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Family satisfaction with palliative care: A test of four alternative theories

Kristjanson, Linda Joan, Ph.D.
The University of Arizona, 1991

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FAMILY SATISFACTION WITH PALLIATIVE CARE:  
A TEST OF FOUR ALTERNATIVE THEORIES

by

Linda Joan Kristjanson

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A Dissertation Submitted to the College of  
NURSING  
In Partial Fulfillment of the Requirements  
For the Degree of  
DOCTOR OF PHILOSOPHY  
In the Graduate College  
THE UNIVERSITY OF ARIZONA

1 9 9 1
As members of the Final Examination Committee, we certify that we have read the dissertation prepared by Linda J. Kristjanson entitled Family satisfaction with palliative care: A test of four alternative theories. and recommend that it be accepted as fulfilling the dissertation requirement for the Degree of Doctor of Philosophy.

Final approval and acceptance of this dissertation is contingent upon the candidate's submission of the final copy of the dissertation to the Graduate College.

I hereby certify that I have read this dissertation prepared under my direction and recommend that it be accepted as fulfilling the dissertation requirement.

Dissertation Director
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SIGNED: Linda J. Kretzmer
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ABSTRACT

The experience of dealing with end-stage cancer in a family member has been reported to be stressful. One source of stress experienced by family members may be dissatisfaction with care received by the patient and themselves. For health professionals to provide care that promotes family satisfaction, it is essential to measure this phenomenon and understand the elements that contribute to satisfaction.

An examination of the literature revealed four competing explanatory theories of satisfaction, none of which has solid empirical support. Moreover, these theories had not been tested with families or those experiencing cancer care in particular. Therefore, the aim of this research was to test these alternative theories using theoretical and empirical modeling with the expectation that a useful model would be identified to guide clinical practice of families in terminal care situations. The theories tested 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.

A correlational design with a causal modeling methodology was used. One hundred and nine family members of patients with advanced cancer were obtained from three different palliative care services. Five instruments were used to collect data: (1) FAMCARE Scale, (2) F-Care Needs Scale, (3) F-Care Expectations Scale, (4) F-Care Perceptions Scale, and (5) a short demographic questionnaire. Data analysis
included use of descriptive statistics to summarize the sample in terms of demographic variables, reliability and validity testing of the instruments, and theoretical and empirical model testing using multiple regression techniques and residual analysis.

Of the four theories tested, Discrepancy theory was the most credible, accounting for 68 percent of explained variance in family care satisfaction. Empirical modeling resulted in identification of the Family Care Satisfaction Model, which explained 78 percent of the variance in care satisfaction. Implications for theory construction and clinical practice are presented and recommendations for further research offered.

The family constitutes perhaps the most important social context within which health and illness occur. As more families are required to care for dependent or ill members at home, understanding the needs, expectations, and satisfactions with care experienced by families will become increasingly important.
CHAPTER I
STATEMENT OF THE PROBLEM

Introduction

Care of dying patients and their families has been described as a unique type of care requiring special skills and knowledge of health professionals (Kastenbaum, 1979; Parkes, 1985). Hospice programs have emerged as an alternative type of care for these patients, in part, because of dissatisfaction with traditional care for dying patients and their families (Edwardson, 1985; Paradis, 1984) and in response to the number of patients with end-stage cancer requiring special care during the terminal phase of the illness. Hospice considers the patient/family as the unit of care (Smith, 1984) and hospice professionals are reported as evaluating family members to ensure that their psychosocial needs are met (Hays & Arnold, 1986). As participants, recipients and observers of care, family members also evaluate the care received by the patient and themselves. For health professionals to provide care that promotes family satisfaction with palliative cancer care, it is essential to be able to measure this phenomenon and determine the elements that contribute to satisfaction.

An examination of the theoretical literature related to satisfaction revealed four competing explanatory theories of satisfaction, none of which has solid empirical support. Moreover, these theories have not been tested with families or those
experiencing palliative cancer care in particular. Therefore, the aim of this research was to test these alternative theories using theoretical and empirical modeling with the expectation that a useful model will be identified to guide nursing practice with families in palliative cancer care situations.

The research problem addressed, the purpose of the study, and the significance of the research for nursing and other health professionals interested in understanding family satisfaction with palliative cancer care are outlined in this chapter.

**Research Problem**

An increasing number of authors have called attention to the interdependent nature of the relationship between the family and the health of its members (Gilliss, 1989). According to Griffin (1980), the interdependence of organizational structures and the nature of family functioning mean that no illness can be seen as an isolated event. Families have reported both psychological and physiological health problems in response to the stress of an ill family member (Cassileth et al., 1985; Klein, Dean, & Bogdonoff, 1967; Kristjanson, 1983; McCubbin & Patterson, 1981; Parkes, 1985; Wellisch, Jamison, & Pasnau, 1977). In particular, diseases with protracted illness trajectories place extensive and demanding pressures on families. Every year over 70 percent of deaths in the United States result directly from cancer, heart disease, cerebrovascular disease, or chronic obstructive lung disease (Silverberg, 1985).
In response to increased longevity and the rise in the incidence of chronic and terminal disease, palliative care has emerged as an alternative approach to care. Emphasis in palliative care is on the family as the unit of care, symptom control and expertise in comfort measures, acceptance of the inevitability of the patient's death, and attention to psychosocial needs of patients and families during the end-stage of disease. Although some palliative care programs accept a small number of non-cancer patients, the majority of patients who receive palliative care have end-stage cancer (Gotay, 1985; Hillier, 1985). As Loomis and Williams (1983) pointed out, different chronic illnesses are characterized by varying dying trajectories and care needs. Unique to end-stage cancer care is the delineation of a terminal phase of the illness, identifiable by physicians, patients, families, and evidence from medical records (Gotay, 1985; McCusker, 1984a). It is also predicted that despite improved health education and development in the prevention and treatment of disease, the prospects of a cure for "cancer" by the year 2000 is negligible (Hillier, 1985). It is expected that while some cancers may decline (e.g., stomach, pharynx), others such as lung cancer in women, cancer of the cervix, and testicular cancer are expected to increase in prevalence by the year 2000 (Hillier, 1985). Therefore, cancer patients will continue to be the primary target population for palliative care services in the foreseeable future.

estimates that each year more than 1,040,000 people are diagnosed as having cancer. If one considers that each of these individuals has at least one family member, the number of individuals affected by this disease each year is staggering. The impact of cancer on the family is documented in the forms of role shifts (Tiblier, 1989), physical and mental exhaustion (Rosenbaum & Rosenbaum, 1980), sleep disorders (Kristjanson, 1983; Rose, 1976), depression and anxiety (Tiblier, 1989), and exacerbations of chronic health problems (Dewi-Rees, 1972; Kristjanson, 1983; Parkes, 1985). There is little question that cancer is a prevalent disease which has effects extending far beyond the patient and into the lives of family members who surround the patient.

Trends in health care also point to increased involvement of the family in caring for terminally ill cancer patients. The movement to shorter hospital stays, to treatment of serious illness in ambulatory care settings (chemotherapy), and provision of palliative care in community settings, all indicate a continued and increasing role of family members in palliative cancer care (American Nurses’ Association, 1980). Family members have repeatedly been identified as the primary source of psychosocial support to the cancer patient (Giacquinta, 1977; Northouse, 1981; Stolar, 1982) and as primary providers of physical care in the home (Googe & Varricchio, 1981; Parkes, 1985; Wellisch, Jamison, & Pasnau, 1978; Wright & Dyck, 1984). Family members may also receive care themselves in forms of emotional support, information about the disease, and assistance with physical care. As they participate in this experience, family members evaluate the care received by the patient and themselves. The
experience of dealing with end-stage cancer in a family member has been reported to be stressful (Cassileth & Hamilton, 1979; Kristjanson, 1986; McCubbin & Patterson, 1981; Northouse, 1984; Olsen, 1970). Much of the stress that families experience is beyond the control of health professionals. However, understanding the elements that contribute to satisfaction with care would allow health professionals to better address the needs, expectations and concerns of family members, and decrease the strain associated with negative care evaluations.

Efforts to understand the theoretical structure of satisfaction with health care come primarily from patient satisfaction literature and to some extent, work in the area of consumer satisfaction. The consumer satisfaction writing has contributed some interesting theoretical alternatives but has produced conflicting empirical results. Much of the patient satisfaction research has focused on a search for sociodemographic correlates of satisfaction, rather than developing a solid sociopsychological theory of satisfaction (Locker & Dunt, 1978). However, there are a few studies in the area of patient satisfaction that are based on what Linder-Pelz (1982a) described as social-psychological theories. Social-psychological theories are defined as perceptions, evaluations, and comparisons which antecede the positive or negative evaluations. These theories have not been systematically tested with the phenomenon, family satisfaction with care, and have produced inconsistent empirical findings in the patient satisfaction literature. Definitions are inconsistently and incompletely explicated in some of the research. Alternative theories are proposed as explanations of satisfaction
with care, some of which appear complimentary, while others are conflicting. There is a paucity of research specific to family satisfaction with palliative cancer care. Given the under-developed state of the art in family satisfaction research, testing of alternative theoretical explanations of family satisfaction with this population is timely and relevant.

**Purpose of the Study**

An alternative theory testing approach is one way of efficiently building scientific knowledge, especially in the study of a complex phenomenon (Popper, 1968; Stinchcombe, 1968). Therefore, the aim of this research was to investigate the relative impact of variables common to different social-psychological theories that attempt to explain satisfaction. The purpose of the study was to use theoretical and empirical modeling to identify the model that best explains family satisfaction with palliative care as an outcome of terminal cancer in one member.

**Significance of the Study**

The family constitutes perhaps the most important social context within which health and illness occur. It is consequently the primary unit in health care (Litman, 1974). It has been argued that the vulnerability of the small nuclear family to the stresses imposed by the illness of one of its members is partly responsible for the dramatic extension of hospital facilities (McEwan, 1974).
Evaluations of health care services frequently employ measures of length of stay and recovery rates to assess treatment effectiveness. These measures are obviously not appropriate for programs which provide services for the terminally ill (Wilkinson, 1986). For hospice programs, satisfaction of the patient and the patient’s family is particularly important and an appropriate outcome measure.

Oberst (1984) stated that quality assurance programs rely heavily on standards generated by professionals. This approach yields incomplete knowledge on the functioning of the health care system. She recommended assessment of care that includes the client’s perspective, particularly in the area of cancer care. Stamps and Finkelstein (1981) suggested that a change in the concerns over the last decade has occurred; a decade ago the question was whether or not consumer opinion was of any value at all; now the issue is how much weight to give it, and how to measure it.

As more families are being encouraged to care for dependent or ill members at home as a result of the use of Diagnosis Related Group (DRG) system of reimbursement, the impact of terminal illness on the family will become an issue of increasing magnitude. Understanding needs, expectations, and satisfaction ratings of these families will be critical to decreasing the strain experienced by family members associated with palliative care.

Literature related to health care satisfaction in general (Fox & Storms, 1981; Locker & Dunt, 1978; Pascoe, 1984) and patient and family satisfaction in particular (Hays & Arnold, 1986; LaMonica et al., 1986; McCusker, 1984a; Wilkinson, 1986),
indicate that there are weaknesses in the empirical work because the research has not been based on explicit and clear theoretical formulations of the necessary concepts. Therefore, research that aims to empirically derive a theoretical model of family satisfaction with palliative care will facilitate understanding about this phenomenon. This knowledge would be useful to health professionals interested in improving the quality of care to families experiencing the stress of a terminal illness. Nurses in particular are faced with the challenge of promoting positive outcomes during end-stage palliative cancer care. Nurses plan and directly deliver palliative care in hospices, nursing homes, and patients' homes. They have more consistent, instrumental, and direct contact with patients and families than other caregivers, and their assessments and interventions are an essential component of the care process (Lillard & Marietta, 1989). Although nurses may have experiential knowledge that informs them about how to meet the needs of, and satisfy family members experiencing terminal cancer in a member, more complete and systematically based understanding of how to improve care to these recipients of palliative care is required.

**Summary**

Although there is considerable literature related to consumer satisfaction and patient satisfaction with physician services and health care in general, the area of family satisfaction with care has received little attention. In particular, the area of family satisfaction with palliative care is poorly described and lacks empirical work.
The theoretical work that has been done related to patient satisfaction with care is minimal and has not presented conclusive support for one particular theoretical explanation. As well, the applicability of these findings to family satisfaction with care has not been demonstrated.

Therefore, the relative informative power of alternative theories of satisfaction for understanding this phenomenon was tested in this study. Planned testing also permitted the identification of an empirical model that specified relevant variables and relationships which may be more appropriate to understanding family satisfaction with palliative cancer care.

The impact of terminal cancer on the family is deep and vast. Despite improvements in treatment options, it is estimated that current cancer therapies cure three or four patients out of every 10 (Stjernsward, 1989). Thus, the problem of caring for the majority of incurable cancer patients continues; they number 4.3 million per year. If each patient has only one significant family member the number of individuals affected by the illness is staggering. The literature documents that spouses, children, parents, and extended family members experience both mental and physiological health changes during a terminal illness in the family and in the bereavement period that follows (Cassileth & Hamilton, 1979; Kristjanson, 1983; Parkes, 1985; Wellisch, Jamison, & Pasnau, 1978). Therefore, the magnitude and consequences associated with palliative care for terminal patients and their families underscores the significance of the research.
CHAPTER II
BACKGROUND AND THEORETICAL FRAMEWORK

Introduction

In the first section of this chapter the four alternative competing explanatory theories to be tested are presented. Constructs, concepts, conceptual definitions and relationships among these are discussed. Literature based support is provided from relevant research for concepts and variable linkages in each theory. The last section of this chapter included theoretical and empirical support for inclusion of key demographic variables.

The Four Alternative Theories

According to Popper (1968), although scientific knowledge building occurs through testing hypotheses that are tied to theoretical explanations, it is a more efficient process when the tested hypotheses are representative of alternative theoretical explanations. To do this it is essential to discover a way of linking multiple divergent hypotheses under a theoretical framework in such a way that underlying assumptions of the theories are compatible.

The four alternative theories used to attempt to explain satisfaction with care are:
1) Fulfillment Theory (Morse, 1953; Schaffer, 1953; Vroom, 1964),
2) Discrepancy Theory (Katzell, 1964; Locke, 1969; Porter, 1961),
3) Social Comparison Theory (Festinger, 1942; Lewin et al., 1944; Merton, 1957; Thibaut & Kelley, 1959), and
4) Expectancy-Value Theory (Ajzen-Fishbein, 1980; Linder-Pelz, 1982a, 1982b)

Each of these theories is briefly described to reveal similarities and differences in the conceptualizations and relationships specified. This analysis permits a synthesis of common elements into a theoretical framework that allows testing of the theories. Three assumptions are common to the four theories. These 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. No incompatible assumptions were identified among the four theories. Constructs, concepts, and conceptual definitions to be tested are represented in Table 1. The links among the constructs, concepts, and instruments used to index the concepts are diagrammed in Figure 1.
Table 1 Constructs, Concepts, and Conceptual Definitions

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<th>CONCEPTUAL DEFINITION</th>
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<tr>
<td>NEED FULFILLMENT</td>
<td>Fulfillment of Care Needs</td>
<td>The degree of gratification of perceived requirements from health care providers (Kristjanson, 1989a; Morse, 1983; Schaffer, 1953).</td>
</tr>
<tr>
<td>EXPECTATIONS</td>
<td>Family Care Expectation</td>
<td>The degree to which actions provided by health care providers are believed by family members to be usual (Ajzen &amp; Fishbein, 1980; Kristjanson, 1989a; Porter, 1961).</td>
</tr>
<tr>
<td>VALUING</td>
<td>Importance of Family Care</td>
<td>The degree of value associated with actions provided by health care providers that family members believe to be usual (Kristjanson, 1989a; Thibaut &amp; Kelley, 1959).</td>
</tr>
<tr>
<td></td>
<td>Expectations</td>
<td></td>
</tr>
<tr>
<td>PERCEPTIONS</td>
<td>Family Care Perceptions</td>
<td>Family member’s awareness of actions of health care providers (Ajzen &amp; Fishbein, 1980; Kristjanson, 1989a; Porter, 1961).</td>
</tr>
<tr>
<td>SATISFACTION</td>
<td>Family Care Satisfaction</td>
<td>The degree of valuation of distinct dimensions of actions of health care providers (Ajzen &amp; Fishbein, 1980; Kristjanson, 1989b; Linder-Pelz, 1982a).</td>
</tr>
</tbody>
</table>
Figure 1: Construct, Concept and Instrument Links to be Tested

<table>
<thead>
<tr>
<th>CONSTRUCT:</th>
<th>EXPECTATION</th>
<th>VALUING</th>
<th>PERCEPTION</th>
<th>SATISFACTION</th>
</tr>
</thead>
<tbody>
<tr>
<td>NEED FULFILLMENT</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Concept:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Fulfillment of Family Care Needs</td>
<td>Family Care Expectations</td>
<td>Importance of Family Care Expectations</td>
<td>Family Care Perceptions</td>
<td>Family Satisfaction with Palliative Care</td>
</tr>
<tr>
<td>Instrument:</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>F-Care Needs Scale</td>
<td>F-Care Expectations Scale</td>
<td>F-Care Expectations Scale</td>
<td>F-Care Perceptions Scale</td>
<td>FAMCARE Scale</td>
</tr>
<tr>
<td>(Needs Met Subscale)</td>
<td>(Expectations Subscale)</td>
<td>(Importance Subscale)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

FULFILLMENT THEORY: tests relationships between Fulfillment of Family Care Needs & Family Satisfaction with Palliative Care

DISCREPANCY THEORY: tests relationships between Family Care Perceptions, Family Care Expectations & Family Satisfaction with Palliative Care

SOCIAL COMPARISON THEORY: tests relationships between Importance of Family Care Expectations (Stage I), Family Care Expectations, Family Care Perceptions (Stage II), & Family Satisfaction with Palliative Care (Stage III)

EXPECTANCY-VALUE THEORY: tests relationships between Family Care Expectations, Importance of Family Care Expectations, & Family Satisfaction with Palliative Care
The four alternative explanatory theories are represented in Figure 2 in order of increasing complexity. Arrows represent hypothesized causal relationships and signs indicate whether a relationship is positive or negative (Asher, 1983). The time sequence of variable effect is hypothesized to occur from left to right in the equations.

**Figure 2: Diagrammatic Representation of Four Competing Theories of Satisfaction**

**Fulfillment Theory**

\[ fx \left( \frac{\text{Fulfillment of Care Needs}}{} \right) = \text{Family Care Satisfaction} \]

**Discrepancy Theory** (Porter, 1961)

\[ fx \left( \frac{\text{Family Care Expectations}}{- \text{Family Care Perceptions}} \right) = \text{Family Care Satisfaction} \]

**Social Comparison Theory**

\[ fx \left( \frac{\text{Importance of Family Care Expectations}}{\rightarrow} \right) \rightarrow \left( \frac{\text{Family Care Expectations}}{- \text{Family Care Perceptions}} \right) \rightarrow \text{Family Care Satisfaction} \]

**Expectancy-Value Theory**

\[ \sum \left( \frac{\text{Family Care Expectations} \times \text{Importance Family of Care Expectations}}{\text{Family Care Satisfaction}} \right) \]

The organization of variables into a testable framework is diagrammed in Figure 3. Each theory is identified and separated as noted by the dotted lines. Social Comparison theory includes the Discrepancy model and is therefore shown in the same
linear path. Variables are staged according to the time sequence that is hypothesized to occur in relation to this causal format. Concepts that are located in the same stage are hypothesized to occur at approximately the same time.

Figure 3: Testing Framework for Theoretical Models

A - Fulfillment Theory
B - Discrepancy Theory
C - Social-Comparison Theory
D - Expectancy-Value Theory

1. Fulfillment Theory

This theory was originally developed in the area of job satisfaction research (Morse, 1953; Schaffer, 1953; Vroom, 1964). According to fulfillment theory,
satisfaction is a function of the amount of fulfilment received from a situation regardless of how much one feels he/she should and/or wants to receive. The construct unique to this theory of satisfaction is need or need fulfillment. Schaffer (1953) has argued that satisfaction will vary directly with the extent to which those needs of an individual which can be satisfied, are actually satisfied. Morse (1953) also viewed satisfaction in terms of perceived need fulfillment. The existence and perception of needs and need fulfillment is hypothesized to be an antecedent to the judgment regarding satisfaction made about care.

As shown in Figure 1, Fulfillment of Family Care Needs is conceptualized to be a type of Need Fulfillment. The awareness of Family Care Needs, Importance of Family Care Needs, and Fulfillment of Family Care Needs is indexed by the F-Care Needs Scale.

As shown in Figure 2, Family Care Satisfaction is hypothesized to be some function of Fulfillment of Family Care Needs. The latter concept is defined as the family member's perception of gratification of requirements from health care providers for themselves and the patient (Kristjanson, 1989a; Morse, 1953; Schaffer, 1953).

Examination of empirical work related to need fulfillment in terminal illness revealed an increasing body of research related to family needs (Freihofer & Felton, 1976; Hampe, 1975; Skorupka & Bohnet, 1982; Wright & Dyck, 1984). A summary of this literature is presented in Table 2. Hampe (1975) interviewed 27 spouses of terminally ill patients to determine their perceptions of their own needs and whether
they had been helped in these areas by nurses. Less than half of the needs of grieving spouses were reportedly met for at least half of the subjects: the needs to be with (63%) and helpful to the dying person (74%), and to be informed of impending death (74%). Although the sample for this study was small, the study significance included 1) clear articulation of needs by the bereaved, 2) relative pre- and post-mortem constancy of the needs, and 3) the magnitude of the unmet needs.

