34 (p = .010)

Continued/...

.../Continued Table 5.11

Pearson's Correlation Coefficients for Major Variables of Interest

<b>Variables of Interest</b>	<b>Family Care Expectations</b>	<b>Discrepancy (Expectations-Perceptions)</b>	<b>Family Care Perceptions</b>	<b>Family Care Satisfaction</b>	<b>Family Functioning</b>
<b>Family Functioning</b>					1.00
<b>Age</b>	.19 (NS)	.03 (NS)	.11 (NS)	.30 (p = .028)	-.10 (NS)
(N = 55)					
NS Not Significant					



Relationship Between Family Care Expectations and Selected  
Sociodemographic Variables

Correlations were performed to determine the relationship between the variable Family Care Expectations and the variables: marital status of family member (MARITAL), relationship to patient (RELAT), age of family member (AGE), sex of family member (SEX), highest education level achieved (EDUCAT), income of family member (INCOME), work and other commitments (TOTCOMIT), number of months since cancer diagnosis (MTHSDX), length of time with home hospice (TIMEHHC), frequency of care visits (FREQV), other sources of support (TOTOSS) and family functioning (FAMF). The findings are presented in Table 5.12.

The results show that there were no statistically significant relationships between the Family Care Expectations variable and the sociodemographic variables of age of family member, relationship to patient, sex, highest level of education achieved (of the family member), marital status, months since cancer diagnosis, length of time with home hospice care, frequency of team member visit, family functioning and other sources of support. None of these variables influenced the variable Family Care Expectations in this sample.

Table 5.12

Correlation Coefficients for Family Care Expectations and Selected

Sociodemographic Variables

Family Care Expectations	<u>r</u>	<u>rho</u>
MARITAL		.11
RELAT		-.08
AGE	.19	
SEX		.22
EDUCAT	-.04	
INCOME	-.20	
TOTCOMIT	-.15	
MTHSDX	.05	
TIMEHHC	.10	
FREQV	.10	
TOTOSS	.18	
FAMF	-.21	
(N = 55)		

Note. Variables did not achieve statistical significance.

Relationship Between Family Care Perceptions and Selected

Sociodemographic Variables

Correlations were performed to determine the relationship between the variable Family Care Perceptions and the variables: marital status of family member (MARITAL), relationship to patient (RELAT), age of family member (AGE), sex of family member (SEX), highest education level achieved (EDUCAT), income of family

member (INCOME), work and other commitments (TOTCOMIT), number of months since cancer diagnosis (MTHSDX), length of time with home hospice (TIMEHHC), frequency of care visits (FREQV), other sources of support (TOTOSS), family functioning (FAMF). The results are presented in Table 5.13.

Table 5.13

Correlational Coefficients for Family Care Perceptions and Selected Sociodemographic Variables

Family Care Perceptions	r	rho
MARITAL		-.08
RELAT		.02
AGE	.11	
SEX		.01
EDUCAT	.06	
INCOME	.01	
TOTCOMIT	-.25	
MTHSDX	.03	
TIMEHHC	-.26	
FREQV	.07	
TOTOSS	.04	
FAMF	-.33*	
(N = 55)		

\*p < .05

The results show that of the sociodemographic variables investigated in this study, family functioning (FAMF) was found to have a statistically significant

relationship to the Family Care Perceptions variable. That is, the higher the family functioning score the less the specific aspects of care were perceived to have occurred. The higher family functioning score ( $>2$ ) represents unhealthy family functioning. However, these two variables can be considered to have a relatively weak relationship. The variable length of time with home hospice was approaching statistical significance ( $t(55) = -.26, p = .051$ ). The trend was a negative relationship with perceptions of care as length of time with the HCS increased. That is, perceptions of care decreased as time in HCS increased.

#### Relationship Between Family Care Satisfaction and Selected Sociodemographic Variables

Correlations were performed to determine the relationship between the variable Family Care Satisfaction and the variables: marital status of family member (MARITAL), relationship to patient (RELAT), age of family member (AGE), sex of family member (SEX), highest education level achieved (EDUCAT), income of family member (INCOME), work and other commitments (TOTCOMIT), number of months since cancer diagnosis (MTHSDX), length of time with home hospice (TIMEHHC), frequency of care visits (FREQV), other sources of support (TOTOSS), family functioning (FAMF). The results are presented in table 5.14.

The results show that of the sociodemographic variables investigated in this study, age of family member (AGE), family functioning (FAMF) and work and other commitments (TOTCOMIT) were found to be statistically significant. However, as presented further on in this chapter, the variable work and other commitments (TOTCOMIT) does not have a linear relationship to the variable Family Care Satisfaction when viewed on a scatterplot.

Table 5.14

Correlational Coefficients for Family Care Satisfaction and Selected Sociodemographic Variables

<b>Family Care Satisfaction</b>	<b><u>r</u></b>	<b><u>rho</u></b>
MARITAL		-.23
RELAT		.12
AGE	.30*	
SEX		-.04
EDUCATION	-.55	
INCOME	.03	
TOTCOMIT	-.39**	
MTHSDX	.20	
TIMEHHC	-.12	
FREQV	.04	
TOTOSS	.06	
FAMF	-.34*	
(N = 55)		

\* $p < .05$ . \*\* $p < .01$

Testing Discrepancy Theory

Evidence for non-violation of assumptions for this theory was assessed. There was no clear relationship between the residuals and the predicted values consistent with the assumption of linearity. The mean of the residual was zero. Verran and Ferketich (1987) state that residual means are essential and violation of this assumption cannot be tolerated.

Multivariate outliers were sought using Mahalanobis distance establishing that the assumption was not violated. Examination of the scatterplot for the tested equation revealed that there was not a true rectangular appearance reflecting complete homoscedasticity. The equal variance and linearity assumptions were not violated. The normality assumption was not violated as evidenced by a normal probability plot. Therefore, it was accepted that there were no major violations of the assumptions. The only violation to occur in relation to homoscedasticity was minor, reflecting a good result given the number of participants.

Discrepancy theory as operationalised by Kristjanson (1991) specifies that the difference between an individual's expectations and perceptions (PDIFF) will predict satisfaction (FAMCARE). Regression analysis was used to test the predicted relationship stated in this theory. The adjusted  $R^2$  obtained from the regression analysis was used as the measure of explained variance for the effect variables. Kristjanson reported results of regression analysis using the adjusted  $R^2$  and these are reported here for the purposes of comparison.

The multiple regression equation constructed to test this theory was:

$$\text{FAMCARE} = \text{PDIFF} + e$$

where  $e$  = error and is depicted in Figure 2 (previously described by Kristjanson, 1991).

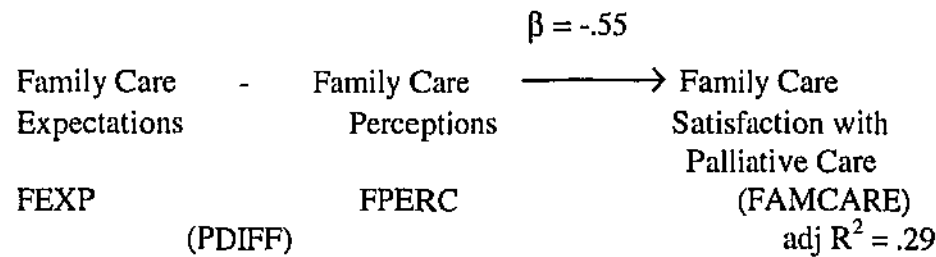


Figure 2. The extent to which the discrepancy variable explains the variance in Family Care Satisfaction (N = 55)

Two sociodemographic variables, family functioning (FAMF) and age (AGE) were added to the regression analysis. These two variables were found to best fit the criteria for selection. The criteria were, high or the highest correlations with the dependent variable and low correlations with each other on the correlational matrix (Appendix M). Whilst particularly high correlations with the dependent variable were not evident, the relationship between the dependent and independent variables was statistically significant. Multicollinearity of the variables AGE and total number of commitments (TOTCOMIT) was evident ( $t(55) = -.71, p = .000$ ). Therefore, only one of these could be entered into the regression. An examination of the scatterplots revealed a curvilinear and mixed linear relationship between the dependent variable Family Care Satisfaction (FAMCARE) and TOTCOMIT variable. Combining the TOTCOMIT variable with the AGE variable did not prove useful as the relationship between these two variables increased non linearity as evidenced by the scatterplot. The hypothesis tested therefore was that there would be no further increase in the variance when the family functioning score and age of the family member is added to the equation. These variables also offered a plausible explanation to being influential

variables affecting satisfaction with care. The independent variables were then regressed on the dependent variable FAMCARE and entered in the following order: discrepancy variable, family functioning and age of family member using hierarchical multiple regression. Statistical assumptions were not violated for this analysis as evidenced by normal probability plot and scatterplot of residuals. Confirmation of zero mean was obtained. Multivariate outliers were sought using Mahalanobis distance establishing that the assumption was not violated. The resulting equation was:  $FAMCARE = (-.53) PDIFF + (-.24) FAMF + (.29) AGE + e$ . The adjusted  $R^2$  for this equation was .42. Significance values for beta coefficients were PDIFF .0000, FAMF .0259, AGE .0079. When FAMF was added to the equation a further 6% of the variance was explained. When AGE was added to the equation a further 7% of the variance was explained. Therefore, the inclusion of the demographic variables increased the explanation of variance in family care satisfaction by 13%.