The relative importance of needs according to family members has also been studied with the belief that understanding needs will contribute to improved care for these individuals. Skorupka and Bohnet’s (1982) exploratory study featured a Q-sort methodology to determine which nursing behaviors were perceived to be helpful in meeting the needs of primary caregivers in a home care hospice setting. Most helpful behaviors referred to the needs of the patients and included items relating to assurance that nursing services would be available and, if needed, emergency care. Of lesser importance were health care behaviors directed toward the primary caregivers. In particular, the least helpful behaviors applied almost exclusively to the psychosocial needs of the primary caregiver. These findings were useful in identifying nursing behaviors of relative importance to families. The results are limited, however, by the small sample size and the fact that the list of behaviors was derived by nurse experts and does not necessarily reflect behaviors that families would identify. Also, only nursing (not palliative care team) behaviors were included.
<table>
<thead>
<tr>
<th>AUTHORS, YEAR</th>
<th>TITLE</th>
<th>DESIGN, N</th>
<th>FINDINGS</th>
<th>LIMITATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hampe, 1985</td>
<td>Needs of the grieving spouse in a hospital setting.</td>
<td>qualitative, descriptive</td>
<td>-&lt;50% needs met&lt;br&gt;- articulate needs&lt;br&gt;- pre &amp; post mortem constancy of needs</td>
<td>- sample size&lt;br&gt;- non-probability sample</td>
</tr>
<tr>
<td>Skorupka &amp; Bohnet, 1982</td>
<td>Primary caregivers’ perceptions of nursing behaviors that best meet their needs in a home care hospice setting.</td>
<td>Q sort</td>
<td>- 4 of 5 most important needs relate to patient&lt;br&gt;- availability of nursing care &amp; emergency services most important</td>
<td>- sample size&lt;br&gt;- nurse generated (possible items validity problem)</td>
</tr>
<tr>
<td>Grobe, Ilstrup, &amp; Ahmann, 1981</td>
<td>Skills needed by family members to maintain the care of an advanced cancer patient.</td>
<td>Descriptive. 28 family caregivers 24 bereaved patients (random)</td>
<td>- family caregivers learn patient care by trial &amp; error</td>
<td>- sample size</td>
</tr>
<tr>
<td>AUTHORS, YEAR</td>
<td>TITLE</td>
<td>DESIGN, N</td>
<td>FINDINGS</td>
<td>LIMITATION</td>
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</tr>
<tr>
<td>Grobe, Ahmann, &amp; Ilstrup, 1982</td>
<td>Needs assessment for advanced cancer patients and their families.</td>
<td>Descriptive. 30 patients 28 family members 24 bereaved (random)</td>
<td>- two groups of family members had different needs - disparity between views of patient &amp; family member dyads - family members had more needs for services than patients - family members were unaware of resources available</td>
<td>- no validity &amp; reliability reported - only one family member interviewed</td>
</tr>
<tr>
<td>Linder-Pelz, 1982b</td>
<td>Social psychological determinants of patient satisfaction: A test of five hypotheses.</td>
<td>Prospective 125 (convenience)</td>
<td>- did not support fulfilment theory</td>
<td>- non-probability sample - problem operationalizing variables</td>
</tr>
<tr>
<td>AUTHORS, YEAR</td>
<td>TITLE</td>
<td>DESIGN, N</td>
<td>FINDINGS</td>
<td>LIMITATION</td>
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</table>
| Welch, 1985  | Planning nursing interventions for family members of adult cancer patients. | Exploratory, 25 (convenience) | - identified nursing & physician behavior helpful in coping  
- emphasis on meeting patient's need for comfort  
- patient's need for comfort of care most critical | - psychometric properties of needs scale not reported  
- theoretical basis of research not explicit, untested rationale for study  
- retrospective study |
| Hinds, 1985  | The needs of families who care for patients with cancer at home: Are we meeting them? | Descriptive, 83 (stratified random) | - family members identified needs for assistance with physical care (31% unmet need)  
- unmet needs in psychosocial domain | - psychometric properties of scale not reported  
- theoretical framework not explicit  
- not directly tied to care satisfaction |
<table>
<thead>
<tr>
<th>AUTHORS, YEAR</th>
<th>TITLE</th>
<th>DESIGN, N</th>
<th>FINDINGS</th>
<th>LIMITATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Tringali, 1986</td>
<td>The needs of family members of cancer patients.</td>
<td>Descriptive 25 (convenience)</td>
<td>- identified relative rankings of family needs, lending support to previous findings - reinforced importance of information needs - revealed needs across illness stages</td>
<td>- sample size - non-probability sampling method - psychometric properties of tools not reported - theoretical framework not explicit</td>
</tr>
</tbody>
</table>
Wright and Dyck (1984) attempted to measure the importance of various needs of the next-of-kin of hospitalized adult cancer patients. Although the needs scale achieved an internal consistency estimate of .73, no measures of validity were reported. Validity and reliability of the interview guide were also not addressed. The need to be assured that the patient is comfortable and to communicate with the patient received the highest rankings. These findings are again limited by small sample size.

Structured interviews were undertaken by Grobe and colleagues (Grobe et al., 1981; 1982) with family members providing care at the time of the interview, bereaved family members, and terminally ill patients. Issues of validity and reliability of the structured interviews were not addressed by the researchers. Despite this, the findings resulted in some interesting points related to disparity among groups regarding needs and the need for specific information about caring for a family member.

A notable gap in the research is examination of the relationship between need fulfilment and family care satisfaction. Given the reports of incongruent assessments of needs (Grobe et al., 1981; Grobe et al., 1982) and quality of care between patients and family members (McCusker, 1984b; Oberst, 1984; Pascoe, 1984), a systematic examination of the relationship between these variables from the family member's perspective is necessary.
2. Discrepancy Theory

Discrepancy theory has been presented by a number of theorists in the field of job satisfaction. Conceptualizations of the discrepancy approach, although similar, present some alternative interpretations. Katzell (1964) viewed satisfaction as the difference between what there actually is and some desired amount. But unlike most discrepancy theorists, he assumed that this difference should be divided by the amount of the stimulus that is desired. In other words, the more a person wants of a stimulus the less dissatisfied he/she will be with a given discrepancy. Katzell offered no evidence for this assumption, and on a logical basis it is difficult to accept.

Locke (1969) presented a discrepancy theory that is somewhat different. He emphasized that it is the perceived discrepancy that is important and not the actual discrepancy. Katzell made no mention of this distinction. Also, Locke (1969) argued that satisfaction is determined by the simple difference between what the person wants and what he/she perceives he/she has.

A few researchers have argued that satisfaction is determined by what one expects to receive rather than by what one wants. Porter’s (1961) discrepancy approach was used to study perceived need satisfactions of workers in bottom and middle management jobs. Porter used expected stimulus rather than desired stimulus to assess satisfaction. This discrepancy approach has been most widely used (Lawler, 1971) and is tested in this study. As shown in Figure 2, Family Care Satisfaction is
hypothesized to be some function of the discrepancy between Family Care Expectations and Family Care Perceptions.

Research findings in the area of job satisfaction indicate that both management and industrial employees consistently give higher answers to the "how much do you want" question than to "how much should there be" question (Lawler, 1971). This conceptualization of expectations introduces the notion of fairness. People may feel satisfied with the fairness of what they receive, and yet want more. The problem with this perspective is that the theory does not provide clarity about how to interpret situations in which someone receives more than he/she expects. Does a discrepancy lead to dissatisfaction, and if so, is it the same type of dissatisfaction that occurs for individuals who receive less than they expect? It seems unlikely that receiving more than expected should produce less satisfaction than obtaining what is anticipated.

Research findings related to care satisfaction using this theoretical orientation are shown in Table 3. Empirical evidence has shown that confirmation of expectations correlates with extremes of satisfaction, depending on what those expectations are (Linder-Pelz; 1982b).
<table>
<thead>
<tr>
<th>AUTHORS, YEAR</th>
<th>TITLE</th>
<th>DESIGN, N</th>
<th>FINDINGS</th>
<th>LIMITATION</th>
</tr>
</thead>
<tbody>
<tr>
<td>Fox &amp; Storms, 1981</td>
<td>A different approach to sociodemographic predictors of satisfaction with health care.</td>
<td>Telephone survey 2592 (random)</td>
<td>Congruence between expectations &amp; care perceptions was related to higher satisfaction ratings, then when there was incongruence between these two variables.</td>
<td>Preliminary model testing may have culturally specific limits (U.S. population).</td>
</tr>
<tr>
<td>Linder-Pelz, 1982b</td>
<td>Social psychological determinants of patient satisfaction: A test of five hypothesis.</td>
<td>Prospective 125 (convenience)</td>
<td>- those with highest expectations confirmed were most satisfied. - those with lowest expectations confirmed were most dissatisfied. - overall satisfaction was inversely correlated with discrepancy (p&lt;.02).</td>
<td>- sampling limits. - single item measures for care perception.</td>
</tr>
<tr>
<td>AUTHORS, YEAR</td>
<td>TITLE</td>
<td>DESIGN, N</td>
<td>FINDINGS</td>
<td>LIMITATION</td>
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</table>
| LaMonica, Oberst, Madea, Wolf, 1986 | Development of a patient satisfaction scale.                                      | Measurement Study 75 | - satisfaction instrument achieved good internal consistency results (alpha coefficients of .92 & .95.  
- support for construct validity.  
- factor analysis did not support subscales. | - expectations & perceptions implied in definition of satisfaction.  
- theory not explicitly tested. |
Fox and Storms (1981) conducted a telephone survey to identify predictors of patient satisfaction with health care. The sample was similar to national norms for access and utilization of health services, racial composition, and income distribution and represented a 78 percent response rate. The congruence between expectations and perceptions of care, found to result in higher satisfaction levels than in instances of incongruence between these variables suggests an explanation for the commonly reported finding of negatively skewed satisfaction ratings with little variance (everybody is happy). The extent to which samples represent uniform or variable expectations and/or perceptions of care may influence the range of satisfaction ratings reported.

La Monica et al. (1986), reported three studies designed to develop and test a tool to measure hospitalized patients' satisfaction with nursing care. A discrepancy theory definition of satisfaction, similar to that used by Risser (1975) guided the research. However, an indirect approach was used to measure satisfaction by asking about the extent to which certain behaviors occurred. Expectations were not clearly measured. Therefore, the discrepancy model implied in the definition of satisfaction, was not specifically operationalized.

The value of discrepancy theory for research in the area of health care satisfaction lies in the fact that ratings of care have been reported to be generally high (Oberst, 1984; Wilkinson, 1986). Perhaps consumers of health care use lower expectations of care as a standard against which perceptions of care are evaluated.
Given the lack of testing of this model with families of terminally ill patients and imprecise instrumentation of variables in the model in some of the prior research, further study is warranted.

3. Social Comparison Theory

Although previous social comparison theories have been developed and are appropriate for use with comparison of social groups, Thibaut and Kelley (1959) proposed a social comparison theory as a way of explaining satisfaction in small groups of dyadic relationships. This theory may be particularly applicable to the dyadic interplay between families and health professionals. The theory is rooted in Lewin's (1944) studies and theories of levels of aspiration, Merton's (1957) work on reference groups, and Kelley's own distinctions between comparative and evaluative groups.

The theory includes reference to social influence processes and comparative evaluations. The central concept in the theory is a "comparison level" or neutral standard against which stimuli are evaluated and could be described as an average expectation. According to Thibaut and Kelley (1959), the outcomes a person has experienced or knows about affect expectations he/she holds about future similar events. These past experiences are evaluated or judged by the individual as well and are not stored as neutral events. The authors described this as idealization (positive evaluations of past events) or negative evaluations of past events. Therefore, the
construct "Valuing" represents this aspect of expectations. Expectations may be elevated by positive evaluations and decreased by negative evaluations. Figure 1 diagrams the validity links among the construct, Valuing, the concept, Importance of Family Care Expectations, and the instrument used to measure the concept, the F-Care Expectations Scale.

Family Care Expectations in this study are conceptualized to be expectations that individuals hold about what kind of care is typical or usual given the circumstances. Although some individuals may have "ideal" expectations that reflect what they consider to be superior or perfect care, this type of expectation is less reality-bound and, according to Thibaut and Kelley (1959), tends not to be used in evaluations.

This theory also includes the constructs "satisfaction with outcomes" and "perceptions of stimuli". Social Comparison theory specifies a linear relationship among three constructs: Valuing, the discrepancy between Expectations and Perceptions, and Satisfaction. At the concept level, this is represented as a linear relationship among the concepts, Importance of Family Care Expectations, the discrepancy between Family Care Expectations and Family Care Perceptions, and Family Care Satisfaction (Figure 2).

This theory has not been formally tested with families of terminally ill patients. It takes into account the discrepancy theory specifying the relationship between Expectations and Perceptions, but adds the concept, Importance of Family Care
Expectations. This variable may increase the explained variance associated with predicting levels of family care satisfaction.

4. Expectancy-Value Theory

This attitude theory framework was developed by Fishbein and Ajzen (1980) who distinguish attitudes from perceptions. One type of perception is beliefs, which refers to information an individual has about an object or stimulus. Beliefs in combination with the value or importance of the outcomes associated with beliefs lead to the formation of attitudes. Expectations are beliefs that a given response will be followed by some event; an event has either a positive or negative valence of effect. Thus, according to the expectancy-value model, beliefs and associated evaluations are the determinants of an attitude (Linder-Pelz, 1982a).

An attitude is hypothesized to depend on two distinct pieces of information: belief strength and attribute evaluations. Measures of belief strength (B) about attributes and measures of evaluation (E) of those attributes are multiplied and the products summed. In this study, beliefs are the expectations subjects have regarding care of the patient and family. Evaluations are represented by the value placed by family members on the relative importance of those expectations. Attitude refers to satisfaction with care.

Evidence from patient satisfaction research is conflicting and is summarized in Table 4. In two field studies, Ware et al. (1978) constructed scales to measure beliefs
(B) and evaluations (E). He showed BE measures correlated significantly with direct measures of patient satisfaction, thereby supporting Fishbein and Ajzen’s theory.

Table 4  Care Satisfaction Literature Related to Expectancy-Value Theory

<table>
<thead>
<tr>
<th>Author</th>
<th>Title</th>
<th>Year</th>
<th>N</th>
<th>Design</th>
<th>Findings</th>
<th>Limitations</th>
</tr>
</thead>
<tbody>
<tr>
<td>Linder-Pelz</td>
<td>Social psychological determinants of patient satisfaction: A test of five hypotheses</td>
<td>1982b</td>
<td>N=125</td>
<td>Experimental</td>
<td>-failed to support Expectancy-Value Theory -Expectations accounted for eight percent of variance for satisfactory physician conduct</td>
<td>-may have been error in operationalization of variables -may have used instruments that were too generic and indirect in assessment of care satisfaction</td>
</tr>
<tr>
<td>Ware, Snyder &amp; Wright</td>
<td>Development and validation of scales to measure patient satisfaction with health care services</td>
<td>1976</td>
<td>N=323 N=432</td>
<td>Methodological (correlational)</td>
<td>Σ-Beliefs x Expectations measure correlated significantly (p&lt;.05) with direct measure of patient satisfaction -support Expectancy-Value Theory</td>
<td>-satisfaction may not discriminate among behavioral intentions in response to less severe medical problems</td>
</tr>
</tbody>
</table>
Linder-Pelz (1982b) developed and tested five hypotheses based on this theory and others from the job satisfaction research. Data included each patient’s health care values, expectations, and sense of entitlement to care, as well as post-visit satisfaction with different aspects of care. Results failed to support the expectancy-value model. Pascoe (1984) critiqued Linder-Pelz’s research and suggested that some problems may have occurred because of errors in operationalizing the variables. For instance, the "values" scale and the "entitlement" scale contained items referring to physician behavior and convenience, and expectations about physician behavior were used to construct the predictor of satisfaction with convenience.

There may have also been a problem with the conceptualization of satisfaction as an expectancy-value attitude. Satisfaction may include a broad domain represented by prior expectations and general values. However, satisfaction with individual services may be influenced more by reactions to immediate care received (Pascoe, 1984).

With these criticisms in mind, attempts were made to overcome these limitations in the current study by carefully distinguishing and defining variables, using a qualitative approach to tool development, and by validity and reliability testing of the instruments. As well, prior use of the theory did not account for the individual’s perception of care in the moment. Linder-Pelz (1982b) measured beliefs, evaluations, importance of expectations and expectations in a general way based on the individual’s
past experience and were not specific to the actual care received. This may be a limitation of the theory.

**Satisfaction Model Based Hypothesis.** Specific hypotheses indicated by the four alternative theoretical model tested were:

**Fulfillment Theory**

1. The greater the number of care needs fulfilled the greater the family's satisfaction with care.

**Discrepancy Theory**

2. The greater the discrepancy between family care expectations and family care perceptions, the lower the family's care satisfaction rating.

**Social Comparison Theory**

3. a) The greater the discrepancy between family care expectations and family care perceptions, the lower the family's care satisfaction rating.

   b) The greater the importance of family care expectations the greater the discrepancy in care expectations and perceptions.

   c) No direct relationship exists between importance of family care expectations and family care satisfaction.

**Expectancy-Value Theory**

4. A positive relationship exists between the sum of the product of care expectations and importance of care expectations and family care satisfactions.
**Demographic Variables**

Key demographic variables have also been identified in the literature as having a relationship to family care needs and care provider behaviors of relative importance (Fox & Storms, 1981; Hinds, 1985; Kristjanson, 1986, 1989b; McCusker, 1984b). These include the age of the family member, the age of the patient, education level of the family member, religious affiliation, gender, and relationship to patient. Previous research has suggested that white family members are more satisfied with care than non-white family members (Kristjanson, 1989c) and older persons are more satisfied than younger (Fox & Storms, 1981; Kristjanson, 1989c). A pilot test of the FAMCARE Scale (Kristjanson, 1989c) generated the hypothesis that family members with a college education or higher are more satisfied with care than family members with less than college education. In contrast, Fox and Storms (1981) reported that those with less education are more satisfied than the more educated. Fox and Storms (1981) also reported that females are more satisfied than males and those with lower family incomes are more satisfied than those with higher family incomes.

Kristjanson (1989b) used a Q-sort methodology with 210 family members of advanced cancer patients, asking them to sort health care provider behaviors according to their relative importance. Religion, age of patient, age of family member, and relationship to patient were found to be significantly related (p<.05) to health care provider behaviors identified as important. This earlier work suggested that further examination of these demographic variables may help to increase the explanatory
power of the theories. These demographic variables are considered in the context of empirical model testing.

Summary

Three of the four competing, explanatory theories proposed for testing, Discrepancy theory, Expectancy-Value theory, and Social Comparison theory proposed different ways that expectations and perceptions of care relate to affect satisfaction. Discrepancy theory is the simplest of these three, expressing satisfaction as a consequence of the difference between care expectations and care perceptions. Social Comparison theory includes this discrepancy portion, but proposes that the discrepancy is influenced by the importance of the expectations held. Expectancy-Value theory states a different mathematical relationship between expectations and the importance of those expectations. Perceptions of care are not included in Expectancy-Value theory. The fourth theory, fulfillment theory, suggests simply that if needs are met, an individual will be satisfied. In all theories the concept, Family Care Satisfaction is conceptualized to be the dependent variable.

The researcher acknowledges that a more complete model might in fact be represented by a non-recursive model. For instance, Family Satisfaction with Palliative Care might feed back into the cognitive process experienced by family members. As well, a number of researchers have defined care satisfaction as an independent variable affecting such things as compliance with care and health seeking behavior (Fox &
Storms, 1981; Pascoe & Attkisson, 1983). However, the theories to be tested are linear. As well, the purpose of the study is in identifying relevant antecedents to family satisfaction with palliative care as suggested by relevant theoretical work in the area. Therefore, punctuation of this process of arriving at a care satisfaction rating is theoretically congruent and clinically meaningful.

Stinchcombe (1968) discussed a crucial test as a description of a set of observations which will decide among alternative theories. Testing competing theoretical models also provides a means of generating new theory based on the uncovering of complimentary relationships or based on empirical findings not consistent with theoretical predictions. It is expected that a model would need to explain approximately 20 percent of the variance in the dependent variable to be clinically useful. As well, a minimum difference of 10 percent between models would be used as the criterion on which to accept one model over another. Based on empirical findings, a new Family Care Satisfaction Model may be generated and, after replication in multiple tests, may serve as an accurate model of family satisfaction with palliative care.
CHAPTER III

METHODOLOGY

Introduction

The first section of this chapter presents the causal format used to specify variables and linkages. The format represents the causal modeling approach of Asher (1983) and Blalock (1964; 1969). Key theoretical assumptions central to the methodology are discussed. In the second section of the chapter the research population, sample and setting are described. Prior pilot testing is discussed and instrumentation is presented with attention to reliability and validity assessment of the instruments. This chapter also includes the data collection procedure, data analysis plan, and approaches used to protect the rights of human subjects participating in the study.

Causal Modeling

Causal modeling attempts to resolve questions about possible causes by providing explanations of phenomena (effects) as a result of previous phenomena (causes) (Asher, 1983). According to Asher (1983), causal modeling is both an heuristic and an analytic tool useful in studies of social phenomena. As an heuristic device, causal modeling specifies relationships between independent variables and
dependent variables of interest, and also makes explicit relationships among prior
variables. Each included linkage implicitly represents an hypothesis that is tested by
estimating the magnitude of the relationship. Kerlinger (1986) stated that causal
modeling is the ultimate approach to the analysis of complex data structures. A causal
modeling methodology is appropriately used in theoretical model testing when cause
and effect relationships are investigated where experimental designs cannot be
implemented due to lack of control over the settings (Asher, 1983; Hinshaw, 1984).

Causality is considered to depend on three conditions: covariation, time
ordering, and nonspuriousness (Asher, 1983). The first condition, mandatory
concomitant variation or covariation between X and Y, is met through specification of
major variables and their relationships within the theoretical framework. Theoretical
and empirical evidence for this assumption was described in Chapter II. The second
condition specifies that a temporal asymmetry or time ordering between the two
variables must occur. Time ordering of variables is satisfied by staging the variables.
Staging of the variables within the theories was also discussed in Chapter II and
shown in Figure 2. And thirdly, other possible causal factors must be eliminated. The
third condition is more problematic because there are possibly an infinite number of
variables that may influence the relationship in question. However, the condition of
nonspuriousness may be met by specifying extraneous variables and controlling for
their effect through statistical operations and by closing the model through the
assumption that all major variables are included in the theoretical model (Asher, 1983; Blalock, 1964; Hinshaw, 1984).

Blalock (1969) described the merits of causal modeling in addressing four major issues:

1) Prevention of oversimplification leading to deletion of certain variables or combinations of variables from consideration. Blalock maintains that if oversimplification occurs, unnecessary measurement error may result.

2) Provides for the possibility that independent variables may be theoretically related. Other theoretical models that do not account for this possibility imply zero total correlations among all causes of the dependent variable. This produces a simple inventory of most plausible causes of the dependent variable. Allowing for various explanations of relationships of independent variables to each other may be more explanatory and realistic.

3) Allows linkage among dependent variables which may also be important for explanatory purposes.

4) Allows for feedback and reciprocal types of causation explanations.

Satisfaction research has not been guided by a theory that states causal relationships. The work has been consistently correlational (Fox & Storms, 1981; Linder-Pelz, 1982b; McCusker, 1984b). Therefore, some information is known about factors that are related to satisfaction, but very little is understood about the causal basis for the relationships. Social-psychological theories have provided incomplete and
conflicting empirical evidence about satisfaction with care (Linder-Pelz, 1982b; Ware et al., 1978). There were some common concepts in the various theories and similar presumed linkages among some of the concepts, suggesting that testing of these theories within a causal framework might be possible. Therefore, a correlational design with a causal modeling methodology to test the four competing alternative theories was used in this study.

**Population, Sample Criteria, and Setting**

The population for this study consisted of family members of patients with terminal cancer. Terminal cancer was operationalized as third or fourth stage cancer. Clinical examination in Stage III reveals an extensive primary tumor with fixation to deeper structures, bone invasion, and regional lymph nodes. The lesion may be operable, but not amenable to complete resection. Gross residual disease is left behind. Five-year survival rates are low (25%). Stage IV is characterized by distant metastasis beyond the primary tumour site. The malignant lesion is inoperable and there is little or no chance for 5-year survival (less than 5%) (Griffiths, Murray, & Russo, 1984).

Family member was defined as a spouse, adult child, sibling, or parent of the patient who was most involved in the patient’s illness experience. In the event that more than one person was identified, the spouse was used as the informant. If the spouse was not one of the two identified as closest to the patient, the relative closest in age to the patient was the participant. Use of consistent sample selection rules
prevented subjective decisions based on less explicit criteria. Subjects were adults (18 years of age or older), willing to participate in the study, and able to read and speak English. A sample of 109 family members of patients from two urban hospice programs was obtained. Sample size was based on a statistical power analysis (Borenstein & Cohen, 1988) for multiple regression. A sample of 109, an alpha of .05, error model 2, and an R-squared of .30 for four variables resulted in a power of 1.00 and a large effect size (>.40). The most variables included in any one theory is four, making a sample of 109 subjects acceptable for the theoretical modeling analysis.