#### Post Hoc Analysis

##### Less Satisfied Family Members

Ten family members representing 18.18% of the study sample had family care satisfaction scores less than 80. An overall score of less than 80 indicated that these participants were neither very satisfied (reflecting a score of 100% on the FAMCARE scale) nor satisfied (reflecting a score between 80 - 99%) overall. Surveys indicate that the majority of consumers, usually 80% or more, express overall satisfaction with their care, with few participants responding negatively to any given item (Carr-Hill, 1992; Evason and Whittington, 1991; Fitzpatrick, 1991). This group, with family care satisfaction scores less than 80, would have indicated some of their responses on the questionnaire as undecided or a definite negative response.



### Comparisons of Less Satisfied Subgroup with Satisfied Group

The family care perceptions' rating was found to be significantly lower in the less satisfied group ( $t(53) = -4.40, p = .000$ ). The discrepancy variable score was found to be significantly lower in the less satisfied group ( $t(23.75) = 4.21, p = .000$ ) and the less satisfied group were significantly younger ( $t(12.06) = -2.48, p = .029$ ). There were no significant differences in the means of the two groups with the variables: family care expectations, months since cancer diagnosis, length of time with home hospice service, frequency of team member visit, family functioning, total of other sources of support (see Appendix O).

### Testing An Alternative Model

#### Family Care Perceptions Variable

The Family Care Perceptions variable was found also be highly correlated with the Family Care Satisfaction variable,  $r(55) = .74, p = .000$  indicating a strong relationship between these two variables. A further regression equation was constructed to test the extent to which Family Care Perceptions (FPERC) predicted Family Care Satisfaction (FAMCARE). This was:

$$\text{FAMCARE} = \text{FPERC} + e.$$

Evidence of non-violations of assumptions of linear regression analysis were also assessed. Statistical assumptions were not violated for this analysis as evidenced by normal probability plot and scatterplot of residuals. Confirmation of zero mean was obtained. Multivariate outliers were sought using Mahalanobis distance establishing that the assumption was not violated. The results are shown in Figure 3.

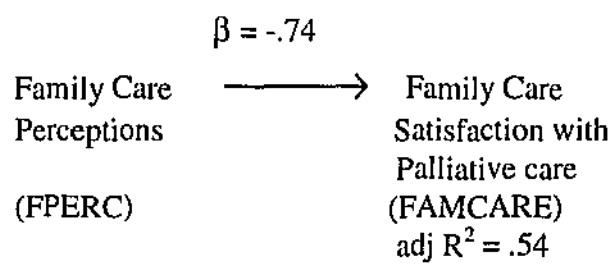


Figure 3. The extent to which Family Care Perceptions explains the variance in Family Care Satisfaction (N = 55)

For this sample, 54% of the variance in family member satisfaction was explained by family care perceptions alone.

Summary

The demographic characteristics of the 55 participants in this study were reported. Overall, the participants indicated high levels of expectations of care, perceptions of care and satisfaction with care. The discrepancy variable was found to have a moderately strong relationship to family member satisfaction with care. Results of residual analysis used to test violations of statistical assumptions in regression analysis were reported. Results of the regression analysis of discrepancy theory were presented. Discrepancy theory explained 29% of the variance in family care satisfaction. When the variables family functioning and age of family member were added to the regression analysis, 42% of the variance in family member satisfaction was explained. However, the variable family care perceptions was found to be a better predictor of family care satisfaction than the discrepancy variable explaining 54% of the variance in family care satisfaction for this sample. A small number (18.18%) of participants in this sample were less satisfied.

## CHAPTER 6

### Discussion and Conclusions

The findings presented in chapter 5 are interpreted and discussed in this chapter. The main purpose of this study was to examine the relationship between family care expectations, perceptions of care and level of satisfaction with palliative care in the home hospice setting. The relationship amongst these variables was tested using Porter's Discrepancy Theory (1961) as operationalised by Kristjanson (1991). The application and testing of this theory in the Australian context was the overall purpose of the study, having been successfully tested previously in a palliative care population in Canada by Kristjanson (1991).

#### Summary of Major Findings

The study produced findings to support the main hypothesis tested, namely that the greater the discrepancy between family members' care expectations and family members' care perceptions, the lower the family members' care satisfaction rating. Discrepancy theory explained 29% of the variance in family care satisfaction in the home hospice setting and therefore offers a theoretical explanation of the relationship between family care expectations, care perceptions and satisfaction with palliative care. Two sociodemographic variables, family functioning and age of the family member, explained the variance in satisfaction with care by a further 13%.

A better predictor of satisfaction was the family members' perceptions of care which explained 54% of the variance in family care satisfaction with palliative care. This suggests that family members' awareness of the details of care and the results of the care provided was the best indicator of their satisfaction. This finding supports Kristjanson (1991) who found that the family members' perceptions of care was the strongest predictor of family members' care satisfaction.

### Psychometric Assessment of the Instruments

The psychometric assessment of the instruments with this sample's data provided additional evidence of the reliability of the instruments used. High internal consistency estimates were achieved by the FAMCARE, F-Care Perceptions, F-Care Expectations Scales and Family Assessment Device: General Functioning Subscale. The instruments developed by Kristjanson (1986, 1989, 1991) although in early stages of development had previously undergone rigorous testing for reliability and validity. The results for this study showed that although reliability results were not as high as Kristjanson's they were still within the range ( $>.80$ ) recommended by Nunnally (1978). Low variability of scores on the F-Care Expectations Scale suggests that the instrument may have lacked sensitivity as most participants indicated expectations at the higher end of the scale. Post hoc analysis revealed that family members' care perceptions alone contributed more to the explained variance in family care satisfaction than did the discrepancy between the family members' expectations of care and perceptions of care. This may be explained by the limited variation in the F-Care Expectations Scale scores of the participants.

The Family Assessment Device: General Functioning Subscale showed respectable reliability results. Byles, Byrne, Boyle and Offord (1988) also report good reliability results for this subscale of the Family Assessment Device.

Factor analysis to assess internal construct validity of the scales was undertaken by Kristjanson (1991) and during the development of the tools in previous studies (1986, 1989). In this study, a high correlation between the Family Care Perceptions variable and the Family Care Satisfaction variable was identified and therefore correlational analysis was computed by matching paired items in the instruments. Only two items scored high correlations suggesting that there was little evidence that the

scales measured the same phenomena. That is, the scales did make enough distinction between the two concepts. During the data collection period the participants did not offer any comments to suggest that the questions were repeated in both scales. Nunnally (1978) acknowledges that in a very strict sense one can never prove that any set of measurement precisely fits a construct name, and suggests that when measures correlate highly then it can be concluded that they are measuring the same thing. Whilst there were two items which correlated highly, the remainder of the items did not evidence this. Therefore, given the previous construct validity testing of the instruments (Kristjanson, 1991) and lack of consistently high paired item correlations, the concepts measured and the instruments are distinct and separate. These findings concur with previous research (Linder-Pelz, 1982b; Kristjanson, 1991).

In summary, the instruments used in this study continue to maintain their rigour. All the instruments exhibited respectable reliability estimates. Limited variation in the F-Care Expectations Scale score suggests that the scale may lack sensitivity.

### Influencing Variables

The theoretical framework, with reference to Porter's Discrepancy Theory, proposed that family care satisfaction with palliative care was a function of the discrepancy between family care expectations and family care perceptions. It was hypothesised that the variables Family Care Expectations, Family Care Perceptions and Family Care Satisfaction were potentially influenced by a number of sociodemographic variables including: marital status, relationship to patient, age, sex, education, work and other commitments, income, number of months since patient's cancer diagnosis, length of time with home hospice care, frequency of a team member visit, other sources of support and family functioning. Some of these variables had been found previously, though with inconsistent results across studies, to influence satisfaction in the patient

and family satisfaction literature (Fox and Storms, 1981; Kristjanson, 1991; Ware, Davies-Avery and Stewart, 1978). The remaining variables work and other commitments, months since cancer diagnosis, length of time with home hospice care, frequency of care visits and other sources of support were thought to be potentially influential by palliative care clinicians. Previous research had indicated a significant positive relationship between length of time with home care service and satisfaction (Beck-Friis and Strang, 1993).

The results of this study demonstrated that very few of the sociodemographic variables correlated with the Family Care Expectations, Family Care Perceptions and Family Care Satisfaction variables. Family functioning correlated with perceptions of care forming a weak, negative but statistically significant relationship. Family members' perceptions of care decreased as family functioning became increasingly dysfunctional. Other research has not previously identified this relationship. Length of time with home hospice when correlated with Family Care Perceptions approached statistical significance. The trend showed that as length of time with the HCS increased the family members' perceptions of care decreased. A larger sample size may have indicated a clearer relationship between these two variables. With terminal cancer, as time increases so do the requirements of care and hence the burden of care on the family member caring for the person with cancer. The decrease in the perceptions of care may be the result of the interplay between these factors. Regular assessment and provision for meeting caregivers' needs including respite may improve family members' perceptions of care in situations where caring for the person with cancer by the family member is required over a long period of time.

Age of the family member and family functioning correlated with the Family Care Satisfaction variable forming weak but statistically significant relationships.

Increasing age has previously been identified as positively influencing patient satisfaction with care (Fitzpatrick, 1991; Fox and Storms, 1981; Ware, Davies-Avery and Stewart, 1978). In this study the relationship indicated that as the age of the family members increased the family members' care satisfaction increased which supported previous findings of other studies.

Previous research has not identified the relationship between family functioning and family members' satisfaction with care. The relationship identified here was that as family functioning scores increased, indicating unhealthy functioning, the family members' satisfaction with care decreased. Thus, family functioning may well influence family members' satisfaction with care in the hospice setting. Research pertaining to this relationship has not been reported. Research utilising the Family Assessment Device tested family functioning with participants grouped into clinical and nonclinical samples indicated higher scores overall for the clinical sample. However, the relationship between family functioning and satisfaction with care was not tested (Kabacoff, Miller, Bishop, Epstein and Keitner, 1990).

Research is needed to further explore these interesting findings. Caring for people with cancer has already been identified as being a particularly stressful time for the whole family (Holing, 1986). Care experiences perceived as unsatisfactory or stressful by families may complicate recovery during the grief process (Parkes, 1985). Therefore, identifying factors which negatively influence perceptions of care and satisfaction with care form an important first step toward implementing actions which may diminish negative perceptions.

#### Relationship Amongst Major Variables Of Interest

There was no significant relationship between expectations and satisfaction suggesting that satisfaction may be independent of expectation. This finding is in

contrast to the previous research findings of Linder-Pelz (1982b) who found that the most important antecedent social-psychological variable was 'expectations' and that expectations had an effect on satisfaction irrespective of the perception of needs fulfillment.

In this study, family care expectations were defined as the degree to which actions provided by health care professionals are believed to be usual or reasonable. The family members in this sample indicated high expectations scoring on the upper end of the scale consistently. However, expectations were measured after commencement with the HCS. It can only be hypothesised, that once the participants had experienced the care provided, the sample population may well have adjusted upward their expectations. Measurement of family care expectations may therefore best be undertaken at the first contact with the patient and family members at the time of referral to the service or when care begins. Future research should also consider measuring family care expectations, family care perceptions and family care satisfaction at different times during the family's association with the home hospice, rather than accessing the data at only one point in time. This would clarify whether the high expectations scores recorded by this study were expectations acquired by the participants after receiving care from the HCS or that these family members' expectations were unchanged from their pre-service expectations.

#### Discrepancy Theory

Previous studies investigating patient satisfaction with health care have reported support for Discrepancy theory (Fox and Storms, 1981; Linder-Pelz, 1982b; Kristjanson, 1991). The variance explained in this study does not reflect the results achieved by Kristjanson (1991) in a Canadian population where 68% of the variance in family care satisfaction with palliative care was explained by Discrepancy theory. This



may be a result of differences in the sample populations in each of these studies. This study used one discrete population receiving care from one hospice home care service. The Canadian population consisted of family members from two different care facilities, one providing home hospice care and the other an inpatient facility providing home hospice care as well. The amount of explained variance in family care satisfaction may be a result of the smaller sample size when compared to the Canadian study ( $n = 109$ ) or of sample bias. Kristjanson relied entirely on a convenience sample while this study relied in the main on random selection for its participants.

Further, as was described in chapter 4, the home hospice service from which this sample was selected provided a comprehensive service to its clients. This comprehensive service may well contribute to the high expectations, perceptions and satisfaction scores obtained from the sample in this study, and therefore the lack of variability of the scores, when compared with the Canadian population.

The discrepancy variable as operationalised by Kristjanson (1991) may need further research development. Porter (1961) described satisfaction as being a 'need fulfillment' and found that those managers whose expectations (the amount of characteristic there should be) were greater than perceptions (how much of the characteristic there is) had a deficiency in need fulfillment. Porter therefore identified one possible relationship between these two variables as an explanation of dissatisfaction. Kristjanson (1991) identified that this explanation did not provide information about how to interpret other situations such as when perceptions were greater than expectations. That is, when someone perceives they have received more than they expected; does this discrepancy lead to dissatisfaction? While this study did not attempt to provide answers to that question a small number of family members were identified as less satisfied. The relationship between the family care expectation and

family care perceptions variables for this less satisfied group is discussed in the following section.

### Comparisons of Less Satisfied Subgroup with Satisfied Group

A small subgroup of the sample (18.18%) were less satisfied than the majority. The family member care perceptions rating and discrepancy variable score were significantly lower. The less satisfied group was significantly younger but there were no significant differences in the means of the two groups with other sociodemographic variables. A small less satisfied subgroup was also identified by Kristjanson (1991) and Evason and Whittington (1991).

The finding that this group has a lower discrepancy variable score is interesting. This group's low discrepancy score does not follow the theoretical explanation for satisfaction with care. The family care expectations score remained consistently high with the rest of the study sample score (the difference in the mean scores for each group were not statistically significant). However, the family perception score was significantly less than the satisfied group and therefore the discrepancy margin was reduced. This may have been compounded by the unequal number of items in the scales. The F-Care Perceptions Scale contained more questions than the F-Care Expectations Scale and therefore potentially a situation could occur where family member care perceptions could be greater than family member care expectations. However, the less satisfied group in this sample did not have large discrepancy scores. The characteristics in terms of the scores obtained for the variables was that in overall terms this subgroup represented those who had high expectations, low perceptions of care and low satisfaction with care. This result can only be regarded as tentative given the small number (ten) in the group who were less satisfied. Further investigation is

warranted to examine relationships between lower levels of satisfaction, a reduced discrepancy between expectations and perceptions and age.

### Alternative Model

Another finding of this study was that family members' care perceptions contributed more than the discrepancy variable to the explained variance in family member care satisfaction with palliative care. Similarly, Kristjanson (1991) found that family care perceptions contributed as much to the explained variance as did the discrepancy variable. A possible explanation for this may well be the low variability obtained in the scores on the F-Care Expectations Scale as the responses indicated a high level of expectations in this sample thus affecting the variability.