In the empirical modeling phase of analysis the maximum number of variables that could have been included in the regressions was 16. With a sample of 109, an alpha coefficient of .05, error model 2, and an R-squared of .30; a power of .99 and a large effect size were also estimated.

Sample size was also considered in terms of the planned factor analysis. According to Aleamoni (1973; 1979), the minimum case-to-variable ratio required for factor analysis is five to one. Given that the maximum number of items on a scale is 21, the sample size of 109 was deemed sufficient for this analysis.

Instrumentation

Four instruments represented in Figure 1 were used to collect the data for this study: FAMCARE Scale, F-Care Needs Scale, F-Care Expectations Scale, F-Care Perceptions Scale, as well as a short demographic sheet (Appendix A). All instruments
were adapted from existing instruments or were developed based on existing qualitative data. All but the demographic sheet were scaled according to a summative scaling model. A total of 87 items was included in the instruments.

Pilot Studies

Two pilot studies were conducted in preparation for this research. The first pilot study involved validity and reliability testing of the F-Care Perceptions Scale and the FAMCARE Scale with a purposive sample of 30 family members of patients with advanced cancer. The full report of this pilot test is available for review in Appendix B. The purposes of this pilot test were to 1) provide preliminary tests of the instruments for internal consistency, stability over time, criterion and construct validity, 2) time this part of the data collection procedure, and 3) identify potential problems that could arise in carrying out the full study. Acceptable internal consistency estimates and evidence of test-retest reliability were obtained. Support was also obtained for the criterion validity and validation of three of the four FAMCARE Subscales. Testing was relatively brief (approximately 22 minutes) and data collection using this method was simple and easily accommodated to the clinical setting.

The second pilot study involved testing the F-Care Expectations Scale and F-Care Needs Scale for clarity, apparent internal consistency, and content validity using a panel of six content experts. The full report of this pilot test is available in Appendix C. The results from this test provided preliminary estimates of instrument reliability.
and support for the clarity and content validity of the tools. On the basis of this work, one item on each scale was judged to be redundant by the panel and was deleted.

**Subsequent Psychometric Assessment of the Instruments**

Reliability and validity estimates were also obtained based on this study’s data. Internal consistency reliability included Cronbach’s alpha coefficient and theta coefficient with a criterion of greater than or equal to .80, inter-item correlations within scales, 50 percent of which should range from .30 to .70, and expected item-to-total correlations from .50 to .70 (Nunnally, 1978). According to Carmines and Zeller (1979), if the items making up the scale are parallel measurements, then all alpha and theta coefficients will be equal to one another and will equal the reliability of the scale. Otherwise, alpha will be a lower bound estimate for the reliability of multi-item scales. Information regarding the structure of the concepts was helped by this analysis. Table 5 reports the number of items, total scale Cronbach’s coefficient alphas, coefficient thetas, and number of respondents who had no missing data and thus participated in the analysis for each of the five scales. All scales evidenced internal consistency reliabilities above the .80 standard recommended by Nunnally (1978).

Construct validity of the instruments was further assessed using factor analysis, predictive, and empirical modeling. The criteria for factor analysis estimates of construct validity were factor loadings of at least .40 with at least .15 differences in factor loadings for items on different, but meaningful factors, as reported in Chapter
III. Factor analyses of the scales using principal component analysis and principal axis factoring with varimax rotation were performed to assess the internal construct validity of the scales.

Table 5  Calculated Reliability Estimates, Cronbach's Coefficient Alphas and Coefficient Thetas for Scales

<table>
<thead>
<tr>
<th>Total Scale</th>
<th># of Items</th>
<th>Unstandardized Alpha</th>
<th>Standardized Alpha</th>
<th>Coefficient Theta</th>
<th>N Out of 109</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Care Needs Scale</td>
<td>20</td>
<td>.81</td>
<td>.83</td>
<td>.85</td>
<td>84</td>
</tr>
<tr>
<td>Family Care Perception Scale</td>
<td>21</td>
<td>.90</td>
<td>.90</td>
<td>.96</td>
<td>69</td>
</tr>
<tr>
<td>Family Care Expectation Scale</td>
<td>16</td>
<td>.88</td>
<td>.91</td>
<td>.92</td>
<td>99</td>
</tr>
<tr>
<td>FAMCARE Scale</td>
<td>20</td>
<td>.95</td>
<td>.95</td>
<td>.96</td>
<td>74</td>
</tr>
</tbody>
</table>

The predictive modeling criteria were significant path coefficients (p < .05) in the predicted direction with a magnitude of .05 or greater as reported in Chapter IV.

Instruments

F-Care Needs Scale: Index of Awareness of Care Needs, Importance of Care Needs, and fulfillment of Care Needs. The F-Care Needs Scale measures three
concepts: the family member’s awareness of care needs, the family member’s perception of the importance of the care needs, and whether or not the family member believes that the needs were fulfilled.

Content in the F-Care Needs Scale was based on Molter and Leske’s (1983) Critical Care Family Needs Inventory (CCFNI), developed to measure the extent to which family care needs exist and work by Tringali (1986) who used the CCFNI with family members of advanced cancer patients. The original CCFNI consisted of 45 need statements rated on a 4-point Likert-type scale (Likert, 1932). Tringali (1986) developed a 53 item forced choice Likert scale to measure the needs of 27 family members of cancer patients.

On the basis of prior research with this population (Kristjanson, 1986, 1989a, 1989b, 1989c) the length of these scales was considered to be too long given the stressed population to be tested. As well, other instruments were used in this study making subject fatigue a major concern. Therefore, 20 items were selected and adapted from the CCFNI using Tringali’s (1986) findings to help guide item identification. The items receiving a mean of 3.5 to 4.0 represented the needs of greatest concern to the sample. Given that the sample for Tringali’s study and the sample for this research project arise from a similar population (family members of advanced cancer patients) these items were considered relevant. Items 1 through 17 and item 20 on the F-Care Needs Scale were adapted from Tringali’s (1986) list of important items. Items 18 and 19 were adapted from the original CCFNI (Molter & Leske, 1983).
The Awareness of Family Care Needs and Importance of Family Care Needs were indexed by asking subjects to rate the importance of the needs by giving each item a score between 0 and 10. Number 10 represents a very great need and 0 represents no need at all. If a subject scored zero on a need he/she was considered not to have the need. A score of one or higher indicated that the need existed.

A second question relating to whether or not the need was met indexed fulfillment of Care Needs. Subjects indicated whether or not each need was met or not met. The format for this scale was based on the work of Atwood et al. (1989) who developed the Caregiver Needs Scale, a tool that indexes needs of family members of cancer patients who are providing care to these individuals.

Evidence for the clarity, apparent internal consistency, and content validity of this instrument was obtained in an earlier pilot test (Appendix C). All items achieved the preset criterion of 66 percent for clarity, with 17 of the 20 items achieving 100 percent agreement and a mean percent agreement for the total scale of 96. All 20 items met or exceeded the criterion of 70 percent agreement for apparent internal consistency, with a mean percentage agreement of 97 percent. Nineteen items met the criterion of 83 percent agreement for content validity, and items 5 and 6 were judged redundant. However, a decision was made to retain both items in order to assess their meaning with a larger sample. Subsequent testing with this study’s data resulted in an inter-item correlation of .53 for this pair of items, indicating that redundancy was not a
problem. Item #9 was reworded in keeping with comments of the panel. The resulting instrument contained 20 items.

Although the scale indexed presence or absence of a need and importance of the need, only the latter is meaningful in terms of internal consistency. Reliability estimates of the Importance of Care Needs subscale using this study's data resulted in a mean item mean of 9.1 with a range of 2.6 for the 84 of 109 who had all 20 needs, and thus complete data. The possible score range was 0 to 10 for the scale, indicating that an upper range abbreviated scale was used. Internal consistency as measured by Cronbach's alpha coefficient was .83. Only five of the 20 items achieved the preset inter-item correlation criterion of 50 percent between .30 and .70. Items 2, 5, 6, 8 and 14 correlated well in the scale. Six of the 20 item-total correlations met the preset criterion of .50 to .70, and only one over .70.

A theta coefficient of .85 was calculated for the scale using the results of a principal components analysis with varimax rotation (Table 5). Given the fact that the coefficients obtained were within .05 of each other (unstandardized alpha of .81, standardized alpha of .83, and the theta coefficients of .85), the items were parallel and, therefore, the alpha model was the most appropriate reliability model for the scale.

Construct validity of the Importance of Care Needs subscale was assessed using factor analysis techniques. Results of the principal component analysis with varimax rotation produced seven factors with eigenvalues greater than 1.0. However,
the scree test indicated three primary factors and four secondary factors. Eigenvalues ranged from 1.09 to 5.14. Percent of variance ranged from 25.7 percent for the first factor extracted, to 5.5 for the seventh factor. Item factor loadings meeting the preset criteria ranged from absolute values of .50 to .89. Efforts to interpret factor analysis results in terms of substantive meaning, revealed that although the items listed commonly represented care needs, there were many different kinds of needs, and that there was no necessary expectation that a minimum number of factors would be extracted to represent those varied needs.

Assessment of the fulfillment of Care Needs subscale using this study’s data resulted in a mean item mean of .81 with a range of .39. The possible scale range was 0 (not met) to 1 (met). Answering one need met does not necessarily mean that other needs have been met, making an alpha assessment that tests for parallelism in the subscale inappropriate. Ideally, a test-retest of this subscale would have provided a more complete estimate of the reliability of the scale; however, given the practical problems associated with accessing the sample twice, this piece of information was not collected.

A calculation of the percentage of needs met was obtained. These results indicated that between zero and 100 percent of the needs were met. Fifty-one percent (n=54) of respondents indicated that over 85 percent of their care needs were met, 31 percent (n=33) indicated that between 52 and 84 percent of their care needs were met, and 18 percent (n=19) reported that less than 50 percent of their needs were met.
Factor analysis for this subscale was not appropriate because the response options for the scale structured it as a dichotomous variable. According to Kim and Mueller (1978; p.74) use of factor analysis on dichotomous variables is not acceptable because in factor analysis "each variable is assumed to be a weighted sum of at least two underlying factors (one common and one unique). Even if these underlying factors have two values, the resulting values in the observed variable must contain at least four different values, which clearly is inconsistent with a dichotomous variable."

Therefore, the internal structure of the subscale was assessed using cluster analysis. A euclidean dissimilarity coefficient matrix was computed and a hierarchical cluster analysis (dendogram) using average linkage (between groups) was examined to identify the underlying theoretical structure of the subscale. Although the results suggested that four clusters of items were present, examination of the items supported that there were many different types of needs and all items clustered reasonably, resulting in a conclusion that the subscale represents the needs variable as a unidimensional one.

**F-Care Expectations Scale: Index of Family Care Expectations and Importance of Family Care Expectations.** The F-Care Expectations Scale measures two concepts: Family Care Expectations which are the kind of actions from health providers that family members believe to be usual or reasonable, and the Importance of Family Care Expectations, the value associated with those expectations.
The F-Care Expectations Scale was developed based on Linder-Pelz’s (1982b) work in the area of patient satisfaction with care and prior qualitative research that identified indicators of quality of care that family members of advanced cancer patients considered important (Kristjanson, 1986). Items 1, 3, 4, 5, and 8 were adapted from Linder-Pelz’s (1982b) Expectation scale. The remaining items were developed from the qualitative study mentioned above.

Family Care Expectations was indexed by a response option ranging from 0 to 10. A response of 0 indicated that the family member did not have this expectation of health professionals. A response of 1 or greater indicated that the family member expected this behavior from health professionals.

Importance of Family Care Expectations was indexed by considering a response of 1 or higher an indication that the expectation was important and a higher number reflected greater importance. Importance of Family Care Expectations is different from Importance of Family Care Needs. The former refers to the value associated with actions of health care providers that family members believe to be usual, whereas the latter refers to the value placed on the family member’s perceived requirements from health professionals. A judgment about the importance of care needs does not include reference to any anticipation about whether or not the need will be met. In contrast, implicit in a judgment about the importance of an expectation is the belief that an action can be anticipated or is likely to occur.
The F-Care Expectations Scale was also tested for clarity, apparent internal consistency, and content validity and met all pre-specified criteria for inclusion of items (Appendix C). All items achieved or exceeded the required criterion of 66 percent agreement for clarity with a mean percent agreement for the total scale of 94 percent. All items also met the criterion of 70 percent agreement for apparent internal consistency, with a mean percentage agreement of 95 percent. All items achieved 100 percent agreement for content validity and items four and 10 were judged redundant by two panel members. Consequently item 4 was deleted resulting in a 16 item scale.

Although no comments were made during the pilot testing to indicate confusion between needs and expectations, there was a concern that subjects might find it difficult to distinguish the two. Therefore, to ensure more accurate responses, instructions to subjects were explicit in orienting them to the concept to be measured on each of the scales. Subsequent factor analysis of the two scales together indicated that subjects in this study distinguished the two concepts. The results are reported later.

Psychometric assessments of the Importance of Family Care Expectations Subscales using this study’s data resulted in a mean item mean for the scale of 9.5 with a range of .76, for the 99 of 109 with complete data. The possible score range for this item was from 0 to 10 with all item means above 9.0, indicating that an especially abbreviated upper portion of the scale was used. The scale achieved an internal consistency estimate as measured by Cronbach’s standardized alpha coefficient of .91,
at the upper end of the preset criterion of >.80. The mean inter-item correlation for the scale was .39 with a range of .85.

Ten of the 16 (63%) items achieved the preset criterion of 50 percent inter-item correlations between .30 and .70. Items 5, 6, 7, 11, and 12 did not meet this criterion. High inter-item correlations were found between items 7, 11, 12, and 15 (r=.78 - .88) suggesting some redundancy. Eleven of the 16 item-total correlations met the pre-specified criterion of 50 percent between .50 and .70 ranging from r=.21 (Item 5) to r=.84 (Item 4).

Results of principal component analysis with varimax rotation were used to calculate a coefficient theta for the scale. Since the theta coefficient obtained (.92) for the scale was within .05 of the alphas; unstandardized alpha coefficient =.88, standardized alpha coefficient =.91, a judgment was made that the alpha model more accurately fit the scale.

Factor analysis for the scale using principal component analysis with varimax rotation resulted in four factors with eigenvalues ranging from 1.05 to 7.17. The four factors accounted for 44.6 percent of the variance ranging from factor 1 to 6.6 percent of the variance by factor 4. Item factor loadings meeting the pre-specified criteria ranged from .65 to .92. Two items (#4 and 9) double loaded, and all other items loaded distinctly on one of the factors. An exploratory PAF using all scale items resulted in comparable eigenvalues, percent of variance distributors, and factor loadings. Given the fact that the alpha model was accepted as the most appropriate
reliability model for the scale, these four factors were judged to represent expectation groupings for the unidimensional concept, Importance of Family Care Expectations. These included expectations that care would be competent and safe, that health professionals would be attentive and take enough time with the patient, and that health professionals would communicate honestly with families.

The Family Care Expectations subscale using this study’s data resulted in a total scale mean of 15.80 with a range of 3.00. The possible scale range was from 0 (no expectations) to 16 (all items held as expectations). A calculation of the number of expectations identified revealed that between 13 and 16 expectations were identified by subjects and 86 percent (n=94) of the sample identified that they held all 16 expectations.

**F-Care Perceptions Scale: Index of Family Care Perceptions.** This scale is a 21-item instrument that measures a family member’s awareness of the health care provider behaviors directed toward the patient and themselves. This tool was developed based on prior qualitative work (Kristjanson, 1986) and relevant literature. Linder-Pelz’s (1982b) work in the area of measurement of perceived occurrence was used as a basis for generating the tool.

Pilot testing of the developed scale (Kristjanson, 1989c) with a convenience sample of 30 family members of cancer patients with advanced disease resulted in internal consistency estimates of .88 and .89 using Cronbach’s alpha coefficient (p<.05). Stability over time was assessed over a 24 hour period using Pearson’s
correlation coefficient. A value of .82 (p<.05) was obtained. A predicted positive correlation of .81 (p<.05) was obtained between the F-Care Perceptions Scale and the FAMCARE Scale (Kristjanson, 1989c). These findings indicate that some redundancy exists between the scales. Although the item content was similar, the questions asked of the items were different. Instructions to subjects may not have made this distinction clear. Therefore, these two concepts were operationalized more distinctly in the revised versions of the scales in an effort to more sharply distinguish the concepts.

Response options for the scale were originally labelled from one to five along a Likert-type format (Likert, 1932). However, in order to not confuse subjects who would be responding to a 0-10 format for the F-Care Needs and F-Care Expectations scales, letters to indicate degree of agreement with the items were used (Strongly Agree to Strongly Disagree).

Psychometric assessments of the scale using this study’s data resulted in a mean item mean for the scale of 3.8 with a range of 1.4. Given the possible range of 4.0 with an expected mean of 3.0, and one third of the means greater than or equal to 3.9, the data suggested that subjects used an abbreviated upper range of the scale. The scale achieved an internal consistency estimate as measured by Cronbach’s standard alpha coefficient of .90. This estimate was well beyond the preset minimum criterion of .80 (Nunnally, 1978).
A theta coefficient of .96 was calculated based on the results of a principal component analysis of the scale with varimax rotation. This result suggests that the theta model is the appropriate model, and that the scale has subdimensions.

Based on the judgment that the scale has subdimensions, internal consistency coefficients for the subscales were computed, and item-to-total correlations examined for the subscales using the above mentioned criteria. The standardized and unstandardized coefficient alphas for the 8-item "Competent Disease Treatment" subscale were both .88. The Spearman-Brown corrected average inter-item correlations for the 3-item "Family Informed" and the 4-item "Lack of Trust" subscales were $r_4 = .93$ and $r_3 = .89$, respectively. All items within each subscale met the criterion of inter-item correlations between .30 and .70, and the criterion of 50 percent of item-total correlations within the .50 to .70 range. Subscale-to-subscale correlations were between .39 and .63 and subscale-to-total correlations ranged from .65 to .84.

Factor analysis for the scale using principal component analysis with varimax rotation resulted in five factors with eigenvalues greater than 1.00 (Table 6). The scree plot of the eigenvalues suggested a three factor solution as did interpretation of the meaning of the items loading on the various factors. Five items did not achieve the criteria of unique loading. Factors 4 and 5 were indexed by only one item each, making an alpha reliability assessment impossible.
Table 6  Factor Names, Items, Loadings, Eigenvalues, and Percent of Variance for F-Care Perceptions Scale Based on Principal Component Analysis, Varimax Rotation

<table>
<thead>
<tr>
<th>Factors</th>
<th>Items</th>
<th>Factor Loadings</th>
<th>Eigenvalues</th>
<th>Percent of Variance</th>
</tr>
</thead>
<tbody>
<tr>
<td>I. Competent Disease Treatment</td>
<td>1 pain management</td>
<td>.69</td>
<td>7.72</td>
<td>36.8</td>
</tr>
<tr>
<td></td>
<td>2 straightforward answer</td>
<td>.72</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>6 referral to specialist</td>
<td>.82</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>7 hospital bed</td>
<td>.65</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>8 family conference</td>
<td>.32</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>9 symptoms treated</td>
<td>.65</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>12 doctors available to family</td>
<td>.52</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>19 symptoms assessed thoroughly</td>
<td>.56</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>20 doctors available to patient</td>
<td>.56 (II)</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>21 tests &amp; treatments followed up</td>
<td>.74</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>11 tests competent</td>
<td>.60</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>16 family excluded from treatment decisions</td>
<td>.54</td>
<td>1.89</td>
<td>9.0</td>
</tr>
<tr>
<td></td>
<td>17 family informed re: plans</td>
<td>.75</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>18 information re: tests</td>
<td>.79</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Exploratory PAF for the scale also suggested a three factor solution. As well, confirmatory PAF for three factors produced almost identical results suggesting that three factors most correctly represent the internal structure of the scale. Given the fact that unhappy families are often under-sampled in this type of research, as they were in this study, retention of all items seemed prudent, as these family perceptions of health workers' behavior may have particular meaning for less satisfied families.

**FAMCARE Scale: Index of Family Satisfaction with Advanced Cancer Care.**

The FAMCARE measures the degree to which family members are content with health care provider behaviors directed toward the patient and themselves. The operational definition of family member satisfaction is congruent with the conceptual definition included in Table 1. The Likert-type scale consists of 20 items based on previous
qualitative work that identified indicators of quality of terminal care from a family member’s perspective (Kristjanson, 1986) and a subsequent study that employed a Q-sort methodology to reduce these indicators to those considered most salient (Kristjanson, 1989b).

A pilot test of the scale resulted in an internal consistency estimate using Cronbach’s alpha of .93 (p<.05) without redundancy. Test-retest findings using Pearson’s product correlation coefficient was .91 (p <.05) within a 24 hour period. Criterion validity estimates of the tool against the McCusker Care Satisfaction Scale were .77 and .79 at time 1 and time 2 respectively. This is considered acceptable given the expected value of greater than or equal to .71, based on an overlap of approximately 50 percent of the questions on the two scales (see Appendix B for pilot study report).

Five abbreviated letters representing words were also used for response options, ranging from Very Satisfied to Very Dissatisfied. Use of this response format was also based on the rationale that combining two different number response options within the questionnaire schedule would be confusing to subjects. Reliability assessments of the scale using this study’s data resulted in a mean item mean for this scale of 3.8 with a range of 1.0. The possible score range for each scale item was from one to five and four of 20 items had means greater than or equal to 3.9, suggesting that an abbreviated upper range of the scale was used by subjects.
The internal consistency estimate was .95 using Cronbach's standardized alpha coefficient. The mean inter-item correlation was .51 with a range of .64. All items met the pre-specified inter-item correlation criterion, with 16 of the 20 items achieving 89 percent or greater inter-item correlations between .30 and .70. There was minimal evidence of redundancy. Items 5 and 19 achieved an inter-item correlation of .75, items 18 and 19 achieved a correlation of .80, and items 11 and 20 showed an inter-item correlation of .77. Eight of the 20 item-total correlations were within the range of .50 and .70, with a range of .45 to .85.

A theta coefficient of .96 was calculated based on results of a principal components analysis with varimax rotation. A comparison of the theta to the unstandardized and standardized alpha coefficients showed that there was only a .01 range among the three, indicating that the items are basically parallel and the alpha model was the appropriate one to use.

Factor analysis using principal component analysis with varimax rotation resulted in three factors with eigenvalues greater than 1.00. These factors together accounted for 67 percent of the variance. The first factor in the PCA results accounted for 54 percent of the variance with factors two and three adding only 7 percent and 5.9 percent respectively to the explained variance. The scree plot results from this analysis supported a one factor solution for this scale.

A confirmatory PAF for three factors was also run for this scale. Only one factor with an eigenvalue greater than 1.00 was obtained, accounting for 52.2 percent
of the variance. This result was also supported by the scree plot distribution of eigenvalues. Based on these combined analyses, the scale was judged to be a unidimensional measure of family care satisfaction.

**Theoretical Distinction Among Concepts**

To confirm that the variables measured were considered distinct by subjects and to evaluate the possibility of a response set due to similarly worded items across scales, factor analysis using principal components analysis with varimax rotation was run with every pair of scales. Results of this analysis are shown in Table 7.