In previous research perceptions of care have been used as an indirect measure of satisfaction (LaMonica, Oberst, Madea, and Wolf, 1986; Oberst, 1984). The finding in this study that perceptions of care explained only 54% of the variance in family member care satisfaction with palliative care suggests that the use of indirect measures to measure outcomes such as patient/family satisfaction offers only a partial explanation of satisfaction. Perceptions of care seems to be the major contributing factor in explaining variance in family member satisfaction with care. However, it is clear that there is more to satisfaction with care than just the perception of care as almost half of the variance in family member satisfaction with care is not explained by this variable.

### Assessing the Usefulness of the Study Tools

One of the objectives of the study was to assess the usefulness of the study instruments with English speaking family members in the home care setting in WA. The tools ( F- Care Expectations Scale, F-Care Perceptions Scale, FAMCARE Scale) received respectable reliability results (Cronbach's Alpha) and overall participants did not exhibit problems in completing the questionnaires. Some participants had difficulty

with the negatively phrased declarative statements requiring them to spend time working out their responses.

The questions/declarative statements relating to doctors proved difficult for some participants to answer as the patient would currently be attended by a number of medical practitioners. These included: cancer specialist, pain specialist, physician, general practitioner and home hospice doctor. In this study the family members were asked to respond to those particular questions using as their frame of reference the doctor currently most involved with their care. As the home hospice services in WA is not the only provider of medical care to its clients, clarification with this area of the questionnaire might prove useful. Patients often elect to continue their care relationship with their own GP and often only use the HHD for emergencies or night calls and so may only meet the HHD on a few occasions.

The instruments proved easy to use by the participants. The match between the questions/declarative statements relating to aspects of care provision by medical practitioners may need to be revised to reflect more closely the system of medical cover provided to palliative care patients in the home hospice setting in WA.

### Comparisons of Two Studies

A comparison of the Canadian sample (Kristjanson, 1991) and the sample in this study revealed some differences when comparing the groups. The difference in the explained variance in satisfaction with care of family members in the two population groups (Canadian (68%) and Australian (29%)) is important to note. The difference may be due to a number of reasons. The sample size differences may have contributed, and/or the source of the participants. This study obtained its sample from one home hospice care facility while the Canadian sample was obtained from two home hospice facilities and an inpatient hospice. The narrow base of this study may be reflected in the

low variance in family members' satisfaction with care given the comprehensive nature of the service provided. Cultural differences may have influenced the participants. For example, Australians may be less inclined to view their care as unsatisfactory or to indicate dissatisfaction compared to people from other cultures such as North American. Australia needs to contribute its own cultural uniqueness in the research area of palliative care and the perceptions and satisfactions with that care provision.

A comparison of the two populations on the main demographic characteristics of age, sex, income and education revealed differences. Forty two percent of the Canadian sample was  $\leq 50$  years of age while only 20% were in the Australian sample. Consequently the Australian sample represented a much older age group than was evident in the Canadian sample. The sex of the family members was similar with 52% being female in the Canadian sample and 56.4% in the Australian sample. When comparing incomes of family members between the two groups the majority (52.7%) of the Australian sample (while only 6% of the Canadian sample) was in the lowest economic group ie less than \$10,000 annual income. This may be a reflection of the difference in ages between the groups and different methods of funding retirement. Most of the older family members in the Australian population relied on the aged pension as their source of income during retirement. Retirees in Canada may be funded at a higher rate as 23% of the Canadians had an annual income of \$11,000 - 20,000 while 30% were over 65 years of age.

In comparing education levels the samples were similar. Forty percent of the Australian sample and 45% of the Canadian sample completed post secondary education, 50% of the Australian sample and 53% of the Canadian sample attended some or all of high school. On these demographic markers it can be seen that the Australian sample was older and poorer than the Canadian population. Increasing age

and lower socioeconomic group have previously been identified (Fox and Storm, 1981) as having a relationship with increasing satisfaction levels. This would seem to be supported in comparing these two studies.

### Conceptual and Methodological Issues

Two important issues arising from this research are discussed. Firstly, the methodological issue of the timing of instruments related to patient/ family satisfaction. The instruments were administered while the person with cancer and the family member were currently clients of the hospice as recommended by previous researchers in patient/ client satisfaction (French, 1981; Pelletier, 1985). Overall, the sample in this study scored the F-Care Expectations Scale at the upper end of the scale, therefore there was a limited variability in the scores. This limited range may be explained by considering the fact that family members had already experienced the service provided by the HCS. Their expectations may have risen from their pre-service expectations confounding findings. Recording family member expectations prior to receiving care from the HCS may identify more clearly the actual importance placed on the expectations prior to care provision.

Secondly, the concept Family Care Perceptions was defined by Kristjanson (1991) as awareness by the family member of the actions of health care providers. Family members were asked to comment on the occurrence of certain events. The F-Care Perceptions Scale, used to measure the concept Family Care Perceptions included declarative statements that identified indirectly the actions of health care providers. An example is the first statement 'the patient's pain is relieved quickly'. Reference to the direct action by health care providers is not made but rather the effect or outcome of the actions. A further example is 'the patient lacks trust and confidence in the doctor'. The occurrence of the health care provider actions cannot be commented on with this

statement but rather the effect of the health care provider behaviour or actions is being judged. Therefore, further refinement to develop more direct measures of the health care provider actions is required to reflect the conceptual definition.

### Limitations of the Study

While a number of variables were measured in this study, the influence of unknown variables must be regarded as a limitation of the study. A further limitation of the study is the small sample size. Therefore, results from this size population can only be regarded as tentative. The sample size precluded factor analysis being undertaken which would have been useful in providing further evidence of the psychometric properties of the instruments as tested in an Australian population for the first time. The instruments, although in early stages of development have previously undergone rigorous testing for reliability and validity in a Canadian population.

The cross-sectional design accessing data at only one point in time was a further limitation. However, the difficulties of recruiting and maintaining participant numbers in this client population are well known. Therefore, longitudinal designs present their own difficulties with this particular group of patients and family member caregivers.

### Implications for Practice

The identification of a small subgroup of less satisfied family members (18.18%) with this sample is the most useful piece of information for clinical nurses and other health professionals. The importance of providing information to the family about the details of the care and the results or effectiveness of actions taken by health professionals is underscored by the finding that the family members' perceptions of care were the best predictors of satisfaction with care. One of the commonly reported communication issues identified in the literature that families of patients with cancer face is the problem of information acquisition (Kristjanson, 1986, 1989; Skorupa and

Bohnet, 1982; Wright and Dyck, 1984). The families' need for better communication with health professionals is well documented. This study revealed that the type of communication that was important in family members' satisfaction with care in the home hospice setting was that which included the details of care.

Families who are having difficulties as a functioning unit may well need to have an increased level of communication commitment from health professionals to avoid outcomes such as feelings of dissatisfaction and regret about the perceived quality of care their loved one received. Nurses need to identify these families on admission to the service and ensure that these families are kept informed and are aware of the details of care provided to the person with cancer. The development of suitable methods of nursing assessment would facilitate identification of these families.

The items related to family functioning which scored the least were items related to communication within the family. Families as indicated by family member participants found it difficult to talk about the sadness they felt and avoided discussing their fears and concerns. Nurses need to actively promote sources of help in this area such as the counselling service. Further education for nurses may assist nurses gain more confidence in the area of family counselling.

The finding that satisfaction with family conferences was the lowest scoring item in relation to family member satisfaction with care and also that it is perceived to be the activity least undertaken suggests that there is an expressed need in this area. Nurses on initial assessment or during ongoing contact with the family need to identify whether the patient and family have previously attended a family conference and if there still remains an expressed need by the family to do so.

The trend that as length of time with HCS increased, family members' perceptions of care decreased, may be a result of the interplay of factors such as length



of time in the caring role and increasing burden of care as requirements for care increase in the terminal phase of the illness. Regular nursing assessment and provision for meeting caregivers needs including respite may improve family members' perceptions of care in situations where the care giver role extends for family members over a long period of time.

### Recommendations for Research

Several recommendations for future research based on the findings of this study are suggested. The findings of this study have limited generalisability, therefore further research is strongly recommended. A replication study utilising participants from other palliative care settings should be undertaken to further test Discrepancy theory. The sample should be larger and include a greater cross-section of the palliative care population to enhance generalisability of study findings. A longitudinal design to test expectations of care in particular at the first contact with the care agency needs to be undertaken to elucidate whether there is an increase in the variability of the scores.