<table>
<thead>
<tr>
<th>Scales</th>
<th>NMET</th>
<th>FEXP</th>
<th>FPERT</th>
<th>FAMCARE</th>
</tr>
</thead>
<tbody>
<tr>
<td>FNEED</td>
<td>6</td>
<td>--</td>
<td>--</td>
<td>--</td>
</tr>
<tr>
<td>NMET</td>
<td>3</td>
<td>2</td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>FEXP</td>
<td>3</td>
<td>2</td>
<td>12</td>
<td></td>
</tr>
<tr>
<td>FPERT</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Six of the 20 items on the F-Needs Scale and the Need fulfillment Scale loaded on the same factors. Considering that wording for all 20 items on each scale was identical, this result suggests that subjects did distinguish the majority of variables. Only the F-Care Perceptions scale and the FAMCARE Scale had a large number of items loading.
on the same factor (12). To further assess the distinction between these two scales, a cross tabulation of the items on the two scales was run and the percent of concordance among the items calculated. Five of the 16 item pairs with identical wording achieved a correlation of greater than, but approached the .65 criteria (.69-.70). This criterion was used as it is recommended by Gordon (1968) as the marker for multicollinearity. These results indicate that subjects did distinguish care perceptions from care satisfaction and that a response set based on item wording was not operating. All other scale pair combinations were judged distinct as evidenced by the factor analysis results.

**Data Collection Procedure**

One large urban tertiary hospital and two home care programs provided subjects for the study. The hospital has a 20 bed palliative care unit which provides inpatient care to patients with third and fourth stage cancer. As well, the palliative care unit has a home care service that provides care to patients receiving care in their own homes with a caseload of approximately 100. The second home care program was administered through an urban extended care hospital. This program serves the palliative care population from the remaining tertiary care hospitals in the urban setting. Family members of patients receiving care through the Home Care services were listed. These lists provided the sampling frame. The entire population was used rather than a randomized sample. Family members of patients receiving care on the
Palliative Care Unit were identified from the patient kardex. All family members of patients on the Palliative Care Unit who met the study definition and criteria were considered for participation in the research. Ackoff (1953) described this approach as judgment sampling, whereby a subgroup of the population, in this case, a list of family members out of the total number of persons living in the study area who have a member with terminal cancer are judged as representative of the total population. To obtain a sample of 109 family members in a reasonable amount of time, inclusion of all subjects who fit the criteria was judged to be most feasible. In reviewing Manitoba cancer incidence and mortality statistics available for 1988, it was found that approximately 890 individuals in greater Winnipeg died from cancer during the period May to December of that year (Manitoba Cancer Treatment and Research Foundation, 1988). Based on this statistic, it was estimated that the sample obtained represents approximately 12 percent of the terminally ill cancer population in greater Winnipeg.

A list of family members was provided to the researcher by the Head Nurse on the Palliative Care Unit. Family members were then contacted by telephone or in person during patient visiting times and invited to participate (Appendix D). If agreeable, the subject completed the questionnaires in an interview room adjacent to the hospital unit.

Home care family members were also identified through a list provided to the researcher by coordinators of the Home Care Programs. The Home Care Coordinators provided family members on the list with a letter from the researcher describing the
project (Appendix D). If the family member was interested in participating the
research assistant then contacted the family member by telephone to arrange a data
collection time. Family members signed a consent form prior to participating in the
research (Appendix E). Although individual contact with each subject to collect data
was time-consuming, the researcher's past experience with this population suggested
that the stressful nature of the patient's illness and the need for a sensitive research
approach necessitated this data collection method. The presence of the research
assistant was especially necessary for family members who were older, had some
vision problems, or needed help to follow directions. As well, it was hoped that face­
to-face contact would result in a higher response rate.

Whenever possible, data about non-respondents were recorded with the verbal
permission of the family member. These data included the age of patient, diagnosis,
relationship of family member, and sex of patient and family member.

Herberlein and Baumgartner (1978) reported that the effect of length of a
questionnaire on response rate has been widely studied with no consistent findings to
explain its effects. Longer questionnaires have higher costs to respondents, but likely
signal the respondents that the study is important (Herberlein & Baumgartner, 1978).
They found that the length as measured by number of pages, number of items, or
estimated time of completion had no zero-order correlation with the final response
rate. Childers and Ferrell (1979) discovered that the size of pages had a significant
negative effect on response rate, but the number of pages was not significant. As well,
Shelley (1984) recommended use of a booklet format for ease in turning pages and to reduce the likelihood of lost pages. Shelley (1984) also emphasized the importance of not crowding questions to limit number of pages. Therefore, based on this rationale a well-spaced, large print, nine page questionnaire with alternative colored pages for each instrument in a booklet format was used. More important with this population may be the simplicity of the questions and the brevity of the instruments. Previous research with individuals experiencing the stresses of terminal illness in a member (Kristjanson 1989a, 1989c) indicated that the use of negatively worded items and lengthy questionnaires are experienced as confusing and frustrating to subjects, and contribute to a reluctance to complete the questionnaire. Response set seemed not to be a factor with this population. Therefore, each scale was reduced to the shortest number of items considered reasonable to capture the concept. As well, instruments were worded simply and positively in accordance with earlier pilot test results (Kristjanson, 1989c).

It was estimated that data collection would take between 40 and 60 minutes. Subjects were offered a summary report of the findings if they were interested and received a follow-up note from the investigator thanking them for their time and effort.
Data Analysis Plan

The data analysis plan consisted of three parts. The plan included: 1) descriptive statistical summary of the sample in terms of demographic variables, 2) residual analysis, and 3) alternative theory testing, and are described in detail in chapter IV.

Protection of Human Subjects

Approval from the Human Subjects Committee of the University of Arizona and the Ethical Review Committee of the University of Manitoba was obtained prior to data collection. A written consent was read and signed by subjects (Appendix E) assuring their rights and confidentiality of data collected. Subjects were also assured that participation in the study would in no way influence care received as data would not be shared with health care providers involved in providing care to the patients. Subjects were advised that a summary report with grouped data would be available to the participating institution.

To ensure confidentiality, the subjects’ responses were coded in a manner so that neither the patient or family member could be identified. Raw data were secured under lock and key. The computer file containing data was protected by a password known only to the researcher and research assistants. The researcher’s advisor, research assistants, and the dissertation committee were the only other persons having access to the data.
Summary

Chapter III presented the theoretical principles of causal modeling and the details and issues associated with use of this methodology for the study. Four summative ratings scales and a demographic data form were used to collect the data. Results of reliability and validity assessments for the instruments were discussed and reports of pilot testing and the current testing included, indicating that psychometric criteria were met. The subject criteria and data collection protocol used were also outlined in this chapter. The data analysis plan was outlined and procedures for assuring subject protection were described.
CHAPTER IV
RESULTS OF DATA ANALYSIS

Introduction

The purpose of this study was to use theoretical and empirical modeling to identify the model that best explained family satisfaction with palliative care as an outcome of terminal illness in one member. Results of the data analysis to test the theoretical alternatives and to generate an empirical model are presented in this chapter.

The results are presented in the following order: 1) description of the participation rate characteristics, 2) comparison of demographic characteristics of respondents and non-respondents, 3) description of the sample, 4) relationships among demographic variables, 5) comparison of subjects across care settings, 6) tests for violations of the causal modeling assumptions and the statistical assumptions underlying the regression analysis, 7) tests of the alternative theoretical models through regression analysis are followed immediately by tests of each augmented theoretical model using demographic variables, 8) empirical modeling results through regression analysis using variables from all four theories and demographic variables, 9) comparison of alternative models, 10) the match between theoretical and empirical models, and 11) assessment of construct validity through predictive modeling.
Description of the Participation Rate Characteristics

Data collection occurred between May and December, 1990. During this time, 186 family members were identified as potential subjects for the study. Of this total, 109 family members agreed to participate for a response rate of 59 percent. Eighty-two family members were identified from an in-patient Palliative Care Unit, 64 were identified from Home Care Program A, and 40 were identified from Home Care Program B. Of the 77 non-respondents, 33 percent provided a reason for not participating. The most frequent reason occurred in instances in which the family member stated they were not interested in participating (n=10). The second most frequent reason given for not participating was that the "family was too stressed" (n=8). Table 8 presents the range of reasons and frequency of reasons for non-participation reported.

The family members were contacted personally by the research assistant; were invited to participate, and if agreeable, completed the questionnaires either in their own home or in a conference room adjacent to the palliative care unit in the hospital. Seventy-eight family members chose to complete the questionnaires at home in the presence of a research assistant. Thirty-one family members chose to complete the questionnaires in the hospital conference room.
Table 8  Frequency Distribution of Reasons Cited by Nonrespondents for not Participating in Study by Care Setting.

<table>
<thead>
<tr>
<th>REASON</th>
<th>Palliative Care Unit n</th>
<th>Home Care (A) n</th>
<th>Home Care (B) n</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Not interested</td>
<td>5</td>
<td>5</td>
<td></td>
</tr>
<tr>
<td>2. Too stressed</td>
<td>7</td>
<td></td>
<td>1</td>
</tr>
<tr>
<td>3. Too busy</td>
<td>2</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>4. Patient too ill</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Not comfortable completing questionnaire</td>
<td>1</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>TOTAL</strong></td>
<td><strong>16</strong></td>
<td><strong>7</strong></td>
<td><strong>1</strong></td>
</tr>
</tbody>
</table>

Comparison of Demographic Characteristics: Participants versus Nonparticipants

Some non-participants provided demographic information about themselves. Response rates to demographic questions ranged from zero to 98 percent. Information obtained included marital status, gender, diagnosis, age of patient, and relationship to patient.

A significant (p<.05) difference was found between respondents and non-respondents according to marital status (Chi-square=4.90, d.f.=1, N=163). Ninety-seven percent of non-respondents were married compared to 83 percent of respondents. No other significant differences were found between the two groups according to demographic characteristics reported using Chi-square statistics.
Description of the Sample

Demographic data were obtained on all subjects. The data are presented in Table 9. Sixty-five (69%) of the family members were females, a male to female ratio approximately 1:2. This is similar to a commonly reported finding in the literature that women tend to be the family caregivers during illness situations (Brody, 1981; Brody & Lang, 1982; Goldner, 1988; Mace & Rabins, 1981).

The most frequent educational level reported for the sample was some high school or a high school diploma (49%). This is consistent with Statistics Canada (1989) data that report the most frequently listed educational category for Manitobans over 15 years of age as grade 9 to 13.

Annual income for the sample was evenly distributed between $11,000 and over $40,000. Approximately 21 percent of the sample reported an income greater than $40,000. The Statistics Canada data (1989) related to income distribution in the province report the mean family income as $16,796 with only six percent of the population earning more than $40,000 per year. The sample obtained represented a higher income group than is typical of the Manitoba population.

The sample was relatively similar to the ethnic mixture of Canadians in general. According to Statistics Canada (1989) the largest ethnic group in Manitoba are those of European descent (28%), followed by those of British origins (21%), and those of French origin (5%). Given the fact that 47 percent of the sample was obtained
from health care services situated in a French speaking community, the slightly higher representation of Francophone Manitobans found in the study (15%), was expected.

The most frequent diagnostic category was lung cancer (23%), followed by breast cancer (14%), genitourinary cancer (10%), and colon cancer (9%). These findings are congruent with the age distribution of the patient population sampled and the most frequently cited primary cancer sites (Statistics Canada, 1988). Ninety-five percent were urban residents while three percent lived in rural areas of the province and two family members resided out of the province. This over-representation of urban subjects may also account for the larger representation from high income groups.

In summary, the average subject was a female, between the ages of 31 and 50, married, with a family member diagnosed with lung cancer. The average participant had a high school education, worked as a homemaker or was retired. Although the modal income level was between $11,000 and $20,000 (23%), the distribution among categories was almost identical. Most often this individual was the patient’s wife.
<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Patients</th>
<th></th>
<th>Family Members</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>n (%)</td>
<td></td>
<td>n (%)</td>
<td></td>
</tr>
<tr>
<td><strong>Age</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>under 30</td>
<td>2 ( 2%)</td>
<td>3 ( 3%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>31-50</td>
<td>9 ( 8%)</td>
<td>43 (39%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>51-65</td>
<td>15 (14%)</td>
<td>30 (28%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt;65</td>
<td>83 (76%)</td>
<td>33 (30%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>male</td>
<td>52 (48%)</td>
<td>34 (31%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>female</td>
<td>57 (52%)</td>
<td>75 (69%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Education Level</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>grade 8 or less</td>
<td>11 (10%)</td>
<td>10 (10%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>some high school/high school diploma</td>
<td>53 (49%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>post secondary education</td>
<td>45 (41%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Occupation</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>white collar</td>
<td>43 (39%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>homemaker/retired</td>
<td>49 (45%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>other</td>
<td>15 (14%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>missing</td>
<td>2 ( 2%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>*** Relationship to Patient**</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>spouse</td>
<td>54 (50%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>son</td>
<td>12 (11%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>daughter</td>
<td>29 (27%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>other</td>
<td>14 (13%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Income</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt;10,000</td>
<td>6 ( 6%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>11-20,000</td>
<td>25 (23%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>21-30,000</td>
<td>20 (18%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>31-40,000</td>
<td>22 (20%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&gt;40,000</td>
<td>23 (21%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>missing data</td>
<td>13 (12%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>n</td>
<td>(%)</td>
<td>n</td>
<td>(%)</td>
</tr>
<tr>
<td>------------------</td>
<td>-----</td>
<td>-----</td>
<td>-----</td>
<td>-----</td>
</tr>
<tr>
<td><strong>Religion</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Catholic</td>
<td>49</td>
<td>(45%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Protestant</td>
<td>39</td>
<td>(36%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Jewish</td>
<td>5</td>
<td>(5%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>8</td>
<td>(7%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>None</td>
<td>6</td>
<td>(6%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td>2</td>
<td>(2%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>European</td>
<td>31</td>
<td>(28%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>British Isles</td>
<td>24</td>
<td>(22%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Anglophone</td>
<td>20</td>
<td>(18%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Francophone</td>
<td>16</td>
<td>(15%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>5</td>
<td>(5%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td>13</td>
<td>(12%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Diagnosis (Primary Site)</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>lung</td>
<td>23</td>
<td>(21%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>other**</td>
<td>19</td>
<td>(17%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>breast</td>
<td>15</td>
<td>(14%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>genito-urinary</td>
<td>10</td>
<td>(9%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>colon</td>
<td>9</td>
<td>(8%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>pancreas</td>
<td>7</td>
<td>(6%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>gastric</td>
<td>7</td>
<td>(6%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>brain</td>
<td>6</td>
<td>(6%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>unknown primary</td>
<td>4</td>
<td>(4%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>liver</td>
<td>2</td>
<td>(2%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>missing</td>
<td>7</td>
<td>(6%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Marital Status</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>married</td>
<td>90</td>
<td>(83%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>never married</td>
<td>7</td>
<td>(6%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>widowed</td>
<td>4</td>
<td>(4%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>divorced</td>
<td>3</td>
<td>(3%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>common law</td>
<td>1</td>
<td>(1%)</td>
<td></td>
<td></td>
</tr>
<tr>
<td>missing</td>
<td>4</td>
<td>(4%)</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* Percentage does not equal 100 due to rounding.
** Includes head and neck, leukemia, lymphoma, malignant melanoma, ovarian, sarcoma, and bone cancer, malignant myeloma.
Differences Among Subjects According to Demographic Variables

Six tests of association were of interest. A significant association (Chi-square=4.57, df=1, \(p=.03\)) between patient age and family age was due to 64 percent of patients over 65 years of age having family members less than 65 years, and 89 percent of patients under 65 also having family members in this age category. These findings are consistent with frequency distribution data suggesting that family members tend to be younger than patients and spouses are the most frequent family member participating in the study.

A significant association (Chi-square=14.44, df=4, \(p=.006, \gamma=.49\)) between relationship to patient and family member's education level was due to 91 percent of those with less than grade eight education also being spouses of the patient, and 62 percent of those with post-secondary education reporting their relationship to the patient as "other". Examination of the relationship between gender and relationship to the patient indicated that spouses most often were women (63%) and those in the "other" category were men (54%) (Chi-square=20.22, df=2, \(p=.000\)).

Income and relationship to patient were also associated (Chi-square=11.48, df=4, \(p=.02, \gamma=.37\)). Seventy-one percent (n=54) of those making less than $20,000 were the patient's spouse, and 50 percent (n=26) of those with incomes greater than $40,000 described their relationship to the patient as "other".

The significant relationship (Chi-square=25.17, df=4, \(p=.000, \gamma=.54\)) between family income and education level was due to the majority (58%) of those
with an income greater than $40,000 also having post secondary education, and 82 percent of subjects with less than grade eight reporting incomes less than $20,000. This positive correlation between income and education is expected given the sociological literature describing the relationship between these variables (Forcese, 1980; Hunter, 1986; Veltmeyer, 1986).

Income and patient diagnosis were also significantly associated (Chi-square=10.32, df=4, p=.04). Forty-four percent of those with lung cancer reported incomes less than $20,000 and the most frequent income category for breast cancer patients was the $20,000 to $40,000 range. This finding may reflect national statistics (Health & Welfare Canada, 1986; National Health & Welfare, 1980) indicating that smoking (one of the most predictive risk factors) is more frequent among lower income groups.

A significant association between ethnicity and religion was also observed (Chi-square=41.38, df=8, p=.000, lambda=.42). Eighty-eight percent of Francophone subjects and 58 percent of European subjects were Roman Catholic, compared to 79 percent of British Isles subjects who reported their religion as Protestant.

**Comparison of Subjects Across Care Setting**

The one-sample Chi-square statistic was used to determine if differences existed among subjects from the three care settings due to demographic and the independent variables. For the demographics, significant differences were found
relative to family member's education, age, and religion. In terms of family member's education the significant difference (Chi-square=12.78, df=4, p=.01) was due to the family members from the PCU reporting higher education levels than those from the Home Care programs. Fifty nine percent (n=29) of those in PCU had some post-secondary education or higher compared to 28 percent (n=11) of those in Home Care Program A and 21 percent (n=4) in Home Care Program B.

The significant difference (Chi-square=12.66, df=4, p=.01) among subjects according to their stated religion was due to the fact that 56 percent (n=22) of Home Care A subjects reported their religion as Catholic, compared to 51 percent (n=25) of PCU families and only 11 percent (n=2) of Home Care B subjects. The majority (57.9%) of Home Care B families reported their religion to be Protestant.

In terms of family member's age, the significant difference (Chi-square=8.82, df=2, p=.01) was due to more older (over 65 years) subjects in Home Care setting B. Fifty-eight percent (n=19) of subjects in Home Care setting B were over 65 years of age, compared to only 27 percent (n=51) of PCU families over 65 years of age, and 20 percent (n=39) of family members from Home Care setting A in this age category.

Only one significant difference was found among families in different care settings according to the independent variables specified by the theories. Fourteen of the 16 (74%) family members who rated the importance of their care expectations low, were from the PCU care setting, compared to two in Home Care A and three in Home Care B setting who rated their expectations in this category (Chi-square=6.75, df=2,
Despite these few differences in demographic characteristics and care expectations, no significant differences were found in family care satisfaction ratings, care needs met, importance of family care needs, or family care perceptions across care settings.

**Modeling Assumptions**

The methods used to estimate the extent to which causal modeling and statistical assumptions underlying the use of multiple regression were violated are described in the following section. Residual analysis, an integral part of the theoretical model test (Hinshaw, 1984), was used as one technique to assess for model violations. Residuals, or error terms are that portion of the variance in the dependent variable that is unexplained by the independent variables. The assumptions of a linear regression model are stated about the error terms of the equation (Verran & Ferketich, 1987). Therefore, examination of residuals is a recommended way of testing for assumption violations and has been reported to be an effective aid to the process of model respecification (Daniel & Wood, 1980). As well, results obtained from psychometric assessments of the scales and other statistical tests specific to testing assumption violations were used and are reported here.

Four assumptions underlie causal modeling: 1) all major variables are measured without error, 2) all major variables are included in the model without redundancy, 3) links in the model are linear and additive, and 4) residuals from one
equation are not highly correlated with residuals from another equation in the model (Asher, 1983; Ferketich & Verran, 1984; Verran & Ferketich, 1987).

The first assumption was addressed earlier in the reliability estimates for the measures. Reliability estimates of internal consistency evidenced some measurement error (Table 5). However, as the scales exceeded the minimum criterion level for establishing reliability, this assumption was violated minimally.

The second assumption was assessed in terms of the proportion of explained variance accounted for in the models and lack of multicollinearity of variables entering the regression equations at each stage. It was also expected that the theories specified for testing were sufficiently complete and had been supported by related empirical work to minimize the possibility of a major specification error. Multicollinearity was assessed indirectly by examining the correlation matrices demonstrating the relationship among study variables. High correlations among independent variables can influence results obtained by multiple regression analysis. Multicollinearity may result in attenuated and unreliable regression coefficients between independent and dependent variables, and may prevent calculation of regression coefficients (Gordon, 1968). Correlation matrices demonstrating relationships among study variables were examined as a preliminary screen of the variables for multicollinearity. Table 10 depicts the generated correlation matrix comparing major variables.

The criterion level of $r > .65$ (Gordon, 1968) was used as the criterion for potential multicollinearity. Need fulfillment, Discrepancy, and Expectancy-Value
theories only specified one independent variable; therefore, for these theories, this assumption was not relevant. In the instance of empirical modeling, no independent variables specified in the theoretical models demonstrated correlation coefficients >.65 (PDIFF, F-EXPI, NMETT). However, the Family Care Perceptions variable (FPERT) was one of the components of the PDIFF variable that was highly correlated (.99, p=.001). The management of this instance of multicollinearity is specifically discussed in the empirical modeling section of the chapter. As well, the SPSSx regression procedure that determines the tolerance of the independent variables was used (Norusis, 1983). The tolerance is the proportion of variability in an independent variable not explained by other independent variables already in the model. If either the tolerance of the variable or the tolerance of any variable already in the equation is less than 0.01, a warning is issued and the variable is not entered. The demographic variables were categorical, therefore use of the correlation coefficient to assess multicollinearity was not appropriate and the degree to which they met tolerance is described in the context of each model test.
Table 10  Pearson Correlation Coefficients for Major Independent Variables

<table>
<thead>
<tr>
<th>Major Variables</th>
<th>Family Needs Met</th>
<th>Family Care Expectations</th>
<th>Discrepancy (Expectations - Perceptions)</th>
<th>Family Care Perceptions</th>
<th>Family Care Needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Needs Met</td>
<td>1.000</td>
<td>NS</td>
<td>.43** *(108)</td>
<td>.43** *(108)</td>
<td>.27* *(108)</td>
</tr>
<tr>
<td>Family Care Expectations</td>
<td>1.000</td>
<td>NS</td>
<td>NS</td>
<td>NS</td>
<td>.55** *(109)</td>
</tr>
<tr>
<td>Discrepancy (Expectations - Perceptions)</td>
<td>1.000</td>
<td>.99* *(109)</td>
<td>NS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family Care Perceptions</td>
<td></td>
<td>1.000</td>
<td>NS</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Family Care Needs</td>
<td></td>
<td></td>
<td>1.000</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* Significant at p < .01
** Significant at p < .001
NS Non Significant

The third assumption of linear relationships was assessed by examining the bivariate residual plots generated for each equation against the independent variable with the expectation of random scatter about the residual zero line, and are also discussed later in relation to each model’s theoretical and empirical tests. The fourth assumption, uncorrelated error terms, was assessed directly by looking at the plots of independent variables versus residuals. Neter and Wasserman (1974) stated that independence may be violated when one residual value depends on the value of another (e.g., time, data collection artifacts). In this instance time was not a relevant variable, and no other variable relevant to this assessment was addressed.
Statistical assumptions of the regression equations tested were: 1) the mean of the residuals is zero: assessed by examining the stated mean, 2) the variance of the residuals is equal along the dependent variable: assessed with the expectation of equal scatter in a standardized plot of predicted scores and actual residuals, 3) the independent variables are measured without error, and 4) residuals are normally distributed: assessed by the shape of the curve and histogram of the standardized residuals, (Verran & Ferketich, 1984). Discussion of violated assumptions are specifically reported in relation to each theory tested. Approaches used to handle any assumption violations are described and results of regression analysis reported.

Test of the Alternative Theoretical Models

The initial purpose of this study was to identify which of four alternative competing theories best explains family satisfaction with palliative care. Regression analysis was used to test the predicted relationships addressed in the theories.

fulfillment, Discrepancy and Expectancy-Value theories were evaluated using regression. Social Comparison theory was evaluated using multiple regression with forced entry of variables in the order specified by the staged model.

The regression coefficient indicates the direction and magnitude of the direct influence of a variable hypothesized as the cause of another variable, the effect variable (Asher, 1983). Because the aim was to assess the relative importance of
variables, the standardized regression coefficients (B’s) were examined. The B provides the same scale of measurement for the variables (Pedhazur, 1982).

The adjusted R squareds obtained from the regression analysis were used as the measure of explained variance for the effect variables. The adjusted R squared equalizes the influence of number of cases and allows for the number of independent variables in the regression equation. Adjusted R squareds for the models were compared.

A stepwise multiple regression technique of regressing dependent variables on the independent variables specified in each theory and demographic variables thought to increase the power of the model was used to generate an empirical model based on each theory. Adjusted R squareds for each theoretical model were compared with adjusted R squareds for each augmented theoretical model (demographic variables included).

Finally, as a method of exploration outlined as one study purpose, a stepwise multiple regression technique of regressing dependent variables specified in all four theories on the independent variables specified in all four theories and demographic variables was used to generate an empirical model. The empirical model provides a cross check on the theoretical modeling approach above; it represents parameters determined by computer selection of which independent variables best explain the staged dependent variables. Testing of the overall models involved use of the Chi-square distribution to compare total computed R squared for the overidentified models
which included all variables with the total computed R squared for each of the just identified model.

The significance criterion level for the regression coefficients and explained variance measure was preset at p less than or equal to .05. It is possible with large samples for path coefficients of trivial magnitude to be statistically significant (Ferketich & Verran, 1990). Therefore, coefficients less than or equal to a magnitude of .05 were considered substantively nonsignificant (James, Mulaik, & Brett, 1982; Pedhazur, 1982).

Fulfillment Theory. Evidence for non-violations of causal modeling assumptions related to this model was assessed. The theoretical model resulted in 31 percent explained variance, indicating that other independent variables not included in the model may increase explained variance further. However, Neter and Wasserman (1974) stated that models that can be improved materially by adding one or more independent variables cannot be said to be "wrong", and that only a few of the variables influencing a dependent variable in real-world situations can be explicitly induced in a regression model.

The assumption of linear relationship was assessed by examining residual plots for the equation. Equation residuals were plotted against the independent variable and no evidence of curvilinearity was found. The mean for each error term was zero. This result lends support to the assumption that the proposed relationship is linear (Draper
According to Verran and Ferkeitch (1987), the presence of a zero mean for residuals is essential and violations of this assumption cannot be tolerated.

Violations of the homoscedasticity assumption were assessed by examining the distribution of residuals about zero (Verran & Ferkeitch, 1984). The equal variance assumption was not violated as evidenced by the plot of standardized residuals versus the predicted variable (FAMCARE). The normality assumption was not violated as evidenced by the normal probability plot and histogram plot for the tested equation. Therefore, a judgment was made that no major violations to causal modeling assumptions occurred, and interpretation of the model based on multiple regression results was appropriate.

One multiple regression equation was constructed for the fulfilment theory model. This was: FAMCARE = F-Care Needs Met + e. Figure 4 depicts the parameters specified in the theoretical test and the results.

Stage 1
Family Care Needs Met

Stage 2
B=.56
Family Satisfaction
with Palliative Care
(FAMCARE) adj R^2=.31

Figure 4: Results of Testing of Fulfillment Theory (N=108)

The equation specified met the statistically significant criterion level indicating a moderate positive effect of needs met on care satisfaction (B=.56, adj R^2=.31).
Family care satisfaction (FAMCARE) was then regressed on the demographic variables and NMETT variable using stepwise multiple regression to create an augmented theoretical model. No violation to causal modeling and statistical assumptions were observed as evidenced by histogram plots, normal probability plots, and scatterplots of residuals. The resulting structural equation was: \[ \text{FAMCARE} = (.55) \text{NMETT} + (-.24) \text{Patient Diagnosis} + (-.19) \text{Patient Sex} + e. \] The adjusted R squared for this equation was .37. Significance values for standardized Beta coefficients ranged from <.001 for NMETT to .03 for PSEX. Therefore, inclusion of demographic variables increased the explained variance of the model by six percent.

The standardized scatterplots of independent variables versus residuals revealed a small number of cases that clustered together. In an effort to explore the meaning of this visually identifiable subset, these six cases with standardized residuals > 2.0 were identified and frequencies, t-tests, and chi-square analyses were used to distinguish particular characteristics of this subgroup. These results indicated that demographic factors did not account for differences in the responses of these individuals. However, these individuals did report that a significantly lower number of their care needs were met (t=-2.38, df=106, p<.019). This type of subsample was also observed in tests of subsequent theories and the results are reported later in relation to each theory.

**Discrepancy Theory.** Evidence for non-violations of causal modeling assumptions related to this model was also assessed prior to model testing. This theoretical model resulted in 68 percent explained variance, suggesting that minimal
violation to the assumption that all major variables are included in the model without redundancy occurred. There was no evidence of violation to other assumptions.

Discrepancy theory specifies that the difference between an individual's expectations and perceptions (PDIF) will predict satisfaction (FAMCARE). The multiple regression equation constructed to test this theory was: FAMCARE = PDIF + e. Figure 5 depicts the parameters specified in the theoretical test and the results obtained.

![Diagram](image)

Stage 1

<table>
<thead>
<tr>
<th>Family Care Expectations</th>
<th>Family Care Perceptions</th>
</tr>
</thead>
<tbody>
<tr>
<td>FEXP</td>
<td>FPERT</td>
</tr>
</tbody>
</table>

Stage 2

B = -0.83

Satisfaction (FAMCARE)

adj R² = 0.68

**Figure 5: Results of Testing of Discrepancy Theory (N=109)**

The equation specified met the statistically significant (p<0.05) criterion level indicating a high negative relationship between the two variables (B = -0.83, adj R² = 0.68). The hypothesis that a higher discrepancy between family care expectations and family care perceptions would be associated with lower family care satisfaction was supported.

Family care satisfaction (FAMCARE) was then regressed on the demographic variables and the PDIF variable using stepwise multiple regression to create an augmented theoretical model. Causal modeling and statistical assumptions were not
violated for this analysis as evidenced by histogram plots, normal probability plots, and scatterplots of residuals. The resulting structural equation was:

\[ \text{FAMCARE} = (-.79) \text{ PDIFF} + (-.20) \text{ Marital Status} + (-.12) \text{ Income} + e. \]

The adjusted R squared for this equation was .72. Significance values for beta coefficients ranged from <.001 for PDIFF to .05 for Income. Therefore, inclusion of demographic variables increased the explained variance of the model by four percent.

**Social Comparison Theory.** Evidence for non-violations of causal modeling assumptions related to this model was also assessed prior to model testing. This theoretical model resulted in 71 percent explained variance, indicating that a substantial amount of explained variance was accounted for by the independent variables, and that minimal violation to the assumption that all major variables are included in the model without redundancy occurred.

Equation residuals were plotted against the independent variable and no evidence of curvilinearity was found. The mean for each error term was zero, further supporting the assumption that the proposed relationship is linear. The equal variance assumption was not violated as evidenced by the histogram plot of standardized residuals, the normal probability plot, and the standardized scatterplots. Although there was a slight negative skew to the histogram of standardized residuals, examination of this graph together with the normal probability plot indicated that the normality assumption was not violated. Therefore, the causal modeling and statistical assumptions were not violated, allowing interpretation of the regression results.
Two multiple regression equations were constructed for the Social Comparison Theory. These were: FAMCARE = PDIFF + e and PDIFF = FEXPI + e. The results obtained from testing the first equation resulted in a regression coefficient of -.83 and is identical to the Discrepancy theory model test. When the stage 1 variable, Importance of Family Care Expectations (FEXPI) was included in the regression, the PDIFF regression coefficient remained the same and FEXPI did not enter the equation.

To confirm the hypothesized lack of a direct correlation between Importance of Family Care Expectations (FEXPI) and Family Satisfaction with Palliative Care (FAMCARE), FAMCARE was regressed on FEXPI. A non-significant (p<.05) regression coefficient was obtained, resulting in a total adjusted R squared of .68. These results are shown in Figure 6.

<table>
<thead>
<tr>
<th>Stage 1</th>
<th>Stage 2</th>
<th>Stage 3</th>
</tr>
</thead>
<tbody>
<tr>
<td>Importance of Family Care of Family Expectations NS</td>
<td>Family Care Perceptions (PDIFF)</td>
<td>Family Satisfaction with Palliative Care (FAMCARE) adj R²=.68</td>
</tr>
<tr>
<td>B=-.83</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

B= Standardized Regression Coefficient  
NS= Non Significant

Figure 6: Results of Testing of Social Comparison Theory (N=109)

Family care satisfaction (FAMCARE) was then regressed on the demographic variables and the PDIFF and FEXPI variables using stepwise multiple regression to
create an augmented theoretical model. Causal modeling and statistical assumptions were not violated for this analysis as evidenced by histogram plots, normal probability plots, and scatterplots of residuals. The resulting structural equation was identical to the Discrepancy theory equation generated using empirical modeling: FAMCARE = (-.78) PDIFF + (-.22) Marital Status + e. The adjusted R squared for this equation was .72. Therefore, inclusion of the demographic variables increased the explained variance by four percent.

Exploratory data analysis (Hartwig & Dearing, 1979) was used to examine a noticeable cluster of seven cases with standardized residuals of 2.0 or greater identified on the standardized scatterplot of Importance of F-Care Expectations and residuals. These cases were examined and no demographic explanation could be found for this subsample. However, comparison of this subgroup with the total sample using t-tests indicated that this subgroup achieved lower FAMCARE scores (t=-3.29, df=6.27, p=.016), F-Care Perceptions scores (t=-2.79, df=6.2, p=.030), and had fewer care needs met (-3.73, df=106, p=.000), than the rest of the sample. The implications of identifying this subgroup are discussed in Chapter V in the context of theory building, measurement issues, and clinical implications.

**Expectancy-Value Theory.** Evidence for non-violations of causal modeling assumptions related to this model was also assessed prior to model testing. This theoretical model resulted in an adjusted R squared of .03, suggesting that other independent variables not included in the model may account for explained variance
and that a violation to the assumption that all major variables are included in the model without redundancy occurred.

Some violations to the equal variance assumption occurred as evidenced by the fan shaped distribution of residuals plotted against the predicted scales (FAMCARE) shown on the standardized scatterplot. As well, the normality assumption was violated as shown by the negatively skewed histogram of standardized residuals and normal probability plot. No other violations were evident.

Given the violations to the normality and homoscedasticity assumption, interpretation of the results was not possible and a log transformation was performed and regressions rerun. Causal modeling and statistical assumptions appeared to be supported when the log transformation of the expectancy-value independent variable was used. Consequently, this variable was used in its logged form for subsequent theory testing.

One multiple regression equation was constructed for the Expectancy-Value theory. This was FAMCARE= Σ(F-EXP)(LFEXPI) + e. Figure 7 depicts the parameters specified in the theoretical test and the results obtained.

Stage 1  Stage 2

B=.19

(Log) Importance of Care  Family Care Expectations  Family Care Satisfaction with Palliative Care
Σ (LFEXPI)  (F-EXP)  (FAMCARE) adj R²=.03

Figure 7: Results of Testing of Expectancy-Value Theory (N=109)
The equation indicated a small, but significant direct relationship between the variables ($B=.19; \text{adj } R^2=.03$). The hypothesis that the sum of the product of the importance of family care expectations and family care expectations is positively associated with family care satisfaction was supported.

Family care satisfaction (FAMCARE) was then regressed on the demographic variables and the $\Sigma FEXP (LFEXPI)$ variable using stepwise multiple regression to create an augmented theoretical model. No violations to causal modeling and statistical assumptions occurred as evidenced by histogram plots, normal probability plots, and scatterplots of residuals. The resulting structural equation was: $\text{FAMCARE} = (-.30) \text{Marital Status} + (-.25) \text{Income} + (.22) \text{LFEXPI} + e$. The adjusted $R$ squared for this equation was $.15$. Significance levels for the betas ranged from .004 for Marital Status to .03 for LFEXPI. Therefore, inclusion of demographic variables in the theory testing increased the explained variance by 12 percent.

Seven cases with large standardized residuals were also identified on the standardized scatterplot of F-Care Expectations and residuals, resulting in an uneven distribution around the zero. These cases had lower family care expectations ($t=-5.14$, $\text{df}=6.19$, $p=.002$) and lower importance of family care need scores ($t=-2.91$, $\text{df}=6.30$, $p=.026$), than the rest of the sample.

**Predictions Held in Common.** The predicted negative relationship between the discrepancy between family care expectations and perceptions and family care satisfaction was held in common by Discrepancy Theory and Social Comparison
Theory. This prediction was supported by a strong negative relationship (B=-.83) that contributed to 68 percent of the explained variance in care satisfaction.

**Generation of the Family Care Satisfaction Empirical Model**

The purpose of this phase of the analysis was to combine the predictions of the four theories to identify if a more explanatory model that makes substantive sense would emerge. Evidence for non-violations of causal modeling assumptions related to this model was also assessed prior to model testing. This theoretical model resulted in 78 percent explained variance. This high explained variance indicates that the assumption that all major variables are included in the model without redundancy was minimally violated.

The assumption of linear relationships was assessed by examining residual plots for each equation. Equation residuals were plotted against the independent variable and no evidence of curvilinearity was found. The assumption of uncorrelated error terms of model equations, was violated because PDIFF and FPERT were highly correlated (r=.99, p=.000). FPERT is a subvariable used in the calculation of PDIFF, making this high correlation predictable. Therefore, the simplest variable (FPERT) was selected for use in the empirical modeling phase. Eleven of the demographic variables exceeded the tolerance specification for multicollinearity and did not enter the equation.
The equal variance assumption was violated for the FEXPI variable when regressed on FNEEDT, as evidenced by the histogram plot of standardized residuals, the non-normal probability plot, and the funnel shaped distribution of residuals on the standardized scatterplots. The normality assumption was also violated for the FEXPI variable when regressed on FNEEDT, as evidenced by the normal probability plot and histogram plot for the tested equation.

These violations indicated that interpretation of the results was not possible, therefore, a log transformation was performed and regressions were rerun to examine the causal modeling and statistical assumptions underlying use of regression. This transformation produced residual means of zero, a normal distribution of residuals as evidenced by probability plots and histograms. The standardized scatterplot for the Log of FNEEDT variable demonstrated a distribution more evenly distributed around zero. Therefore, the causal modeling and statistical assumptions were not violated when the transformed variable was entered and the LFNEEDT variable was used for subsequent theory testing. Given that the log transformation of FNEEDT was specified in testing stage 1 and stage 2 equations, the log transformed variable was used for testing in both stages.

An empirical family care satisfaction model was generated from the data using multiple regression (Figure 8). No variables were predicted to precede stage 1 variables, therefore no findings are generated at this stage.
Figure 8: Empirical Model. Factors Influencing Family Satisfaction with Palliative Care (N=109).

Test 1 Results of the first test represent testing of hypothesized links in the model. The first equation tested aimed to examine whether the log of importance of family care needs would predict the importance of family care expectations. The second equation tested aimed to examine whether the transformed variable, log of importance of family care needs and family care perceptions would explain the extent to which
care needs were fulfilled. The third equation was structured to test the extent to which fulfillment of care needs, importance of care expectations, family care perceptions, and the demographic variables would increase the explained variance in family care satisfaction. Three structural equations resulted from the following operations:

1. stepwise entry of importance of family care expectations on the log of importance of family care needs (Stage 1);
2. stepwise entry of fulfillment of family care needs (Stage 2) on log of importance of family care needs and family care perceptions (Stage 1); and
3. stepwise entry of family satisfaction with palliative care (Stage 3) on fulfilment of care needs, importance of family care expectations, family care perceptions, and demographic variables (using dummy coding).

The resulting structural equations were:

1. \( \text{FEXPI} = (0.47) \text{LFNEEDT} + e \)
2. \( \text{NMETT} = (0.44) \text{FPERT} + 0.30 \text{LFNEEDT} + e \)
3. \( \text{FAMCARE} = (0.68) \text{FPERT} + (0.25) \text{NMETT} + (-0.18) \text{MARITAL STATUS} + (0.12) \text{FEXPI} + e \)

The first equation explained 21 percent of the variance in importance of family care expectations. The second equation explained 27 percent of the variance in fulfilment of family care needs. The total explained variance resulting from the third equation was 78 percent of the variance in family care satisfaction.
Test 2 In this phase of testing, hypothesized zero relationships in the model were tested using the data. All of the hypothesized zero links were confirmed. These included the relationships between demographic variables and Need fulfillment and the relationship between Log of Importance of Family Care Needs and Need fulfillment. Table 11 shows the order of entry and relative contribution of each independent variable to explanation of family care satisfaction.

Table 11 Order of Entry and Relative Contribution of Each Independent Variable Entering by Stepwise Regression on Family Care Satisfaction (n=109)

<table>
<thead>
<tr>
<th>Independent Variable in Order of Entry</th>
<th>Beta</th>
<th>Multiple R</th>
<th>FR² Change</th>
<th>R² Change</th>
<th>F</th>
<th>Adjusted R²</th>
</tr>
</thead>
<tbody>
<tr>
<td>Family Care Perceptions (FPERT)</td>
<td>.68**</td>
<td>.83</td>
<td>190.26**</td>
<td>.69**</td>
<td>106.13**</td>
<td>.69**</td>
</tr>
<tr>
<td>fulfillment of Care Needs (NMETT)</td>
<td>.25**</td>
<td>.86</td>
<td>16.43**</td>
<td>.05**</td>
<td>14.43**</td>
<td>.74**</td>
</tr>
<tr>
<td>Marital Status (MARITAL)</td>
<td>-.18**</td>
<td>.88</td>
<td>9.04**</td>
<td>.03**</td>
<td>7.01*</td>
<td>.76*</td>
</tr>
<tr>
<td>Importance of Family Care Expectations (FEXPI)</td>
<td>.12*</td>
<td>.89</td>
<td>5.85*</td>
<td>.02*</td>
<td>4.98*</td>
<td>.78*</td>
</tr>
</tbody>
</table>

** significant at p<.001     * significant at p<.05
Table 12 indicates the total direct and indirect causal effects of independent variables on their respective dependent variables. The means, standard deviations and variances of the variables are shown in Table 13.

Table 12  Family Care Satisfaction Model Effects

<table>
<thead>
<tr>
<th></th>
<th>Direct Effect</th>
<th>Indirect Effect</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>FEXPI</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>LFNEEDT</td>
<td>p51=.47</td>
<td></td>
<td>.47</td>
</tr>
<tr>
<td><strong>NMETT</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>LFNEEDT</td>
<td>p61=.30</td>
<td></td>
<td>.30</td>
</tr>
<tr>
<td>FPERT</td>
<td>p62=.44</td>
<td></td>
<td>.44</td>
</tr>
<tr>
<td><strong>FAMCARE</strong></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>NMETT</td>
<td>p76=.25</td>
<td></td>
<td>.25</td>
</tr>
<tr>
<td>FPERT</td>
<td>p72=.68</td>
<td>p76X6.p62X2=.11</td>
<td>.79</td>
</tr>
<tr>
<td>MARITAL</td>
<td>p73=-.18</td>
<td></td>
<td>-.18</td>
</tr>
<tr>
<td>FEXPI</td>
<td>p75=.12</td>
<td></td>
<td>.12</td>
</tr>
</tbody>
</table>

All coefficients significant at p<.01
Table 13  Descriptive Statistics for Family Care Satisfaction Model

<table>
<thead>
<tr>
<th>Variable</th>
<th>Mean</th>
<th>Standard Deviation</th>
<th>Variance</th>
</tr>
</thead>
<tbody>
<tr>
<td>NMETT</td>
<td>14.05</td>
<td>4.92</td>
<td>24.16</td>
</tr>
<tr>
<td>FPERT</td>
<td>76.80</td>
<td>13.29</td>
<td>176.64</td>
</tr>
<tr>
<td>FEXPI</td>
<td>150.34</td>
<td>14.16</td>
<td>200.61</td>
</tr>
<tr>
<td>LFNEEDT</td>
<td>5.13</td>
<td>.26</td>
<td>.07</td>
</tr>
<tr>
<td>MARITAL</td>
<td>1.17</td>
<td>.38</td>
<td>.15</td>
</tr>
<tr>
<td>FAMCARE</td>
<td>72.97</td>
<td>14.23</td>
<td>202.42</td>
</tr>
</tbody>
</table>

Plots of residuals against FEXPI and LFNEEDT suggested that a small set (7) of cases with standardized residuals > 2.0 might be present. These cases were identified and frequencies, t-tests, and chi-square analyses were used to identify distinguishing characteristics of this subgroup. These results indicated that demographic factors did not account for differences in the responses of these individuals. However, these individuals did report significantly lower importance of family care needs scores (t=-2.91, df=6.30, p=.026) and lower family care expectations (t=-5.14, df=6.19, p=.002), than the remainder of the sample.

Plots of residuals against NMETT and LFNEEDT revealed a small set (4) of cases with standardized residuals > 2.0. These cases were identified and frequencies, t-tests, and chi-square analyses were used to identify distinguishing characteristics of this subgroup. No demographic explanation could be found to interpret these cases either. However, these individuals did report significantly lower importance of family
care perception scores ($t=1.97$, df=107, $p=.051$), lower family care expectations ($t=6.374$, df=84.38, $p=.000$), and had fewer of their care needs met ($t=-15.32$, df=14.60, $p=.000$), than the remainder of the sample. Only one case was common to these two subgroups with large standardized residuals.

**Analysis of Unusual Cases**

Exploratory data analysis techniques can be useful in detecting different types of underlying data structures (Verran & Ferketich, 1987). The emphasis of EDA is on using visual displays to reveal vital information about the data being examined (Hartwig & Dearing, 1979). This technique was used to help interpret the visually apparent cluster of subjects with lower scores on a number of variables reported earlier in the context of each theory's model testing.