Further research focusing on the family members less satisfied is indicated by these findings. Focus studies as a research method, although in their infancy may prove to be useful in identifying unmet needs and expectations in this small but significant group of recipients of palliative care in the home hospice setting.

Identifying factors which negatively influence perceptions of care and satisfaction with care is important. This study's findings that decreased level of family functioning and the trend that length of time with home hospice negatively influence perceptions of care need further testing. Establishing which factors contribute toward negative perceptions can lead to the implementation of actions that improve family members' care perceptions.

### Conclusions

The conclusions that have emerged from this study have a number of implications for health professionals and the recipients of care in the home hospice setting. The finding that the discrepancy between family care expectations and family care perceptions has a negative effect on family satisfaction with palliative care in the home hospice setting provides useful information for health professionals. Minimising this discrepancy by the early identification of expectations of care would prove helpful to nurses and families alike.

Age had a small but significant effect on family member satisfaction with care. This study showed the relationship indicated that as the age of the family members increased the family members' care satisfaction increased which supported previous findings of other studies. Nurses need to be aware that younger recipients of hospice care therefore are more likely to be dissatisfied and that they may have special needs.

Family functioning as measured by the FAD: General Functioning Subscale had a small negative but significant effect on family member care perceptions and family member satisfaction with care. Family members' perceptions of care and family members' satisfaction with care decreased as family functioning became increasingly dysfunctional. Nurses need to actively promote sources of help in this area. Seeking and receiving assistance from trained counsellors may improve dysfunctional aspects of the family and therefore increase perceptions of care and satisfaction with care levels.

Family member care perceptions was a better predictor of family member care satisfaction with palliative care than Discrepancy theory and therefore, the family member's awareness of the details or results of care provided were the best indicators of their satisfaction. Perceptions of care seems to be the major contributing factor in explaining variance in family member satisfaction with care. However, it is clear that

there is more to satisfaction with care than just the perception of care as almost half of the variance in family member satisfaction with care is not explained by this variable. The importance of providing information to the family about the details of the care and the results or effectiveness of actions taken by health professionals is emphasised by the finding that the family members' perceptions of care were the best predictors of satisfaction with care.

This study contributed to the theoretical understanding of satisfaction with palliative care in the home hospice setting by the further testing of Discrepancy theory. The testing of the instruments F-Care Expectations Scale, F-Care Perceptions Scale and the FAMCARE Scale was undertaken in an Australian setting for the first time. Issues for practice and recommendations for further research were suggested.

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## Appendix A

Letter of Introduction

3 September 1996

SILVER CHAIN  
NURSING  
ASSOCIATION

██████████  
██████████████████  
██████████

Dear Carer

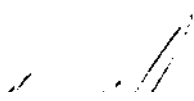
This letter introduces to you Kristina Medigovich, Registered Nurse, who is undertaking research to complete an Honours Degree in Nursing at Edith Cowan University. Kristina is studying how families of patients view the care received by their relative/loved one. She is also interested in learning about the expectations that family members have of health professionals. The information provided by family members will be helpful to doctors and nurses caring for patients with cancer and their families because it will provide information about how they can improve the care they give. Kristina is also interested in looking at family members satisfaction with care.

This research has been approved by the Silver Chain Nursing Association and Edith Cowan University.

Silver Chain needs permission from you to release your name and phone number to Kristina Medigovich as a possible participant. Attached is a release form which you will need to sign and post back in the envelope provided if you are interested in participating in the study. Kristina will then contact you by phone to explain her study and answer any questions you may have. A suitable time for interview can be arranged at this time.

Should you choose to participate, any information you give about yourself or your family will be confidential. Your decision to participate or not participate will in no way affect the care you and your relative/loved one receive.

Thank you kindly for considering this request. Kristina has asked me to inform you that she understands that this may be a particularly stressful time for you and appreciates the time you might be able to offer.

Yours sincerely 

Dr Michael Smith  
Director of Clinical Services  
HOSPICE CARE SERVICE

MS:MB [G4.42]

encs

HOSPICE CARE SERVICE

6 Sundercombe Street Osborne Park Western Australia 6017  
Telephone (09) 242 0289 Facsimile (09) 444 7904

Appendix B

**HOME HOSPICE CANCER CARE: FAMILY MEMBERS' EXPECTATIONS,  
PERCEPTIONS AND SATISFACTION WITH CARE**

**PERMISSION TO RELEASE NAME AND PHONE NUMBER:**

[Name].....

[Phone Number].....

I give my consent for Silver Chain Nursing Association to pass on my name and phone number to Kristina Medigovich.

**Signature:**.....

**Date:**.....

**PLEASE RETURN BY [DATE ONE WEEK] IN THE ENVELOPE PROVIDED**

Thank You

## Appendix C

### The Study Home Hospice

The HCS is the major home hospice in WA and serves the Perth metropolitan area and some country regions in the state. The HCS in the metropolitan area is divided into eight areas and provides its services from these bases during the day. The after hours service operates from a central base.

The HCS is available to anyone requiring help, support, or symptom control who has a terminal illness, and includes the family as the unit of care. An interdisciplinary team of nurses, doctors, chaplains, counsellors, care aides and volunteers is provided to its clients in their own homes. Access is through referral by the client's general practitioner (GP) or medical specialist. The HCS works closely with GPs and hospital specialists.

Nurses are rostered on duty 24 hours a day. Patients are visited in their homes regularly by nurses according to the care plan that has been developed in conjunction with the patient and family. After hours services are also available for routine care and for urgent matters. Phone calls are answered by registered nurses (24 hours a day) who assess the situation and direct nursing staff to assist as necessary.

Medical care is provided in a number of ways to the patients. The GP can maintain 24 hour responsibility for the medical care by being accessible to the patient, family and visiting home hospice nurses. Alternatively, the GP can work together with the Home Hospice Doctor (HHD), ensuring 24 hour medical cover. Alternately, the 24 hour care of the patient may be the responsibility of the HHD either at the request of the GP or because the GP is the HHD.

Volunteer relief carers are available during the day or overnight to the family member caring for the patient on a needs basis. Care aides are available to patients

during the day and in the evenings to meet personal needs such as bathing, dressing, grooming, toileting, returning to bed and repositioning. Spiritual support is provided by the interdenominational chaplaincy service. Counselling personnel and bereavement support is also available. Equipment and medical supplies are provided to current patients following assessment by the home hospice nurse during a home nursing visit.

The HCS is funded through the Home and Community Care (HACC) Program (Silver Chain Nursing Association, undated), a federally funded program to provide assistance to the frail aged and young disabled to enable them to remain in their homes instead of being cared for in an institution. Public donations and bequests supplement this. The fees of HHDs are covered by Medicare benefits. The HCS does not meet patient costs associated with medications or GP services. These remain the responsibility of the family.



Appendix D

**FAMCARE Scale**

**Instructions:** Think about the care that your family member has received. Please answer the following questions below 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 below that best match your experience.

**HOW SATISFIED ARE YOU WITH:**

1. the patient's pain relief	VS	S	U	D	VD
2. information provided about the patient's prognosis	VS	S	U	D	VD
3. answers from health professionals	VS	S	U	D	VD
4. information given about side effects	VS	S	U	D	VD
5. referrals to specialists	VS	S	U	D	VD
6. availability of a hospital bed	VS	S	U	D	VD
7. family conferences held to discuss the patient's illness	VS	S	U	D	VD
8. speed with which symptoms are treated	VS	S	U	D	VD
9. doctor's attention to patient's description of symptoms	VS	S	U	D	VD
10. the way tests and treatments are performed	VS	S	U	D	VD
11. availability of doctors to the family	VS	S	U	D	VD
12. availability of nurses to the family	VS	S	U	D	VD
13. coordination of care	VS	S	U	D	VD
14. time required to make a diagnosis	VS	S	U	D	VD
15. the way the family is included in treatment and care decisions	VS	S	U	D	VD

**FAMCARE Scale (cont'd)**

**HOW SATISFIED ARE YOU WITH:**

16. information given about how to manage the patient's pain	VS	S	U	D	VD
17. information given about the patient's tests	VS	S	U	D	VD
18. how thoroughly the doctor assesses the patient's symptoms	VS	S	U	D	VD
19. the way tests and treatments are followed up by the doctor	VS	S	U	D	VD
20. availability of the doctor to the patient	VS	S	U	D	VD

c Kristjanson, 1989

Appendix E

**F-CARE PERCEPTIONS SCALE**

**Instructions:** Think about the care that your family member has been receiving through the palliative care program. Please read each statement below and think about whether these things have occurred during the care of your family. **Circle** whether you: **STRONGLY AGREE (SA)**, **AGREE (A)**, are **UNCERTAIN (U)**, **DISAGREE (D)**, or **STRONGLY DISAGREE (SD)** with the statements below.