In total, 21 cases with standardized residuals greater than 2.0 were identified and described. Ten of these subjects appeared in two different subsets. No demographic explanations were found for the subsets identified in each theory or for the combined 21 cases. However, a significantly lower number of care needs were met for the total group of 21 ($t=-3.79$, df=24.19, $p=.001$), their importance of care needs were lower ($t=-2.33$, df=22.96, $p=.029$), their importance of care expectations scores were lower ($t=-2.12$, df=21.74, $p=.045$), and their care satisfaction ratings were lower ($t=-2.77$, df=23.16, $p=.011$), than were reported by the remainder of the sample. The implications of these findings are notable and are discussed in Chapter V.
Comparison of Alternative Explanations for Family Satisfaction with Palliative Care

Stinchcombe (1968) provided a method for comparing the results of multiple tests of theories, whereby empirical data are used to estimate the credibility of a theory. Table 14 uses Stinchcombe’s comparative method to illustrate the relative credibility of the four competing theories.

Table 14 Comparison of Supported and Not-supported Hypotheses from Alternative Explanations of Family Satisfaction with Palliative Care

<table>
<thead>
<tr>
<th>Alternative Theories</th>
<th>Hypotheses</th>
</tr>
</thead>
<tbody>
<tr>
<td>fulfillment Theory</td>
<td>1 Supported</td>
</tr>
<tr>
<td>Discrepancy Theory</td>
<td>2 Strongly Supported</td>
</tr>
<tr>
<td>Social Comparison Theory</td>
<td>3a Strongly Supported 3b Not Supported 3c Supported</td>
</tr>
<tr>
<td>Expectancy Value Theory</td>
<td>4 Supported</td>
</tr>
</tbody>
</table>

Key:  ■ Common Hypotheses

The fulfillment theory hypothesis was supported. The data from the testing provide weak, but significant support for the Expectancy-Value theory. Discrepancy theory was supported strongly in the test of the hypothesis arising from this model. Social comparison theory was supported in part. The hypothesis (3a) specifying that
the discrepancy between care expectations and perceptions is negatively associated with satisfaction ratings was supported strongly. The hypothesis (3b) specifying an indirect effect of care expectations on care satisfaction was not supported. The third hypothesis (3c) specifying no direct effect of care expectations on care satisfaction was also supported.

According to the criteria preset in Chapter II, a model that explains 20 percent of the variance in the dependent variable is considered clinically useful and a minimum difference of 10 percent between models was specified as the criterion on which to accept one model over another. Need fulfillment theory, Discrepancy theory, and Social Comparison theory all met the criterion of explaining at least 20 percent of the variance in family care satisfaction. Social Comparison theory and Discrepancy theory both explained 68 percent of the variance in family care satisfaction. These two theories explained 37 percent more of the variance than did the Need fulfillment model, and 65 percent more of the variance than Expectancy-Value theory, before inclusion of demographic independent variables. Comparison of models with demographic variables included reinforced these results. Discrepancy theory and Social Comparison theory explained 57 percent more than Expectancy-Value theory, and 35 percent more than Need fulfillment theory. Need fulfillment explained 22 percent more than Expectancy-Value theory with demographic variables included. Therefore, given the similarities between Social Comparison and Discrepancy theory and the fact that Social Comparison theory also required that subjects respond to a third questionnaire,
contributing further to subject burden, Discrepancy theory is judged to most parsimoniously account for the greatest explained variance in the dependent variable among the four alternative theories tested.

Although factors from one particular theory, Discrepancy theory, were found to more credibly account for family care satisfaction when compared with factors identified by other theories, some significant factors from other theories also contributed to the explication of family care satisfaction. The combination of these factors into one model provided the parameter estimates of the Family Care Satisfaction Model.

The Family Care Satisfaction Model demonstrated that family care perceptions was the strongest predictor of family care satisfaction and that this variable, which was included in the computation of the discrepancy score, was actually the factor that determined the explained variance. Inclusion of the variables, log of family care need fulfilment and importance of family care expectations increased the explained variance in the dependent variable as evidenced by a combined $R^2$ squared change of .06. As well, the demographic variable marital status entered the regression equation above the Beta coefficient preset as primarily acceptable (> .05) and at the significance level specified ($p<.05$). The total explained variance for this model was 78 percent.
**Test of Overidentified Models**

The reproduction of correlation coefficients is an effective means of examining the validity of a causal model, however, the technique does not provide a test of the total model in relation to the total justified model (Ferketich & Verran, 1990). A test of the overall model involves use of the Chi-square distribution to compare total computed R squared for the overidentified model with the total computed R squared for the just-identified model (Pedhazur, 1982). This test was done to compare all theoretical models with the just-identified model.

Table 15 shows the R squared computations for the Discrepancy, Social Comparison, and Need Fulfillment models which met the criterion for substantive meaning. Comparison of the W’s for the Discrepancy model, Social Comparison model, and Need fulfillment model with and without demographic variables included compared to the just-identified model, indicate that in all these tests the null hypothesis of no difference between models is rejected at p<.01. Even though the results indicate a significant difference, the Q values for the Discrepancy and Social Comparison models are quite high (.69-.79). The closer Q is to 1.00, the better the fit of the model to the data. These results, together with the theoretical rationale for these models, indicate that the models are still supported by the data. The difference in explained variance between both the Discrepancy theory and Social Comparison theory and the empirically generated model, Family Care Satisfaction Model, is 10 percent (with demographic variables the difference is 8 percent). This meets the minimal
preset criterion for accepting one model over another. Therefore, on the basis of these comparisons, the empirical model was judged to be the most credible.
Table 15  Calculation of Chi-Square Statistics for Fit Between Overidentified and Just Identified Models

Equation:

\[ R^2 = 1 - (1 - R^2) \ldots (1 - R^2_n) \]

\[ Q = \frac{1 - R^2_{jc}}{1 - R^2_{oc}} \]

\[ W = -(N - d) \log Q \]

<table>
<thead>
<tr>
<th>Model</th>
<th>$R^2$ (with demographics)</th>
<th>$Q$ (with demographics)</th>
<th>$W$ (with demographics)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Just Identified</td>
<td>$R^2_{jc} = 1 - (1 - .78) = .78$</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td>$Q = \frac{1 - .78}{1 - .68} = .69$</td>
<td>$W = 17.74 \text{ df=1}$</td>
</tr>
<tr>
<td></td>
<td></td>
<td>($Q = \frac{1 - .72}{1 - .72} = .79$)</td>
<td>($W = 11.42 \text{ df=1}$)</td>
</tr>
<tr>
<td>Discrepancy</td>
<td>$R^2_{oc} = 1 - (1 - .68) = .68$</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>($R^2_{oc} = 1 - (1 - .72) = .72$)</td>
<td>$Q = \frac{1 - .78}{1 - .68} = .69$</td>
<td>$W = 17.74 \text{ df=1}$</td>
</tr>
<tr>
<td></td>
<td></td>
<td>($Q = \frac{1 - .72}{1 - .72} = .79$)</td>
<td>($W = 11.42 \text{ df=1}$)</td>
</tr>
<tr>
<td>Need Fulfillment</td>
<td>$R^2_{oc} = 1 - (1 - .31) = .31$</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>($R^2_{oc} = 1 - (1 - .37) = .37$)</td>
<td>$Q = \frac{1 - .78}{1 - .31} = .32$</td>
<td>$W = 54.11 \text{ df=1}$</td>
</tr>
<tr>
<td></td>
<td></td>
<td>($Q = \frac{1 - .72}{1 - .37} = .35$)</td>
<td>($W = 49.80 \text{ df=1}$)</td>
</tr>
<tr>
<td>Social Comparison</td>
<td>$R^2_{oc} = 1 - (1 - .68) = .68$</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>($R^2_{oc} = 1 - (1 - .72) = .72$)</td>
<td>$Q = \frac{1 - .78}{1 - .68} = .69$</td>
<td>$W = 17.74 \text{ df=1}$</td>
</tr>
<tr>
<td></td>
<td></td>
<td>($Q = \frac{1 - .72}{1 - .72} = .79$)</td>
<td>($W = 11.42 \text{ df=1}$)</td>
</tr>
</tbody>
</table>
Match of Theoretical and Empirical Models

The theoretical and empirical models were matched to determine which theory related hypotheses generated the factors that accounted for family satisfaction with palliative care. In terms of specific factors, the regression analysis revealed the following:

1. Family care perceptions have both a direct and indirect positive effect on family satisfaction with palliative care,
2. The extent to which family care needs are perceived as met has a direct effect on family satisfaction with palliative care,
3. The discrepancy between family care expectations and family care perceptions has a direct negative effect on family satisfaction with palliative care,
4. The importance of family care expectations has a small but significant effect on family care satisfaction, and
5. Marital status has a small but significant effect on family care satisfaction.

The purpose of the study, to use theoretical and empirical modeling to identify the model that best explains family satisfaction with palliative care as an outcome of terminal cancer in one member, was achieved. Discrepancy theory was the theoretical model that best accounted for care satisfaction. As well, an empirical model of family satisfaction with palliative care, was generated. In separating the discrepancy variable for inclusion in the empirical model testing, family care perceptions was found to account for care satisfaction as well. One variable from fulfillment theory, Need
fulfillment, and one from Expectancy-Value theory, Importance of Family Care Expectations, also entered into the regression significantly, providing further explication of the dependent variable. The empirical model demonstrated that family members’ perceptions of care will affect their satisfaction with care and the greater they perceive their care needs as being fulfilled, the more satisfied they will be with care.

Construct Validity Through Predictive Modeling

Construct validity for the variables was assessed through predictive modeling in which the regression coefficients were used to determine the existence and direction of relationship between variables (Hinshaw, 1978). If one relationship between variables was found to exist as predicted and if the direction of the relationship was as predicted, evidence for construct validity was accepted. The predicted relationships are shown in Figure 2 and Figure 9 depicts the relationships that were supported.

Initial construct validity for the discrepancy, need fulfillment, and expectancy-value independent variables (sum of the products of expectations and importance of expectations) was established based on the empirical support for the predicted relationships.
Figure 9: Relationships Among Major Study Variables Supported by Predictive Modeling Results (N=109)

\[ B = 0.56 \]

```
Need Fulfillment (NMETT) \rightarrow Family Satisfaction with Palliative Care (FAMCARE)
```

\[ B = -0.83 \]

```
Discrepancy Variable (PDIFF = FEXP - FPERT) \rightarrow Family Satisfaction with Palliative Care (FAMCARE)
```

\[ B = 0.19 \]

```
Expectancy-Value Variable \rightarrow Family Satisfaction with Palliative Care (FAMCARE)
```

Summary

A description of the sample on which the theoretical model was tested was presented. The sample of N=109 represented a 59 percent response rate. Some sources of selection bias were discussed. Results of the residual analysis used to test violations of causal modeling and statistical assumptions were presented. The few violations of causal modeling or statistical assumptions were addressed satisfactorily which allowed regression analyses to proceed. Results of the regression analysis testing both theoretical and empirical models were presented. Of the four theories tested, Discrepancy theory was the most credible, explaining 68 percent of the variance in family care satisfaction. Empirical modeling resulted in identification of the Family Care Satisfaction Model, which explained 78 percent of the variance in care
satisfaction. The theoretical and empirical models matched in their predicted relationships. Construct validity for the five major variables was assessed through predictive modeling and the findings discussed. Of the nine predicted paths for the five variables, eight were validated.
CHAPTER V

INTERPRETATIONS, IMPLICATIONS AND RECOMMENDATIONS

Findings from the data presented in the previous chapter are discussed relative to limitations, methodological issues, theoretical issues, and implications for theory construction and clinical practice. Of particular note are a small group of subjects whose standardized residuals were greater than 2.0, who expressed lower satisfaction ratings, lower importance of care needs scores, lower care expectations, and had fewer care needs met. The theoretical, sampling, and clinical issues raised by this finding are especially provocative. Recommendations for further study are included.

Limitations

In summary, the limitations of the study that were addressed throughout this document included threats of mono operation bias and methods, imperfect measurement, random irrelevancies in study circumstances, random heterogeneity in the sample, a cross-sectional design accessing data at only one point in time, and spurious influence of unknown variables. Because one assumption of the causal modeling design is that concepts be measured without error, the most critical limitation was the immaturity of the scales. In many ways, the measures themselves were on trial as much as the theories represented. However, given the qualitative
foundation of the conceptual phase and instrumentation, the careful specification of
ccepts, and respectable psychometric results obtained on the instruments, the study
provided a reasonable assessment of the tested theories. As well, given the difficulties
associated with accessing the population under investigation, analyzing the data in as
thorough a manner as possible, to elicit the most complete knowledge from the effort
seemed prudent. The researcher also acknowledges that this investigation represents the
first of many studies that will approach continued reliability and validity estimation
and theory testing through replication.

A future research possibility that seems logical would be the use of latent
variable analysis to address some of the problems of measurement error identified in
the study. However, given the fact that the scales are not designed as latent variables,
each item would have to be used as an indicator of its latent variable (Figure 1),
necessitating an inordinately large sample. Access to this population is a challenging
feature of this type of research, making the recruitment of large samples problematic.
According to Dorsey (1991), a simulation study of the LISREL model resulted in
incorrect models being accepted (alpha=.05) slightly over half the time for a sample of
50 with two endogenous and two exogenous variables, and about one third of the time
when samples of 100 were used. Given these recent results, the size of the sample
required for a model with approximately 80 variables (each scale contains
approximately 20 items) in order to be sure of any degree of accuracy, would be
unwieldy. Therefore, efforts to use structure equation models would be undertaken cautiously and with the practical limitations of accessing the sample in mind.

**Interpretation of the Findings**

**Methodological Issues.** All instruments had been used in relatively few studies with modest but appropriate samples. The FAMCARE Scale and the F-Care Perceptions Scale had been previously pilot tested for criterion validity, stability over time, and internal consistency with a small sample. These results provided strong preliminary evidence for the psychometric value of the scales. The F-Care Needs Scale and the F-Care Expectations Scale had been pilot tested for content validity, apparent internal consistency, and clarity with a panel of bereaved family members. The findings from this investigation also supported the validity and apparent internal consistency of the tools.

Psychometric assessment of the scales with this study’s data provided further evidence for the validity and reliability of the instruments. The FAMCARE Scale and F-Care Perceptions Scale achieved high internal consistency estimates, with minimal redundancy. Factor analysis results of the combined scales, together with the calculation of percent of concordance among items on the two scales suggest that these concepts were regarded as distinct by subjects.

The F-Care Needs Scale and F-Care Expectations Scale also met the pre-specified criteria for reliability and validity assessments. Low variability on both scales
was noted however, suggesting that the scales did not evidence sensitivity. An alternative interpretation of this data is that the scales were too sensitive. In other words, these families may truly be those with high care needs and high care expectations. The distinctions offered by the scale may not represent the true variability in this population with respect to these concepts, and knowing that these families have extreme care needs and care expectations in itself, may be clinically significant. As well, factor analysis results indicated that subjects did distinguish needs from expectations.

Both the Need fulfillment portion of the F-Care Needs Scale and the existence of a care expectations portion of the F-Care Expectations Scale were formatted as dichotomous variables. In other words, subjects were asked to indicate whether or not a need was met or not met, after rating the importance of the care need. As well, subjects were asked to rate the importance of care expectations from zero to 10, with zero being no expectation and 10 being a high expectation. The existence of an expectation was dichotomized by a score of one or higher indicating that an expectation existed and a zero response taken to indicate no expectation. The outcome of this method of operationalizing the variables was a 99 percent completion rate of questionnaires by consenting respondents. However, it is possible that these two variables are more accurately represented as continuous ones, and better addressed with response options allowing a difference in degree of expectations or extent to
which a care need was met. A balance with response burden would need to be considered.

The most problematic aspect of this instrumentation choice was the decreased ability to test the Expectancy-Value Theory. This theory posits that the sum of the product of expectations and importance of expectations will predict satisfaction. When the first variable, care expectations was measured as a dichotomous variable, testing of the particular equation specified by Ajzen and Fishbein (1980) was limited. However, according to Pedhazur (1973), when one of the variables is categorical and the other is continuous, the test of the interaction addresses the question whether the regression lines of the dependent variable on the continuous variable are parallel for all the categories of the categorical variable. Although the theory was supported by the study data, the explained variance was low (.03), suggesting that further refinement of the concepts and their measurement is worthwhile.

In reviewing previous empirical work that tested Expectancy-Value theory, conflicting results have been reported (Linder-Pelz, 1982b; Ware et al., 1984). Some of the differences have been explained as problems of operationalizing the variables, clouding interpretation of the actual tests of the theory. Therefore, although some problems in this study could have occurred because care expectations was scaled as a categorical variable and because of low variability on the importance of care expectations scale, difficulties encountered in operationalizing these concepts are not unique and represented the best compromise for this study.
Of importance for nursing, may be the question about the extent to which family members can actually distinguish these variables. Theoretically, the distinctions between expectations and importance of expectations may be real, and can be represented as continuous variables; but clinically, the distinctions may not be as sharp and perceptions of these experiences may blur the boundaries. This is not to say that family members cannot provide useful perspectives on these phenomena, but that the meaning of these concepts for families may be distinguished by different parameters. The need for further study to identify clinical criteria with which to reference these indicators appears warranted.

Another finding in the empirical modeling phase of the research was that family care perceptions alone contributed as much explained variance to family care satisfaction as did the discrepancy variable (expectations minus perceptions). This again, may have been due to the low variability obtained on the care expectations scale. Further testing with subsequent samples in different settings, with attention to scaling of the expectations scale is required to substantiate this finding.

Another methodological issue involves the unit of analysis chosen in studies of family research. In this study, the viewpoints of family members were selected as the unit of analysis, and data collection tools and analysis methods were consistent with this definition. Previous literature has used individual family members, spouses, and primary caregivers as the unit of analysis. Family members have been asked to measure the patient's satisfaction with care using instruments designed for patients.
Other researchers have used patient satisfaction tools to assess family members’ satisfaction ratings. This creates potential problems because there is evidence that patients and families may disagree in terms of perceptions and satisfaction with care. Also, criticisms may be mounted toward those who use scales designed for one population (patients) to measure another (family members).

Despite the challenges involved with measuring the family as a unit, systems theory postulates that the family is greater than the sum of its parts (von Bertalanffy, 1968), suggesting that a different perspective would be obtained by a total family measurement. Use of strategies such as focus group interviewing might be a fruitful way of obtaining more complete information consistent with the family as a unit of measurement. To date, the use of focus groups by nurses has been limited (e.g., Flaskerud & Rush, 1989; Nyamathi & Shuler, 1990). However, this research method might provide an interesting and useful way of obtaining the perspective of the family unit, regarding satisfaction with care. Although these results could not be employed in a theory testing model, the findings might provide useful insights that would “round out” understanding of families in these situations, and be the basis of further instrument development.

A particular methodological strength of the study was the demonstration of the efficiency of alternative theory testing as a means of eliminating alternative theories and generating new theory. Stinchcombe (1968) described the basic logical process of science as one involved in elimination of alternative theories by competitive
investigation of as many empirical consequences of each theory as is practical. The utility of the crucial experiment of critical test was also demonstrated by this study. The crucial experiment as described by Stinchcombe (1968) is a description of a set of observations that would decide between two or more alternative theories, any of which according to present knowledge are quite possible explanations. The critical test incorporated in this study allowed determination of Discrepancy theory as the most credible single theory explicator of family care satisfaction. The testing of four different explanations for family care satisfaction resulted in generation of a new Family Care Satisfaction Model that based its explication of family care satisfaction on complimentary factors found significant across the four theories.

Theoretical Issues. Both Linder-Pelz (1982b) and Fox and Storms (1981) also reported support for Discrepancy theory when testing patient satisfaction with health care. As well, these findings support the theoretical and empirical work on Need fulfillment theory by Schaffer (1953), Morse (1953), and Vroom (1964). These investigators argue that satisfaction will vary directly with the extent to which those needs of an individual which can be satisfied, are actually satisfied; the stronger the need, the more closely will satisfaction depend on its fulfillment.

One study more directly related to health care satisfaction reported negative results. Linder-Pelz (1982b) tested Need fulfillment theory with a prospective design using a convenience sample of 125 patients in an out-patient clinic. Although her
results did not support Need fulfillment theory and are cause for caution, an error in operationalizing the need fulfillment variable may have accounted for the findings.

Despite the emergence of a single most credible theory, the phenomenon of family care satisfaction was better understood by incorporating complimentary relationships depicted in the empirically generated Family Care Satisfaction Model (Figure 8). The theoretical and empirical work in the area of need fulfillment theory was again supported in the empirical model generated. Care perceptions and the importance of care needs explained 27 percent of the variance in need fulfilment. Before a family member can make a judgment about the extent to which care needs are met, the individual considers the care provided together with the importance of their care needs. The theoretical work by Thibaut and Kelley (1959) supported the finding that fulfilment of needs is not the only predictor of care satisfaction, and that a judgment about the importance of those needs and perceptions about actual care received contributes to a satisfaction rating.

The relationship between importance of family care needs and importance of family care expectations is also supported by the work of Morse (1953). Morse (1953) reported that workers modify their judgments about job satisfaction not only in relation to their needs, but also according to their perceptions about what is possible (expectations) in a given situation.

Family care perceptions was identified as the strongest predictor of care satisfaction. Therefore, an individual’s awareness of the details of care provided was
the best indicator of their satisfaction. In previous research (Oberst, 1984) perceptions of care has been used as an index of care satisfaction. This study separated the two concepts, examined the distinctions subjects made between these, and concluded that although they are highly related, the concepts are theoretically and practically distinct.

The newly emerged Family Care Satisfaction Model was sufficiently supported in this initial test to provide a basis for further theory testing exploration. Interpretation of the findings relative to theoretical issues, although requiring caution in making definitive conclusions, generated a wealth of theory building material for future research projects.

**Implications for Theory Construction**

The predicted and unpredicted findings from this study are useful for further theory development and testing. Some modifications in operationalizing variables in the theories were proposed in the discussion of methodological issues raised by this study. Modifications to existing theory as proposed by the Family Care Satisfaction Model empirically generated in this study are expected to emerge as additional scientifically based information becomes available on the variables investigated by this study and on the population addressed by this study.

Modifications, as proposed, have the potential to increase the precision in predicting family care satisfaction, and add to nursing knowledge through elimination
Implications for Clinical Nursing Practice

Recent perspectives on cancer and the family regard the family not only as the principal source of support for the sick but also as the unit that faces the disease (Giacquinta, 1977; Tiblier, 1989). Tiblier (1989) calls for research that would aid in assessment of the psychologic and sociologic impact of cancer on the family and reveal which families are at greatest risk for some dysfunctional pattern or outcome. The identification of a small subgroup of less satisfied families within this sample may be the most clinically useful, and called for, piece of information. There may be a small group of families who have perceptions of care as poorer and perceive that few of their care needs are met. This group may be at greater risk for dysfunctional family patterns or unhealthy outcomes. Subsequent study to investigate FAMCARE ratings as a predictor of family functional status during and after the illness episode is indicated.

A central clinical question arises from the empirical modeling results of this study. Given the finding that family care perceptions is the strongest predictor of family care satisfaction, how do clinicians intervene to influence family care perceptions?

Examination of items on the family care perceptions scale suggests that access to care information, inclusion of the family in the care experience, and attention to the
patient's comfort needs are the actions best implemented by health professionals who aim to improve family care perceptions.

Responses to the F-Care Needs Scale also suggest that liberal access to disease and treatment information, knowing the patient is monitored, understanding the prognosis, and having the opportunity to develop a relationship with health professionals are factors that contribute to care satisfaction. A central determinant of satisfactory family care may be the quality of communication between families and health professionals. Researchers to date have concentrated primarily on the patient in studies about care communication, and, for the most part, communication with family members has either been secondary or has been overlooked altogether (Northouse & Northouse, 1988). However, one of the commonly reported communication issues that families of cancer patients face, is the problem of acquiring information (Kristjanson, 1986, 1989; Morrow, Hoagland, & Morse, 1982; Skorupka & Bohnet, 1982; Welch, 1981; Wright & Dyck, 1984). Families want information about the diagnosis, prognosis, treatment options, and expected course of recovery to lessen their fears and increase their sense of predictability.

A major obstacle to information access is the limited contact that families have with health professionals due to timing of family visits in hospital and the confidence of families to initiate an exchange (Bond, 1982a, 1982b; Krant & Johnson, 1977-78, Northouse & Northouse, 1988). In most instances the onus is on the family to seek information. Some family members report feeling awkward about approaching a busy
physician for information that may already have been given to the patient (Krant & Johnson, 1977-78). When little contact occurs between professionals and family members, family members must rely on indirect routes to obtain information - that is, they must rely on the patient or other members of the family for information and are unable to seek clarification, correct misassumptions, or develop rapport with health professionals. This "second-hand" relationship reinforces a belief that families are peripheral and tangential to the treatment process (Northouse & Northouse, 1988).

The results from this current research, together with the substantial amount of literature related to families' needs for information, suggest that further studies to determine whether or not families want information related to the care experience are not needed. Families of cancer patients want clear, specific, practical information given openly and in large amounts. However, research about how to improve communication with families so that their needs for information can be met appears to be needed. And clinicians might take seriously the findings that do exist and examine barriers to information flow with families in clinical settings.

As well, this study, although not to be taken as conclusive evidence, did provide some clinically relevant insights that, with replication, could provide direction for palliative care. The work provided a description of the responses of families to questions concerning their perceptions of palliative care. Such a comprehensive and theoretically based description has not been previously reported. This information may reinforce to clinicians that families of terminally ill cancer patients identify a
considerable number of care needs that they rate as extremely important to them. Articulation and specification of these care needs may be helpful to clinicians who can then direct care interventions more specifically.

In addition, the finding that families hold high expectations of health professionals is valuable information. The emphasis by families on the caring behaviors of health professionals indicates that families pay attention to the care provided by health professionals and confirms the importance of including and considering families in the care experience. As well, knowing which care expectations in particular are most critical to families may be helpful in planning more personalized family care.

The findings that fulfilment of care needs and the discrepancy between care expectations and care perceptions are predictors of family care satisfaction is also useful information. Recognition of the importance of fulfilment of family care needs may encourage health professionals to legitimize and emphasize families' needs to a greater extent.

The importance of care perceptions also directs health professionals to provide information to families about the care provided. The importance of meeting the comfort needs of the patient is also reinforced by this finding, as it is a major component of the care perceptions and care satisfaction scales.
The results of the Family Care Satisfaction Model are promising. If the model continues to demonstrate credibility in future investigations, the possibility of identifying and testing interventions to increase family care satisfaction will develop.

A limitation of previous research is that often only one family member is included in the study and generalizations are made to other family members based on these results. Difficulties may occur when clinicians use this research as a basis for practice and assume that family members are more alike in their views than may actually be the case. Findings from this study suggest that being married, for example, decreases satisfaction to a small, but significant extent ($B=-.18$, $p=.01$). Although this finding must be replicated, this result may alert clinicians to the importance of assessing care needs, expectations, perceptions and satisfaction ratings for different family members.

And finally, the refinement of instruments used in the study is, in itself, an important clinical contribution to this area of care. After further confirmatory testing, the tools which are simple and brief, might be used in the clinical setting to assess care needs, expectations, perceptions and satisfaction ratings of families. Although the results from this study far from meet the research needs identified by Tiblier (1989), the study does offer a beginning place for clinicians to seek further explication of family care satisfaction in response to a terminal illness.
Recommendations

Several recommendations for future research were suggested based on the findings of this study. Replication of the study with a more representative sample is necessary before results can be generalized to the theoretical model. The use of a longitudinal design would allow the testing of all stages of the theories and provide information about the relationships between care needs, expectations, perceptions, and satisfaction. As well, a longitudinal design would permit measurement of variables at different points in time, providing an opportunity to test these variables within the context of a nonrecursive model.

Concerted effort needs to be made to reduce mono-method and mono-operation bias. Campbell and Fiske (1959) suggest that convergent and discriminate validity can be investigated within the multitrait-multimethod matrix. For example, a future study might employ face-to-face interviews and health professional ratings along with the existing questionnaires to further examine the construct validity of the tools.

The viability of testing multiple theories within a single model needs to be further examined. Are there identifiable limits to this approach? If so, what are they and how can they be addressed?

In addition, the constructs, need fulfilment and care expectations warrant further examination. Re-structuring these scales to represent the concepts as continuous variables might increase the sensitivity of the scales and permit a more precise and accurate specification of the theoretical concepts.
Further qualitative research also would be useful to identify the behaviors that are associated with different care satisfaction ratings. Ajzen and Fishbein’s (1980) theory was designed to predict health behaviors, as a consequence of attitudes toward health. In this study, the first stage of the theory was examined, factors that contribute to the attitude, care satisfaction. Identifying the behaviors that occur during the illness experience may help refine the concepts as they apply to this population.

As well, longitudinal work needs to be done to identify the outcomes associated with different care satisfaction ratings. The importance of family satisfaction ratings is rooted in literature (Kristjanson, 1988; Wright & Dyck, 1984), that suggests that families whose needs are not met and who have negative evaluations of the care, experience greater stress. A number of researchers (Barzelai, 1981; Lack & Buckingham, 1978) have reported that more significant differences between hospice and non-hospice care have been observed among family members than among patients, and that the hospice may be of greater value to the family than to the dying patient. In particular, hospice programs seem to engender relatively more beneficial psychosocial outcomes (Lack & Buckingham, 1978). Benefits of hospice to families may also be experienced in the bereavement stage. Smith and Hill (1978) reported a greater percentage of ‘normal’ grieving responses among family members whose ill family member received care from a hospice program, compared to family members of patients who received care from a non-hospice ward. Therefore, care satisfaction may be a useful predictor of psychosocial health in family members experiencing the illness.
episode and in the bereavement period that follows. Further work to investigate these outcomes is necessary.

Further research to access and identify the family members less satisfied with care is also indicated by these findings. The need to assess the extent to which the measurement tools index the concerns of these families, the theories predict satisfaction for this group, and the clinical behaviors of this subset of families are unique, are challenging yet promising directions for further study.

A final recommendation is that the clinical findings emerging from this research that have been validated in previous empirical work be disseminated. Notwithstanding the limitations discussed previously, there are worthwhile results that, with appropriate interpretation would be useful to clinicians currently practising with this study population.

Summary

The purpose of this study was to use theoretical and empirical modeling to identify the model that best explains family satisfaction with palliative care. Discrepancy theory emerged as the most credible and parsimonious theoretical model. Empirical modeling resulted in identification of the Family Care Satisfaction Model, that could be used to explicate family satisfaction in response to a palliative care situation. This model includes factors from different theories, together with demographic variables found to have statistically significant impact on family care
satisfaction. The findings of the study were also interpreted in terms of limitations, theoretical issues and methodological issues. Implications were presented relative to theory construction and clinical nursing practice. Finally, recommendations for further research were suggested in relation to theory construction and instruments.
APPENDIX A

RESEARCH INSTRUMENTS
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
<table>
<thead>
<tr>
<th></th>
<th>Description</th>
<th>VS</th>
<th>S</th>
<th>U</th>
<th>D</th>
<th>VD</th>
</tr>
</thead>
<tbody>
<tr>
<td>13.</td>
<td>coordination of care</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>14.</td>
<td>time required to make a diagnosis</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>15.</td>
<td>the way the family is included in treatment and care decisions</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>16.</td>
<td>information given about how to manage the patient’s pain</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>17.</td>
<td>information given about the patient’s tests</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>18.</td>
<td>how thoroughly the doctor assesses the patient’s symptoms</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>19.</td>
<td>the way tests and treatments are followed up by the doctor</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>20.</td>
<td>availability of the doctor to the patient</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
**FAMILY NEEDS SCALE**

**Instructions:** The next set of questions are about the needs of family members of cancer patients. Please show how important the following needs are for you as a family member. If a need is not at all important, write 0 beside that need. If the need is very important to you, give it a 10. If the need is somewhere in between, give it a number between 0 and 10 that means how important it is for you. If the need was important to you (1 or higher), check off in the column beside to show if the need has been met or not met.

<table>
<thead>
<tr>
<th>I NEED TO:</th>
<th>RATINGS FROM 0 - 10</th>
<th>MET</th>
<th>UNMET</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. have my questions answered honestly</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. know specific facts concerning the patient’s prognosis</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. feel that the health professionals care about the patient</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>4. be informed of changes in the patient’s condition</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. know exactly what is being done for the patient</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. know what treatment the patient is receiving</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>7. have explanations given in terms that are understandable</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. be told about changes in treatment plans while they are being made</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

IF YOU RATED AN ITEM HIGHER THAN 0, CHECK IF MET OR UNMET
<p>| | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>9.</td>
<td>feel there is hope</td>
<td></td>
</tr>
<tr>
<td>10.</td>
<td>be assured that the best possible care is being given to the patient</td>
<td></td>
</tr>
<tr>
<td>11.</td>
<td>know what symptoms the treatment or disease can cause</td>
<td></td>
</tr>
<tr>
<td>12.</td>
<td>know when to expect symptoms to occur</td>
<td></td>
</tr>
<tr>
<td>13.</td>
<td>know the probable outcome of the patient’s illness</td>
<td></td>
</tr>
<tr>
<td>14.</td>
<td>know why things are done for the patient</td>
<td></td>
</tr>
<tr>
<td>15.</td>
<td>know the names of the health professionals involved in the patient’s care</td>
<td></td>
</tr>
<tr>
<td>16.</td>
<td>have information about what to do for the patient at home</td>
<td></td>
</tr>
<tr>
<td>17.</td>
<td>feel accepted by the health professionals</td>
<td></td>
</tr>
<tr>
<td>18.</td>
<td>help with the patient’s care</td>
<td></td>
</tr>
<tr>
<td>19.</td>
<td>have someone be concerned with my health</td>
<td></td>
</tr>
<tr>
<td>20.</td>
<td>be told about people who could help with problems</td>
<td></td>
</tr>
</tbody>
</table>

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**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 0 to 10 in the column beside each item. If an item is not at all important to you, write down a 0. If an expectation is very important to you give it a 10. If it is somewhere in between, write down a number between 0 and 10 that means how important that expectation is for you.

**I EXPECT THAT:**

<table>
<thead>
<tr>
<th></th>
<th></th>
<th>RATINGS FROM 0 - 10</th>
</tr>
</thead>
<tbody>
<tr>
<td>1.</td>
<td>the doctor will spend enough time with the patient</td>
<td></td>
</tr>
<tr>
<td>2.</td>
<td>nurses will spend enough time with the patient</td>
<td></td>
</tr>
<tr>
<td>3.</td>
<td>the doctor will be as thorough as he/she should be</td>
<td></td>
</tr>
<tr>
<td>4.</td>
<td>the doctor will explain the patient’s condition</td>
<td></td>
</tr>
<tr>
<td>5.</td>
<td>the doctor will listen to what the patient thinks is important</td>
<td></td>
</tr>
<tr>
<td>6.</td>
<td>the doctor will listen to what the family thinks is important</td>
<td></td>
</tr>
<tr>
<td>7.</td>
<td>physical care will be safe and competent</td>
<td></td>
</tr>
<tr>
<td>8.</td>
<td>the doctor will tell why he/she ordered tests and x-rays</td>
<td></td>
</tr>
<tr>
<td>9.</td>
<td>the patient’s pain will be controlled</td>
<td></td>
</tr>
<tr>
<td>10.</td>
<td>family will be informed about the patient’s condition</td>
<td></td>
</tr>
<tr>
<td>11.</td>
<td>the doctor will treat the patient’s symptoms quickly</td>
<td></td>
</tr>
<tr>
<td>12.</td>
<td>nurses will respond to the patient’s needs quickly</td>
<td></td>
</tr>
</tbody>
</table>
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

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**F-CARE PERCEPTIONS SCALE**

**INSTRUCTIONS:** Think about the care that your family member has received through the Palliative Care program. Please read each statement below and think about whether these things have occurred during the care of your family member. Circle whether you:

**STONGLY AGREE (SA), AGREE (A), are UNCERTAIN (U), DISAGREE (D), or STRONGLY DISAGREE with the statements below.**

<table>
<thead>
<tr>
<th>Statement</th>
<th>Strongly Agree</th>
<th>Agree</th>
<th>Uncertain</th>
<th>Disagree</th>
<th>Strongly Disagree</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. The patient’s pain is relieved quickly.</td>
<td>SA</td>
<td>A</td>
<td>U</td>
<td>D</td>
<td>SD</td>
</tr>
<tr>
<td>2. Health professionals are straight forward when answering the family’s questions.</td>
<td>SA</td>
<td>A</td>
<td>U</td>
<td>D</td>
<td>SD</td>
</tr>
<tr>
<td>3. Information is withheld about patient’s prognosis.</td>
<td>SA</td>
<td>A</td>
<td>U</td>
<td>D</td>
<td>SD</td>
</tr>
<tr>
<td>4. The patient lacks trust and confidence in the doctor.</td>
<td>SA</td>
<td>A</td>
<td>U</td>
<td>D</td>
<td>SD</td>
</tr>
<tr>
<td>5. Information about side effects of treatments and drugs is withheld.</td>
<td>SA</td>
<td>A</td>
<td>U</td>
<td>D</td>
<td>SD</td>
</tr>
<tr>
<td>6. The doctor refers the patient to a specialist promptly.</td>
<td>SA</td>
<td>A</td>
<td>U</td>
<td>D</td>
<td>SD</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Uncertain</td>
<td>Disagree</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>----------------</td>
<td>-------</td>
<td>-----------</td>
<td>----------</td>
</tr>
<tr>
<td>7.</td>
<td>A hospital bed is available to the patient when necessary.</td>
<td>SA</td>
<td>A</td>
<td>U</td>
<td>D</td>
</tr>
<tr>
<td>8.</td>
<td>The doctor has arranged a family conference to discuss the patient’s illness.</td>
<td>SA</td>
<td>A</td>
<td>U</td>
<td>D</td>
</tr>
<tr>
<td>9.</td>
<td>The patient’s symptoms are treated quickly.</td>
<td>SA</td>
<td>A</td>
<td>U</td>
<td>D</td>
</tr>
<tr>
<td>10.</td>
<td>Doctor pays little attention to the patient’s description of symptoms.</td>
<td>SA</td>
<td>A</td>
<td>U</td>
<td>D</td>
</tr>
<tr>
<td>11.</td>
<td>Tests and procedures are performed competently.</td>
<td>SA</td>
<td>A</td>
<td>U</td>
<td>D</td>
</tr>
<tr>
<td>12.</td>
<td>Doctors are available to the family.</td>
<td>SA</td>
<td>A</td>
<td>U</td>
<td>D</td>
</tr>
<tr>
<td>13.</td>
<td>Nurses are available to the family.</td>
<td>SA</td>
<td>A</td>
<td>U</td>
<td>D</td>
</tr>
<tr>
<td>14.</td>
<td>One doctor is responsible for the patient’s care.</td>
<td>SA</td>
<td>A</td>
<td>U</td>
<td>D</td>
</tr>
<tr>
<td></td>
<td>Strongly Agree</td>
<td>Agree</td>
<td>Uncertain</td>
<td>Disagree</td>
<td>Strongly Disagree</td>
</tr>
<tr>
<td>---</td>
<td>----------------</td>
<td>-------</td>
<td>-----------</td>
<td>----------</td>
<td>------------------</td>
</tr>
<tr>
<td>15. There was a delay in making the diagnosis.</td>
<td>SA</td>
<td>A</td>
<td>U</td>
<td>D</td>
<td>SD</td>
</tr>
<tr>
<td>16. Family is excluded from treatment &amp; care decisions.</td>
<td>SA</td>
<td>A</td>
<td>U</td>
<td>D</td>
<td>SD</td>
</tr>
<tr>
<td>17. Family is given information about how to manage the patient's pain.</td>
<td>SA</td>
<td>A</td>
<td>U</td>
<td>D</td>
<td>SD</td>
</tr>
<tr>
<td>18. Information is provided about patient's tests.</td>
<td>SA</td>
<td>A</td>
<td>U</td>
<td>D</td>
<td>SD</td>
</tr>
<tr>
<td>19. Doctor assesses patient's symptoms thoroughly.</td>
<td>SA</td>
<td>A</td>
<td>U</td>
<td>D</td>
<td>SD</td>
</tr>
<tr>
<td>20. Doctor is available to the patient.</td>
<td>SA</td>
<td>A</td>
<td>U</td>
<td>D</td>
<td>SD</td>
</tr>
<tr>
<td>21. Tests and treatments are followed up by the doctor.</td>
<td>SA</td>
<td>A</td>
<td>U</td>
<td>D</td>
<td>SD</td>
</tr>
</tbody>
</table>

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Family Information

1. Marital Status: Married
   Divorced
   Never Married
   Widowed
   Common-Law

2. Age: 18-30 years
   51-65 years
   31-50 years
   over 65 years

3. Sex: Male
   Female

4. Education: grade 8 or less
   some high school
   high school diploma
   college degree
   graduate degree

5. Occupation: clerical
   retired
   professional
   laborer
   management
   homemaker
   other

6. Relationship to Patient: spouse
   son
   daughter
   other

7. Income: below $10,000/year
   $11,000-20,000/year
   $21,000-30,000/year
   $31,000-40,000/year
   over $40,000/year

8. Ethnic Background: __________

9. Religion: Catholic
   Protestant
   Jewish
   Other
   None

10. Patient's Diagnosis: ______________________

11. Patient's Age: 18-30 years
    51-65 years
    31-50 years
    over 65 years

12. Patient's Sex: Male
    Female

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PILOT STUDY: VALIDITY AND RELIABILITY TESTING OF THE FAMCARE SCALE

The purpose of the study was to test the reliability and validity of the FAMCARE Scale which was developed to measure family satisfaction with advanced cancer care.

Background Literature: Although the literature related to quality of care issues emphasizes the importance of care satisfaction judgements of patients and their families (Hays & Arnold, 1986; McCusker, 1984; Oberst, 1984; Pascoe, 1984), research related to family satisfaction with cancer care in particular is limited. McCusker (1984) evaluated patient and family satisfaction with chronic and terminal care to find that patients reported higher levels of satisfaction than family members (p<.01), and mean satisfaction levels for family members were in the middle of the possible score range. The internal consistency results for her scale using Cronbach’s alpha ranged from .53 to .90 and McCusker reports reasonable convergent and discriminant validity estimates. This work suggests that family satisfaction is a separate phenomenon from patient satisfaction and that family members may have different care priorities or perceptions than patients. The findings from three other studies (Barzelai, 1981; Creek, 1982; Hannan & O’Donnell, 1984) revealed that families are generally satisfied with care provided, particularly in relation to physical care needs of the patient. However, absence of instrument validity or reliability estimates clouds interpretation.
The literature reveals some interesting and important issues to consider in relation to conceptual and measurement decisions concerning family satisfaction with care. Firstly, there is debate regarding the merits of multiple versus single item instruments for measuring care satisfaction. It appears that multiple-item scales tend to produce greater variability and tend to be more reliable than single-item scales and decrease problems of acquiescence response set (Ware, 1978). Therefore, a multiple-item instrument was designed.

A second issue concerns the use of direct or indirect approaches to measure satisfaction. The direct approach requires fewer items and is deemed to be more appropriate for assessments of satisfaction with services actually received while an indirect approach lends itself better to assessments of satisfaction with health care more generally. Therefore, a direct approach was selected.

Dimensionality of the concept, satisfaction is a third issue. A number of researchers (Oberst, 1984; Ware, Davies-Avery, & Stewart, 1978; Ware, 1981) assert that satisfaction is a multidimensional concept. However, these researchers also use unidimensional scaling models to measure satisfaction (e.g., Likert scales), present inconsistent or poorly specified definitions of the satisfaction construct and have presented conflicting empirical evidence with respect to the factorial composition of the term. Therefore, earlier qualitative work was found to be more specific and informative regarding the question of dimensionality (Kristjanson, 1986; 1989b). Results from a cluster analysis using the Ward method suggested that family
satisfaction with advanced cancer care may be a unidimensional concept encompassing four subdimensions - Information Giving, Availability of Care, Psychological Care, and Physical Patient Care. The results from this research formed the basis for developing the FAMCARE scale.

Methods: A descriptive correlational design was used to test the psychometric properties of the scales. Four instruments were used for data collection: FAMCARE Scale (Index of Family Satisfaction with Advanced Cancer Care), McCusker Scale (Index of Patient and Family Satisfaction and Perceptions of Chronic and Terminal Care), Overall Satisfaction with Care Scale, and a demographic questionnaire. Data collection occurred twice. Initial data collection occurred in person, either in the homes of subjects or in the outpatient cancer clinic. The second data collection procedure involved self-administration of the scales to assess their stability over time. This occurred 24 hours after the initial data collection time and were returned in a self-addressed, stamped envelope.