	<b>Strongly Agree</b>	<b>Agree</b>	<b>Uncertain</b>	<b>Disagree</b>	<b>Strongly Disagree</b>
1. The patient’s pain is relieved quickly.	SA	A	U	D	SD
2. Health professionals are straight forward when answering the family’s questions.	SA	A	U	D	SD
3. Information is withheld about patient’s prognosis.	SA	A	U	D	SD
4. The patient lacks trust and confidence in the doctor.	SA	A	U	D	SD
5. Information about side effects of the treatments and drugs is withheld.	SA	A	U	D	SD
6. The doctor refers the patient to a specialist promptly.	SA	A	U	D	SD
7. A hospital bed is available to the patient when necessary.	SA	A	U	D	SD

**F-CARE PERCEPTIONS SCALE (cont'd)**

	<b>Strongly Agree</b>	<b>Agree</b>	<b>Uncertain</b>	<b>Disagree</b>	<b>Strongly Disagree</b>
8. The doctor has arranged a family conference to discuss the patient's illness.	SA	A	U	D	SD
9. The patient's symptoms are treated quickly.	SA	A	U	D	SD
10. Doctor pays little attention to the patient's description of symptoms.	SA	A	U	D	SD
11. Tests and procedures are performed competently.	SA	A	U	D	SD
12. Doctors are available to the family.	SA	A	U	D	SD
13. Nurses are available to the family.	SA	A	U	D	SD
14. One doctor is responsible for the patient's care.	SA	A	U	D	SD
15. There was a delay in making the diagnosis.	SA	A	U	D	SD
16. Family is excluded from treatment and care decisions.	SA	A	U	D	SD
17. Family is given information about how to manage the patient's pain.	SA	A	U	D	SD

**F-CARE PERCEPTIONS SCALE (cont'd)**

	<b>Strongly Agree</b>	<b>Agree</b>	<b>Uncertain</b>	<b>Disagree</b>	<b>Strongly Disagree</b>
18. Information is provided about patient's tests.	SA	A	U	D	SD
19. Doctor assesses patient's symptoms thoroughly.	SA	A	U	D	SD
20. Doctor is available to the patient.	SA	A	U	D	SD
21. Tests and treatments are followed up by the doctor.	SA	A	U	D	SD

c Kristjanson, 1989

Appendix F

**FAMILY EXPECTATIONS SCALE**

**Instructions:** This section of the questionnaire is a list of expectations that family members may have of health professionals. Expectations are the things done by health professionals that you think are usual or reasonable. Please show how important these expectations are to you by providing a number from 1 -5 in the column beside each item: **Not Important (1), Somewhat Important (2), Average Importance (3), Very Important (4), and Extremely Important (5).**

<b><u>I EXPECT THAT:</u></b>	<b><u>RATINGS FROM</u></b> <b><u>1 - 5</u></b>
1. the doctor will spend enough time with the patient	_____
2. nurses will spend enough time with the patient	_____
3. the doctor will be as thorough as he/she should be	_____
4. the doctor will explain the patient's condition	_____
5. the doctor will listen to what the patient thinks is important	_____
6. the doctor will listen to what the family thinks is important	_____
7. physical care will be safe and competent	_____
8. the doctor will tell why he/she ordered tests and x-rays	_____
9. the patient's pain will be controlled	_____
10. family will be informed about the patient's condition	_____
11. the doctor will treat the patient's symptoms quickly	_____
12. nurses will respond to the patient's needs quickly	_____
13. family will be included in treatment and care decisions	_____
14. nurses will give the family information about how to help the patient at home.	_____
15. I will receive honest answers to my questions	_____
16. health professionals will offer support to help me cope with the patient's illness	_____

# Appendix G

## **FAMILY ASSESSMENT DEVICE:**

### **General Functioning**

This questionnaire contains a number of statements about families. Please read each statement carefully, and decide how well it describes your own family. You should answer according to how you see your family. For each statement, there are four (4) possible responses: Strongly Agree, Agree, Disagree or Strongly Disagree. Try not to spend too much time thinking about each statement, but respond as quickly and as honestly as you can. If you have trouble with one, answer with your first reaction. Please be sure to answer every statement and mark all your answers in the space provided next to each statement.

---

1. In times of crisis we can turn to each other for support.

☐ Strongly Agree    ☐ Agree    ☐ Disagree    ☐ Strongly Disagree

2. Individuals are accepted for what they are.

☐ Strongly Agree    ☐ Agree    ☐ Disagree    ☐ Strongly Disagree

3. We can express feelings to each other.

☐ Strongly Agree    ☐ Agree    ☐ Disagree    ☐ Strongly Disagree

4. We feel accepted for what we are.

☐ Strongly Agree    ☐ Agree    ☐ Disagree    ☐ Strongly Disagree

5. We are able to make decisions about how to solve problems

☐ Strongly Agree    ☐ Agree    ☐ Disagree    ☐ Strongly Disagree

6. We confide in each other.

☐ Strongly Agree    ☐ Agree    ☐ Disagree    ☐ Strongly Disagree

7. Planning family activities is difficult because we misunderstand each other.

☐ Strongly Agree    ☐ Agree    ☐ Disagree    ☐ Strongly Disagree

8. We cannot talk to each other about the sadness we feel.

☐ Strongly Agree    ☐ Agree    ☐ Disagree    ☐ Strongly Disagree

**FAMILY ASSESSMENT DEVICE(cont'd):**

**General Functioning**

---

9. We avoid discussing our fears and concerns.

\_\_\_Strongly Agree    \_\_\_Agree    \_\_\_Disagree    \_\_\_Strongly Disagree

10. There are lots of bad feelings in the family.

\_\_\_Strongly Agree    \_\_\_Agree    \_\_\_Disagree    \_\_\_Strongly Disagree

11. Making decisions is a problem for our family.

\_\_\_Strongly Agree    \_\_\_Agree    \_\_\_Disagree    \_\_\_Strongly Disagree

12. We don't get along well together.

\_\_\_Strongly Agree    \_\_\_Agree    \_\_\_Disagree    \_\_\_Strongly Disagree



**Appendix H**  
**FAMILY INFORMATION**

- 1. Marital Status:** Married \_\_\_\_\_  
 Divorced \_\_\_\_\_  
 Never Married \_\_\_\_\_  
 Widowed \_\_\_\_\_  
 Defacto \_\_\_\_\_
- 2. Relationship to Patient:** Spouse \_\_\_\_\_ Son \_\_\_\_\_ Daughter \_\_\_\_\_  
 Other \_\_\_\_\_
- 3. Age:** \_\_\_\_\_ years
- 4. Sex:** Male \_\_\_\_\_ Female \_\_\_\_\_
- 5. Education Completed:** Primary School \_\_\_\_\_ TAFE/Trade  
 Qualification/  
 Some or Junior \_\_\_\_\_ Diploma \_\_\_\_\_  
 High School \_\_\_\_\_ College of Advanced  
 Senior High School \_\_\_\_\_ Education \_\_\_\_\_  
 or Tertiary Entrance \_\_\_\_\_ University Degree \_\_\_\_\_  
 Exam (TEE) \_\_\_\_\_ Post Graduate Studies \_\_\_\_\_
- 6. Work and/or Other Commitments:** F/T Work \_\_\_\_\_ P/T  
 Work(Hrs) \_\_\_\_\_  
 Clerical \_\_\_\_\_ Skilled Trade \_\_\_\_\_ Retired \_\_\_\_\_ Homeduties \_\_\_\_\_  
 Management \_\_\_\_\_ Professional \_\_\_\_\_ Labourer/Unskilled \_\_\_\_\_ Pre/S  
 Children (No.) \_\_\_\_\_ S/Age Children (No.) \_\_\_\_\_ Elderly/Disabled Adults  
 (No.) \_\_\_\_\_ Other \_\_\_\_\_
- 7. Income:** below \$10,000/year \_\_\_\_\_  
 \$10,000 - \$20,000/year \_\_\_\_\_  
 \$20,001 - \$30,000/year \_\_\_\_\_  
 \$30,001 - \$40,000/year \_\_\_\_\_  
 \$40,001 - \$50,000/year \_\_\_\_\_  
 \$50,001 - \$60,000/year \_\_\_\_\_  
 over \$60,000/year \_\_\_\_\_
- 8. Ancestry:** \_\_\_\_\_
- 9. Religion:** Catholic \_\_\_\_\_ Anglican \_\_\_\_\_ Uniting Church \_\_\_\_\_ Islam \_\_\_\_\_  
 Presbyterian \_\_\_\_\_ Judaism \_\_\_\_\_ Buddhism \_\_\_\_\_ Other \_\_\_\_\_  
 None \_\_\_\_\_

(cont'd)

**10. Number of months since patient's cancer diagnosis:** \_\_\_\_\_

**11. Length of time with Home Hospice Care:** \_\_\_\_\_

**12. Frequency of a team member visit each month:** \_\_\_\_\_

**13. Other sources of support:** Friends \_\_\_\_\_ Family \_\_\_\_\_  
Cancer Support Service \_\_\_\_\_ Cancer Foundation \_\_\_\_\_  
Social Worker of Hospital \_\_\_\_\_ Other \_\_\_\_\_

c Kristjanson, 1992

## Appendix I


Authors' Permission for the Use of Instruments Not in the Public Domain

Enclosed please find the FAD packet that you ordered. You have permission to duplicate the copyrighted Family Assessment Device, the manual scoring sheet and instructions, and the Family Information Form. We may contact you in the future to receive your feedback on the instrument.

Thank you for your interest and good luck in your future project.

Sincerely,



  
Ivan W. Miller, Ph.D.  
Director, Brown University  
Family Research Program  
Rhode Island Hospital  
593 Eddy Street  
Providence, Rhode Island 02903



St. Boniface General Hospital Research Centre  
Hôpital General St. Boniface Centre de Recherche

6 February 1997

Kristina Medigovich  
School of Nursing  
Edith Cowan University  
Churchlands Campus  
Pearson Street, Churchlands  
Western Australia 6018

Dear Ms. Medigovich:

Thank you for your interest in testing the instruments: F-Care Expectations Scale and F-Care Perceptions Scale in a Western Australian sample of family members of advanced cancer patients.

I am pleased to grant permission for you to use these unpublished instruments.

I wish you success with your research.

Yours sincerely,

Linda J. Kristjanson, RN, PhD

## Appendix J

INFORMATION SHEETHOME HOSPICE CARE: FAMILY MEMBERS' EXPECTATIONS,  
PERCEPTIONS AND SATISFACTION WITH CARE

This research is conducted by Kristina Medigovich, Registered Nurse, as part of the course requirements for the Bachelor of Nursing, Honours Program at Edith Cowan University.

The purpose of this study is to gain knowledge and an understanding of factors that contribute to satisfaction with cancer care from a family member's viewpoint. This research is studying family satisfaction as it is important to the health and well-being of family members. The results of the study will be helpful to health professionals caring for cancer patients and their families, because it will provide information about how they can improve the care they give.

This project has been approved by the Edith Cowan University and the Silver Chain Nursing Association and you are invited to take part.

Your responses will be **confidential** and no identifying information will be released to the home hospice service. The information you supply will be analyzed together with the information from all the other participants and the results will be reported as a whole. You will not be identifiable and your name will not be used in any report or publication from this research.

***If I consent to participate, what will I have to do?***

You will be required to answer questionnaires. These questionnaires ask a series of questions related to yourself eg age, gender, nationality, your expectations of care, your perceptions of the care received from health professionals, and satisfaction with the care received. A further short questionnaire contains statements about families and asks how well do these statements describe your family. None of the questionnaires require lengthy answers. *Participation in this study will take approximately 30-45 minutes of your time.*

You are free to choose whether you take part in this research and to withdraw should you so wish. **Your decision to participate or not participate in this research will in no way affect care provided to you or your relative.** You may contact me, Kristina Medigovich, by phone on 398 8672 or my academic advisor Davina Poroeh at Edith Cowan University (in the Nursing Department) on 273 8623 if you have any further questions about the research.

Answering some questions may arouse sad feelings about the illness. You may contact your Silver Chain Hospice nurse to talk about these feelings if you so wish.

Appendix K  
**CONSENT TO ACT AS A SUBJECT IN A RESEARCH PROJECT**

**Home Hospice Cancer Care: Family Members’ Expectations, Perceptions  
and Satisfaction with Care**

I \_\_\_\_\_ agree to participate in the  
above titled study.

The purpose of this study is to gain knowledge and an understanding of factors that contribute to satisfaction with cancer care from a family member’s viewpoint. The results of the study will be helpful to health professionals caring for cancer patients and their families because it will provide information about how they can improve the care they give.

The study is conducted by Kristina Medigovich, Registered Nurse, as part of the course requirements for the Bachelor of Nursing (Honours) program at Edith Cowan University.

My participation involves answering questionnaires and will take approximately 30-45 minutes.

I have read the information sheet provided and any questions I have asked have been answered to my satisfaction. I understand that my participation is voluntary and that I may withdraw this consent at any time by simply telling the researcher. I understand that **my decision to participate or not participate in the study will in no way affect care provided to me or my relative.**

I understand that my responses will be **confidential**, my name will not be on the questionnaires and no identifying information will be released. The information will be analyzed together with the information from all the other participants and the results will be reported as a whole to the home hospice service. Findings from the research may be published.

Answering some questions may arouse sad feelings about the illness and I know that I may contact my Silver Chain Hospice nurse to talk to someone about these feelings. Otherwise, there are no known risks involved with participating in this study. The study offers no immediate or direct benefits to me. I understand that I will receive answers to any questions about the study at any time.

I may contact Kristina Medigovich, should I wish to, by phone on 398 8672 or her academic advisor Davina Poroch on 273 8623 if I have any further questions about the study.

**Signature..... date.....**

**Witness..... date.....**

## Appendix L

### Order of Questionnaire Presentation

The questionnaires were stapled together into a booklet in the following order:

1. F - Care Expectations Scale
2. F - Care Perceptions Scale
3. FAMCARE Scale
4. Family Assessment Device: General Functioning
5. Family Information

## Appendix M

Pearson's Product-Moment Correlation Coefficients

	FAMCARE	FEXP	FPERC	PDIFF
FAMCARE	1.0000 ( 55) P= .	.1105 ( 55) P= .422	.7396 ( 55) P= .000	-.5509 ( 55) P= .000
FEXP	.1105 ( 55) P= .422	1.0000 ( 55) P= .	.1404 ( 55) P= .307	.5484 ( 55) P= .000
FPERC	.7396 ( 55) P= .000	.1404 ( 55) P= .307	1.0000 ( 55) P= .	-.7509 ( 55) P= .000
PDIFF	-.5509 ( 55) P= .000	.5484 ( 55) P= .000	-.7509 ( 55) P= .000	1.0000 ( 55) P= .
AGE	.2959 ( 55) P= .028	.1869 ( 55) P= .172	.1110 ( 55) P= .420	.0309 ( 55) P= .823
EDUCAT	-.0551 ( 55) P= .689	-.0376 ( 55) P= .785	-.0615 ( 55) P= .656	.0269 ( 55) P= .846
TOTCOMIT	-.3864 ( 55) P= .004	-.1487 ( 55) P= .278	-.2527 ( 55) P= .063	.1143 ( 55) P= .406

Continued/



.../Continued

Pearson's Product-Moment Correlation Coefficients

	FAMCARE	FEXP	FPERC	PDIFF
INCOME	.0254 ( 53) P= .856	-.1985 ( 53) P= .154	.0057 ( 53) P= .967	-.1417 ( 53) P= .312
MTHSDX	.1968 ( 55) P= .150	.0526 ( 55) P= .703	.0350 ( 55) P= .800	.0055 ( 55) P= .968
TIMEHHC	-.1246 ( 55) P= .365	.1002 ( 55) P= .467	-.2647 ( 55) P= .051	.2903 ( 55) P= .032
FREQV	.0431 ( 55) P= .755	.1044 ( 55) P= .448	.0718 ( 55) P= .602	.0089 ( 55) P= .948
TOTOSS	.0631 ( 55) P= .647	.1816 ( 55) P= .185	.0354 ( 55) P= .797	.0912 ( 55) P= .508
FAMF	-.3429 ( 55) P= .010	-.2074 ( 55) P= .129	-.3272 ( 55) P= .015	.1380 ( 55) P= .315

(Coefficient / (Cases) / 2-tailed Significance)

". " is printed if a coefficient cannot be computed

Continued/...