Sample: A convenience sample of 40 family members of advanced cancer patients was obtained. The most typical respondent was a white, Protestant, retired married woman over 50 years of age with a college education or higher. The two most frequently reported income levels were between $11,000 and $20,000 per year and a group with an annual income of over $40,000. The three most frequently reported patient diagnoses were lymphoma (20%), breast cancer (17%), and colon cancer (17%).
Results: The FAMCARE scale evidenced stability achieving a test-retest correlation of .92 (representing 77 percent of the sample), and internal consistency estimates using Cronbach's alphas of .93 at two testing times. Internal consistency estimates using Cronbach's alpha coefficient for the subscales ranged from .61 to .88 and are shown in Table B-1. All four subscales achieved over 50 percent of inter-item correlations between .30 and .70 (Table B-1). An inter-item correlation of .84 was found for items 1 and 3 and a correlation of .80 between items 18 and 19, suggesting slight redundancy. Eighty-five percent of item-to-total correlations were between .50 and .70, which was well beyond the preset criterion of 50 percent. Items 5 and 6 did not meet this criterion, with correlations of .36 and .15 respectively. Item 15 achieved an item-to-total correlation of .76.
Table B-1: Psychometric properties of FAMCARE subscales at times 1 and 2: Pilot study results

<table>
<thead>
<tr>
<th>Subscale</th>
<th># of Items</th>
<th># Items Meet Inter-item Correlations</th>
<th>Standard Alpha</th>
<th>Range of Subscale Means</th>
<th>Subscale Mean</th>
<th>s.d.</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information Giving</td>
<td>5</td>
<td>5</td>
<td>0.82(t1)</td>
<td>3.4-4.5</td>
<td>4.3</td>
<td>.27</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>0.82(t2)</td>
<td>3.7-4.3</td>
<td>4.2</td>
<td>.26</td>
</tr>
<tr>
<td>Physical Patient Care</td>
<td>7</td>
<td>7</td>
<td>0.84(t1)</td>
<td>3.9-4.5</td>
<td>4.3</td>
<td>.23</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>0.88(t2)</td>
<td>3.9-4.6</td>
<td>4.3</td>
<td>.27</td>
</tr>
<tr>
<td>Psychosocial Care</td>
<td>4</td>
<td>4</td>
<td>0.83(t1)</td>
<td>3.7-4.5</td>
<td>4.2</td>
<td>.32</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>0.74(t2)</td>
<td>3.6-4.5</td>
<td>4.2</td>
<td>.37</td>
</tr>
<tr>
<td>Availability of Care</td>
<td>4</td>
<td>3</td>
<td>0.73(t1)</td>
<td>4.0-4.4</td>
<td>4.3</td>
<td>.17</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>0.61(t2)</td>
<td>3.9-4.5</td>
<td>4.2</td>
<td>.22</td>
</tr>
</tbody>
</table>

$t1$ - initial testing time
$t2$ - retest time 24 hours later

$n=40$

The scale also evidenced criterion validity, achieving correlations of .80 and .77 with the McCusker Satisfaction Scale at the two testing times. This is acceptable given the expected value of >.71, based on an overlap of approximately 50 percent of the questions on the two scales. Correlations between the FAMCARE and the Overall Satisfaction with Care questions were .68 and .60 for patient care and .64 and .62 for family care. These were within the expected range of .40 to .60. Cluster analysis suggested that family members categorized the items into four subdimensions of care: Information Giving, Availability of Care, Physical Patient Care, and Pain Control. Items 5 and 6 did not cluster meaningfully (Table B-2).
Table B-2: Conceptual structure of FAMCARE based on pilot test cluster analysis

**Information Giving Subscale**

#1 - information given about patient’s prognosis
#3 - answers from health professionals
#4 - information given about side effects of treatments and drugs
#10 - the way tests and procedures are performed *
#13 - coordination of care *
#15 - the way the family is included in treatment and care decisions *

**Physical Patient Care Subscale**

#8 - speed with which symptoms are treated
#9 - doctor’s attention to patient’s description of symptoms *
#14 - time required to make a diagnosis
#17 - information given about the patient’s tests *
#18 - how thoroughly doctor assesses patient’s symptoms
#19 - the way tests and treatments are followed up by doctor

**Availability of Care Subscale**

#11 - availability of doctor to family
#12 - availability of nurses to family
#20 - availability of doctor to patient

**Pain Control Subscale**

#2 - patient’s pain relief *
#7 - family conference arranged to discuss patient’s illness *
#16 - information given about how to manage the patient’s pain *

Items that did not cluster:  
#5 - referral to specialists
#6 - availability of a hospital bed

* identifies items that clustered differently from initial Q-sort analysis
The possible score range for the FAMCARE is 20 to 100. The actual range used by subjects at time one was 61 to 100 and 70 to 100 at retest. The scale means were 85.37 (s.d.=9.56) at time one and 84.87 (s.d.=9.55) at retest. These results indicate that the majority of subjects were in the upper third of the satisfaction ratings. Two items were scored not applicable by most subjects: referral to specialists and availability of a hospital bed. These items were more applicable to subjects sampled from a Canadian population who identified the items for the scale and may reflect differences in health care systems.

Family member’s level of education correlated positively (r=.33, p<.05) with satisfaction ratings. Chi-square results indicated that 60 percent of white family members rated care in the upper half of the satisfaction distribution, while all non-white subjects rated the care in the lower half. A moderate positive correlation (r=.38, p<.05) was also obtained between patient’s age and family member’s care satisfaction ratings.

Limitations: The sample was a small, non-probabilty one limiting generalizability of the findings. Testing of stability over time may have been biased by the effects of learning and recall given the short time frame between time one and time two. However, given the fact that experiences with care vary with a 48 hour period for the subjects tested, this time frame seemed reasonable. Further examination of the stability of the concept, satisfaction is warranted.
Discussion: Preliminary findings suggest that the FAMCARE Scale shows potential as a reliable and valid tool. The moderate correlations of the scale with the questions related to Overall Satisfaction with Care suggest that the concept may be more complex than can be revealed by a single-item question and that use of a multiple-item scale is more sensitive.

A commonly reported finding in satisfaction research is negatively skewed satisfaction ratings with little variance (Fox & Storms, 1981; Oberst, 1984; Ware, 1978). This finding was also reported here. Families may use an abbreviated scale range because of the difficulties they may perceive acknowledging dissatisfaction with care. In order to interpret these findings more meaningfully, more extensive data from representative samples would be useful in developing a normative base for interpreting satisfaction ratings. As well, use of a criterion-model to identify meaningful clinical cutoffs for satisfaction ratings would be helpful.
APPENDIX C

PILOT STUDY: CONTENT VALIDITY OF THE F-CARE EXPECTATIONS SCALE AND THE F-CARE NEEDS SCALE
PILOT STUDY: CONTENT VALIDITY OF THE F-CARE EXPECTATIONS SCALE AND THE F-CARE NEEDS SCALE

The purpose of this work was to construct and test two scales: the F-Care Needs Scale (an index of the needs of family members experiencing advanced cancer in a member) and the F-Care Expectations Scale (an index of the expectations family members have of health professionals in the context of advanced cancer care in a member) for clarity, apparent internal consistency, and content validity. The testing process used was the method described by Imle and Atwood (1988) for assessing the validity and internal consistency of inductively generated domains.

Background Literature: The literature reports that families have many and varied needs during the advanced phases of the cancer patient's illness (Giacquinta, 1977; Hinds, 1985; Tringali, 1986; Wright & Dyck, 1984). If needs go unmet, stress is created which impedes a family's ability to function effectively (McCubbin & Patterson, 1981; Olsen, 1970).

Family members of cancer patients also look to health professionals to provide quality care for the patient and help meet some of their own needs (Kristjanson, 1986; Northouse, 1981). There is evidence that family members may hold expectations of health professionals based on past experiences in the health care system or based on acquired information (Ajzen & Fishbein, 1980). Theoretical writing related to care satisfaction suggests that the extent to which needs (Schafer, 1953) and expectations...
are met has some relationship to care satisfaction (Ajzen & Fishbein, 1980; Linder-Pelz, 1982b; Porter, 1961; Thibaut & Kelley, 1959).

**Instruments:** The F-Care Needs Scale was based on Molter & Leske’s (1983) Critical Care Family Needs Inventory (CCFNI) and work by Tringali (1986) who used the CCFNI scale with families of advanced cancer patients. Tringali’s scale (53 items) was judged to be too long given the stressed population to be tested. Therefore, 20 items were selected and adapted from the CCFNI using Tringali’s (1986) findings to guide item selection. Items 1 through 17 and item 20 on the F-Care Needs Scale were adapted from Tringali’s (1986) list of most important items. Items 18 and 19 were adapted from the original CCFNI (Molter & Leske, 1983).

A summated rating scale format ranging from 0 to 10 was designed based on the work of Atwood et al (1989) who developed the Caregiver Needs Scale. The response choice captures two pieces of information: awareness of need and importance of family care needs. A score of zero indicates no need exists, and a score of one or higher indicates the existence and importance of the need, with a score of 10 representing the greatest need. A second question indexes whether or not the need has been met (need fulfilment).

The F-Care Expectations Scale was developed based on Linder-Pelz’s (1982a) work in the area of patient satisfaction with care and prior qualitative research that identified indicators of quality of care that family members of advanced cancer patients consider important (Kristjanson, 1986). The summated rating scale consists of
16 items formatted along a 0 to 10 response option. Items 1, 3, 4, 5, and 8 were adapted from Linder-Pelz's (1982a) Expectation scale. The remaining items were developed from the qualitative study mentioned above. A response of 0 indicates that the family member does not hold that expectation of the health professionals. Responses of one or greater indicate that the expectation is important and a higher number represents greater importance.

Rating Panel: A panel of six experts were identified to test the scales. These individuals were all over 18 years of age, could speak and read English, and had experienced the death of a family member due to cancer within the last year. They completed a mailed three-part questionnaire that was designed to obtain their assessments of the instruments’ clarity, apparent internal consistency, and content validity.

Results

Clarity: All items on the F-Care Needs Scale achieved the preset criteria (66% agreement for each scale item and 80% for the overall scales) (Irmlé & Atwood, 1988). Seventeen of the 20 items achieved 100 percent agreement. All items on the F-Care Expectations Scale achieved or exceeded the required criteria. The average of the ratings per item yielded the average rating for the scales. The mean percent agreement for the total F-Care Needs Scale was 96 percent and 94 percent for the F-Care Expectations Scale.
Apparent Internal Consistency: All 20 items on the F-Care Needs Scale met or exceeded the preset criterion of 70 percent agreement among raters per item, with a mean percentage agreement of 97 percent. All sixteen items on the F-Care Expectations Scale met the criterion as well, with a mean percentage agreement of 95 percent.

Content Validity: Nineteen of the 20 items on the F-Care Needs Scale met the criterion of 83 percent agreement. Item 9, "I need to feel there is hope" obtained 67 percent agreement. All 16 items on the F-Care Expectations Scale achieved 100 percent agreement.

For uniqueness, 18 of the 20 items met the criterion of at least 83 percent agreement on the F-Care Needs Scale. Items 5 and 6 were judged to be redundant by three panel members. Fourteen of the 16 items on the F-Care Expectations Scale met the criterion of at least 83 percent agreement. Item 4 and 10 were judged redundant by two panel members. The results of this testing are summarized in Tables C-1 and C-2.
### Table C-1: Results of Instrument Testing and Planned Testing: F-CARE NEEDS SCALE

<table>
<thead>
<tr>
<th>Type of Assessment</th>
<th>Particular Kind of Estimate, e.g., internal consistency</th>
<th>Name</th>
<th>Population</th>
<th>Author(s), Date, Coefficient Criteria, Rationale</th>
<th>Source</th>
<th>Empirical Decision</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td>Reliability Consistency</td>
<td>Apparent Internal Needs of Family Care patients Survivors of cancer of advanced cancer patients N=6</td>
<td>Kristjanson, 1989 Percent Agreement &gt;70%</td>
<td>-immature &gt;70% agreement supports apparent internal inconsistency (incorporates Nunnally's (1978) criteria)</td>
<td>Imle &amp; Atwood, (1988) -All items met criterion: mean percent agreement: 97% Items hold together well, based upon this criterion</td>
<td>-retain items after consideration of content</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Reliability Consistency</td>
<td>* Internal Consistency Family Care Needs Family members of advanced cancer patients</td>
<td>-Alpha &gt;.70 -inter-item correlations -.50% between .30 + .70 50% between .50 + .70</td>
<td>-immature scale -screen for collinearity or items that do not &quot;fit&quot;</td>
<td>Nunnally, 1978</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* Planned Testing

Table Format: JR Atwood 3/82
<table>
<thead>
<tr>
<th>Type of Assessment</th>
<th>Particular Kind of Estimate, e.g., internal consistency</th>
<th>Population and Sample Size</th>
<th>Author(s), Date</th>
<th>Coefficient or Means Estimate</th>
<th>Criterion</th>
<th>Rationale</th>
<th>Source</th>
<th>Empirical Decision Estimate</th>
<th>Action</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Validity</strong></td>
<td>Clarity Needs</td>
<td>Family survivors of cancer patients N=6</td>
<td>Kristjanson, 1989</td>
<td>Percent Agreement</td>
<td>&gt;70% for scale items</td>
<td>immature scale</td>
<td>given 6 raters used as closest approximation</td>
<td>&gt;80% for overall scale</td>
<td>Imle &amp; Atwood, 1988</td>
</tr>
<tr>
<td></td>
<td>Content</td>
<td>&quot;</td>
<td>&quot;</td>
<td>&quot;</td>
<td>&quot;</td>
<td>high agreement without</td>
<td>Imle &amp; Atwood, 1988</td>
<td>&gt;80% per item &amp; total</td>
<td>&gt;19/20 met criterion for item agreement</td>
</tr>
</tbody>
</table>

Table C-1 (cont’d): Results of Instrument Testing and Planned Testing: F-CARE NEEDS SCALE
### Table C-1 (cont'd): Results of Instrument Testing and Planned Testing: F-CARE NEEDS SCALE

<table>
<thead>
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<th>Type of Assessment</th>
<th>Particular Kind of Estimate, e.g., internal consistency</th>
<th>Name of Concept</th>
<th>Sample Size</th>
<th>Author(s) and Date</th>
<th>Coefficient or Means to Estimate</th>
<th>Criterion</th>
<th>Rationale</th>
<th>Source</th>
<th>Empirical Estimate</th>
<th>Decision</th>
<th>Action</th>
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</thead>
<tbody>
<tr>
<td>Validity</td>
<td>*Construct</td>
<td>Family members of cancer patients</td>
<td>N=160</td>
<td></td>
<td>Predictive modeling</td>
<td>significant coefficient (p&lt;.05)</td>
<td>Predictive test is valid if there is a significant correlation between variables</td>
<td>Nunnally, 1978</td>
<td></td>
<td></td>
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<tr>
<td>Factor Analysis</td>
<td>&gt;.40 factor loadings</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Internal structures &amp; cross structures for sets of variables</td>
<td>Nunnally, 1978</td>
<td>determine</td>
<td></td>
</tr>
<tr>
<td></td>
<td>&gt;.15 differences between loadings for items on different factors</td>
<td></td>
<td></td>
<td></td>
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<td></td>
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* Planned Testing
Table C-2: Results of Instrument Testing and Planned Testing: F-CARE EXPECTATIONS SCALE

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<tr>
<th>Type of Assessment</th>
<th>Particular Kind of Estimate, internal consistency</th>
<th>Name of Construct Indexed</th>
<th>Population and Sample Size</th>
<th>Author(s), Date</th>
<th>Coefficient or Means Estimate</th>
<th>Criterion Rationale</th>
<th>Source Estimate</th>
<th>Decision</th>
<th>Action</th>
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<tr>
<td>Reliability</td>
<td>Apparent Internal Consistency</td>
<td>Family Care Expectations</td>
<td>Family survivors of cancer patients N=6</td>
<td>Kristjanson, 1989</td>
<td>Percent agreement &gt;70%</td>
<td>immature scale (Nunally, 1978)</td>
<td>all items met criterion mean percent agreement of 95%</td>
<td>evidence of apparent consistency</td>
<td>retain items</td>
</tr>
<tr>
<td>Reliability</td>
<td>*Internal Consistency</td>
<td>Family members of patients with advanced cancer N=160</td>
<td>-Alpha &gt;.70</td>
<td>-immature scale (Nunnally, 1978)</td>
<td>screen for collinearity/</td>
<td>items that do not &quot;fit&quot;</td>
<td>Nunnally, 1978</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>-inter-item correlations</td>
<td>-.50% between .30 + .70</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>-item-total correlations</td>
<td>-.50% between .30 + .70</td>
<td></td>
<td></td>
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* Planned Testing
Table Format: JR Atwood 3/82
### Table C-2 (cont'd): Results of Instrument Testing and Planned Testing: F-CARE EXPECTATIONS SCALE

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<th>Type of Assessment</th>
<th>Particular Kind of Estimate, e.g., internal consistency</th>
<th>Name of Construct</th>
<th>Population and Sample</th>
<th>Author(s), Date</th>
<th>Coefficient or Means to Estimate</th>
<th>Criterion</th>
<th>Rationale</th>
<th>Source</th>
<th>Empirical Estimate</th>
<th>Decision</th>
<th>Action</th>
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</thead>
<tbody>
<tr>
<td><strong>Validity</strong></td>
<td>Clarity</td>
<td>Family Care Expectations</td>
<td>Family survivors of cancer patients N=6</td>
<td>Kristjanson, 1989</td>
<td>Percent Agreement &gt;70% for scale items &gt;80% for overall scale</td>
<td>Immature scale -66% used as closest approximation to 70% with 6 raters -83% used as closest approximation to 80% with 6 raters</td>
<td>-All items met criteria -Mean percent agreement was 94%</td>
<td>Scale items are clear</td>
<td>Retain scale wording</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Validity</strong></td>
<td>Content</td>
<td>&quot;</td>
<td>&quot;</td>
<td>&quot;</td>
<td>&gt;80% for scale items &gt;85% for uniqueness</td>
<td>-Want high agreement without redundancy -validity is crucial clinically</td>
<td>-All items met criterion -2 items judged redundant -Evidence of content validity -minimal redundancy</td>
<td>-reassess items 4 + 10 for possible redundancy</td>
<td></td>
<td></td>
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<tr>
<td>Type of Assessment</td>
<td>Particular Kind of Estimate, e.g., internal consistency</td>
<td>Name of Construct Indexed</td>
<td>Population and Sample Size</td>
<td>Author(s), Date</td>
<td>Coefficient or Means to Estimate</td>
<td>Criterion</td>
<td>Rationale</td>
<td>Source</td>
<td>Empirical Estimate</td>
<td>Decision</td>
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<tr>
<td>Validity</td>
<td>*Construct</td>
<td>Family Care Expectations</td>
<td>Family members of cancer patients N=160</td>
<td>Predictive modelling</td>
<td>Predictive significant (p&lt;.05) path coefficient &gt;.05 in predicted direction</td>
<td>Predictive test is valid if there is a significant correlation between variables</td>
<td>Nunnally, 1978</td>
<td></td>
<td></td>
<td></td>
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<tr>
<td>Factor Analysis</td>
<td>&gt;.40 factor loadings &gt;.15 difference between loadings on different factors</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>Useful way of determining internal structure + cross structure for sets of variables</td>
<td>Nunnally, 1978</td>
<td></td>
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</tbody>
</table>

* Planned Testing
Discussion: The results provide evidence for the clarity, apparent internal consistency, and content validity of the scales. Certain issues were revealed during the development of the tools that are important to highlight before future testing occurs. Firstly, the point in time that the individual uses to assess whether or not needs have been met is a potential source of confusion. Therefore, careful instructions to respondents would be important so that the questions are answered with the same time frame in mind.

A second issue relates to the social desirability effect on reported needs. Self-report measures are known to be affected by social desirability (Feetham, 1984). Families may wish to appear capable, creating biased results. Ensuring that results of the study will not be individually shared with health professionals may facilitate a permissive atmosphere that encourages frank responses.

A third issue concerns the extent to which the response options (0-10) are meaningful. However, in an effort to capture as much information as possible within one question and to increase sensitivity, this approach warrants further testing. A related concern is whether or not need fulfilment should be assessed as a dichotomous variable (i.e., met/not met). Degrees of need fulfilment might more appropriately be assessed with a more continuous response option. However, a balancing concern is the complexity of the task for a stressed population. Therefore, a decision was made to use this response approach in an effort to avoid problems of missing data and subject overload.
Dimensionality of the concepts purported to be indexed by these tools is not known. Prior studies (Leske, 1986; Tringali, 1986; Wright & Dyck, 1984) have used unidimensional scaling models to structure the scales. Leske (1986) factor analyzed the 45 item CCFNI that measures family care needs in a critical care situation and reported four separate dimensions. However, the subscale scores were compiled to obtain one composite score suggesting that the concept is unidimensional. Subsequent research using a cluster or factor analysis of the F-Care Needs Scale would be helpful.

The literature related to expectations is also unclear regarding dimensionality of the concept. Pascoe (1984) reports that expectations may be defined as ideal, minimal, or typical. Theoretical writing (Porter, 1961; Thibaut & Kelley, 1959) suggests that individuals tend to use average expectations rather than ideal expectations when evaluating their satisfaction with an experience. This theory was used as rationale to structure the F-Care Expectations Scale using a unidimensional scaling model, with directions to subjects to consider care that they expected to be usual or typical. Future testing of the scale with larger samples will allow cluster or factor analysis of the scales and provide more data regarding the substructure of this concept.

**Future Testing Plans:** The F-Care Needs Scale and F-Care Expectations Scale will be used in future research to test four competing theories of satisfaction with care in family members of patients with advanced cancer. Planned psychometric testing is shown in Tables C-1 and C-2.
APPENDIX D

INVITATION TO SUBJECTS TO PARTICIPATE
REQUEST FOR PERMISSION TO RELEASE NAMES
(PALLIATIVE CARE FAMILY MEMBERS)

Linda Kristjanson is a registered nurse and doctoral student from the College of Nursing, University of Manitoba who is doing research here about how families of patients view the care received by the patient. She is also interested in learning about the needs of family members during the illness.

Information is strictly confidential. Whether or not you decide to participate will in no way influence the care received by the patient.

Linda’s research assistant, _________ would like to invite you to participate in her study. Would you be willing to speak with her so that she can explain the study and you can decide whether or not you would like to participate?

(If agreeable, the name of the family member is given to the nurse researcher and the nurse thanks them.)

(If the family member declines the nurse thanks them for their time).
LETTER TO SUBJECTS REQUESTING PERMISSION TO RELEASE NAMES
(HOME CARE FAMILY MEMBERS)

Name
Home Care Coordinator
Hospital Address
Winnipeg, Manitoba

Dear

I am mailing you this letter on behalf of Linda Kristjanson, RN, a doctoral nursing student at the University of Arizona. Linda is also a faculty member at the School of Nursing, University of Manitoba. She is studying how families of patients view the care received by the patient. She is also interested in learning about the needs of family members during the illness and what they expect of health professionals.

I am writing to obtain your permission to give Linda Kristjanson your name as a possible participant in the study. If you do not wish your name released please call me at 237-2445. If I do not hear from you by ________ I shall assume it is acceptable to you to give Linda your name. Linda’s Research Assistant, ________ will be contacting those who give their permission by telephone to see if they are interested in participating in the study. She will arrange a suitable interview time and will also answer any other questions about the research then.

Should you decide to participate, no information about you or your family will be shared with health professionals caring for your family member. The information will be strictly confidential. Whether or not you decide to participate will in no way influence the care received by your relative.

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

If you have questions about the research study Linda can be reached at 474-8937.

Sincerely,

Name
Home Care Coordinator
APPENDIX E

HUMAN SUBJECTS LETTER OF CONSENT
FAMILY SATISFACTION WITH PALLIATIVE CARE:
A TEST OF FOUR ALTERNATIVE THEORIES
CONSENT

I ____________________________ agree to participate in the study, "Family Satisfaction with Palliative Care: A Test of Four Alternative Theories. The purpose of the study is to gain an understanding of those factors that contribute to satisfaction with palliative care from a family member's viewpoint.

The results of the study may be helpful to health professionals caring for cancer patients and their families because it may provide information about how they might improve the care they give.

The study is conducted by Linda Kristjanson, Doctoral Student, College of Nursing, University of Arizona.

My participation involves answering five short questionnaires and will take approximately 45 to 60 minutes. I understand that my participation is voluntary and that I may withdraw from the study 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 my relative's care.

The information I provide will be confidential because my name will not be on the questionnaire. Only a report of grouped data will be provided to the participating agency. Findings from the research may be published.

Answering some questions may arouse sad feelings about the care situation. Otherwise, there are no known risks involved with participating in this study. The study offers no direct benefits to participants. I understand that I will receive answers to any questions about the study at any time.

The researcher can be reached locally at: 474-8937. The researcher's advisor is Dr. Jan Atwood (602-621-6659). Chairperson of the Ethical Review Committee approving this research is Dr. Theresa George (474-8218).

__________________________  ____________________________
Signature                          Witness

__________________________
Date
REFERENCES


Litman, T.J. (1974). The family as a basic unit in health and medical care: A social-behavior overview. Social Sciences and Medicine, 8, 495-519.


Ware, J.E., Jr., Snyder, M.K., & Wright, R.W. (1976). Development and validation of scales to measure patient satisfaction with health care services: Volume 1. Part B. Results of scales constructed from the patient satisfaction questionnaire and other health care perceptions. National Center for Health Services Research, Hyattsville, MD, and Southern Illinois University, School of Medicine, Carbondale, (PB-288 330).