.../Continued

Pearson's Product-Moment Correlation Coefficients

	AGE	EDUCAT	TOTCOMIT	INCOME	MTHSDX
FAMCARE	.2959 ( .55) P= .028	-.0551 ( .55) P= .689	-.3864 ( .55) P= .004	.0254 ( .53) P= .856	.1968 ( .55) P= .150
FEXP	.1869 ( .55) P= .172	-.0376 ( .55) P= .785	-.1487 ( .55) P= .278	-.1985 ( .53) P= .154	.0526 ( .55) P= .703
FPERC	.1110 ( .55) P= .420	-.0615 ( .55) P= .656	-.2527 ( .55) P= .063	.0057 ( .53) P= .967	.0350 ( .55) P= .800
PDIFF	.0309 ( .55) P= .823	.0269 ( .55) P= .846	.1143 ( .55) P= .406	.1417 ( .53) P= .312	.0055 ( .55) P= .968
AGE	1.0000 ( .55) P= .	-.2124 ( .55) P= .120	-.7064 ( .55) P= .000	-.2172 ( .53) P= .118	.0494 ( .55) P= .720
EDUCAT	-.2124 ( .55) P= .120	1.0000 ( .55) P= .	.2567 ( .55) P= .059	.5113 ( .53) P= .000	-.0180 ( .55) P= .896
TOTCOMIT-	.7064 ( .55) P= .000	.2567 ( .55) P= .059	1.0000 ( .55) P= .	.2855 ( .53) P= .038	.0794 ( .55) P= .564

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Pearson's Product-Moment Correlation Coefficients

	AGE	EDUCAT	TOTCOMIT	INCOME	MTHSDX
INCOME	-.2172 ( 53) P= .118	.5113 ( 53) P= .000	.2855 ( 53) P= .038	1.0000 ( 53) P= .	.2103 ( 53) P= .131
MTHSDX	.0494 ( 55) P= .720	-.0180 ( 55) P= .896	.0794 ( 55) P= .564	.2103 ( 53) P= .131	1.0000 ( 55) P= .
TIMEHHC	-.1227 ( 55) P= .372	.1459 ( 55) P= .288	.0854 ( 55) P= .535	.2536 ( 53) P= .067	.1999 ( 55) P= .143
FREQV	-.3503 ( 55) P= .009	.2656 ( 55) P= .050	.3544 ( 55) P= .008	.1482 ( 53) P= .290	.0521 ( 55) P= .705
TOTOSS	-.1332 ( 55) P= .332	.0385 ( 55) P= .780	.1825 ( 55) P= .182	.2145 ( 53) P= .123	.1318 ( 55) P= .337
FAMF	-.1039 ( 55) P= .450	-.1353 ( 55) P= .325	.0859 ( 55) P= .533	-.1705 ( 53) P= .222	-.0812 ( 55) P= .556

(Coefficient / (Cases) / 2-tailed Significance)

" . " is printed if a coefficient cannot be computed

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Pearson's Product-Moment Correlation Coefficients

	TIMEHHC	FREQV	TOTOSS	FAMF
FAMCARE	-.1246 ( 55) P= .365	.0431 ( 55) P= .755	.0631 ( 55) P= .647	-.3429 ( 55) P= .010
FEXP	.1002 ( 55) P= .467	.1044 ( 55) P= .448	.1816 ( 55) P= .185	-.2074 ( 55) P= .129
FPERC	-.2647 ( 55) P= .051	.0718 ( 55) P= .602	.0354 ( 55) P= .797	-.3272 ( 55) P= .015
PDIFF	.2903 ( 55) P= .032	.0089 ( 55) P= .948	.0912 ( 55) P= .508	.1380 ( 55) P= .315
TOTCOMIT	.0854 ( 55) P= .535	.3544 ( 55) P= .008	.1825 ( 55) P= .182	.0859 ( 55) P= .533

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Pearson's Product-Moment Correlation Coefficients

	TIMEHHC	FREQV	TOTOSS	FAMF
INCOME	.2536 ( 53) P= .067	.1482 ( 53) P= .290	.2145 ( 53) P= .123	-.1705 ( 53) P= .222
MTHSDX	.1999 ( 55) P= .143	.0521 ( 55) P= .705	.1318 ( 55) P= .337	-.0812 ( 55) P= .556
TIMEHHC	1.0000 ( 55) P= .	.2684 ( 55) P= .048	.2088 ( 55) P= .126	.0148 ( 55) P= .914
FREQV	.2684 ( 55) P= .048	1.0000 ( 55) P= .	.1359 ( 55) P= .322	-.0219 ( 55) P= .874
TOTOSS	.2088 ( 55) P= .126	.1359 ( 55) P= .322	1.0000 ( 55) P= .	.1631 ( 55) P= .234
FAMF	.0148 ( 55) P= .914	-.0219 ( 55) P= .874	.1631 ( 55) P= .234	1.0000 ( 55) P= .

(Coefficient / (Cases) / 2-tailed Significance)

" . " is printed if a coefficient cannot be computed

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Spearman Correlation Coefficient

*RELAT	.5283					
	N( 55)					
	Sig .000					
FEXP	-.1086	-.0844				
	N( 55)	N( 55)				
	Sig .430	Sig .540				
FPERC	.1015	.0171				
	N( 55)	N( 55)				
	Sig .461	Sig .901				
FAMCARE	.2479	.1198				
	N( 55)	N( 55)				
	Sig .068	Sig .383				
PDIFF	-.1513	-.0434				
	N( 55)	N( 55)				
	Sig .270	Sig .753				
SEX	-.2260	-.4300	.2166	.0150	-.0382	.1190
	N( 55)	N( 55)	N( 55)	N( 55)	N( 55)	N( 55)
	Sig .097	Sig .001	Sig .112	Sig .913	Sig .782	Sig .387
**MARITAL	*RELAT	FEXP	FPERC	FAMCARE	PDIFF	

(Coefficient / (Cases) / 2-tailed Significance) / " . " is printed if a coefficient cannot be computed

\*RELAT - dummy variable constructed: all spouses = 1, all others = 0.

\*\*MARITAL - dummy variable constructed: all those married =1, all others = 0

Appendix N

Relationship Between Matched Questionnaire Items on the F-Care Perceptions Scale  
and FAMCARE Scale

<b>F - Care Perceptions</b>	<b>FAMCARE Scale</b>	<b>r</b>	<b>p</b>
<b>Scale Item</b>	<b>Item</b>		
P1	S1	.6371	.000
P2	S3	.4682	.000
P3	S2	.3665	.006
P4 no matching item			
P5	S4	.7658	.000
P6	S5	.4068	.002
P7	S6	.6782	.002
P8	S7	.4423	.001
P9	S8	.4093	.002
P10	S9	.2564	.059
P11	S10	.2436	.073
P12	S11	.4760	.000
P13	S12	.3461	.010
P14	S13	.1663	.225
P16	S15	.0743	.590
P17	S16	.4716	.000
P18	S17	.4729	.000
P19	S18	.3274	.015
P20	S20	.5596	.000
P21	S19	.3778	.004

Appendix O

t-Test of Subgroup Less Satisfied vs More Satisfied

Item	t Value	df	p
PDIFF	4.21	23.75	.000
FEXP	-.64	13.23	.535
FPERC	-4.40	53	.000
MTHSDX	-1.47	24.14	.156
TIMEHHC	-.73	19.38	.476
FREQV	.99	26.89	.330
AGE	-2.48	12.06	.029
FAMF	2.02	13.07	.065
TOTOSS	.27	19.08	.788