ASSESSMENT OF FAMILY QUALITY OF LIFE AMONG FAMILIES WITH A MEMBER WHO HAS CANCER

By

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Dedicated to my parents, my family,

and the families who have lived with cancer

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PREFACE

This dissertation was a scale development project with the purpose of developing a questionnaire to assess FQOL among families with a member who was a cancer patient. This research was conducted in three phases: (a) Phase 1: Item generation, (b) Phase 2: Item review, and (c) Phase 3: Item selection and psychometric evaluation of the questionnaire. Each phase involved a different research design and methods and data analysis. The results of each phase structured how the next phase was conducted. That is, the structure of Phase 2 (item review) was dependent on the results of Phase 1 (item generation), and the structure of Phase 3 (item selection and psychometric evaluation) was dependent on the results of Phase 2. Therefore, the introduction is presented in Chapter 1; literature review and theoretical review are presented in Chapter 2; methodological and results of each phase are reported in a logical, parallel sequence, with the design and results of Phase 1 reported in Chapters 3 and Chapter 4 respectively, the design and results of Phase 2 reported next in Chapters 5 and 6, and the design and results of Phase 3 reported last in Chapters 7 and 8; the discussion is presented in Chapter 9.

CHAPTER I

INTRODUCTION

Statement of Problem

From a family systems perspective, dysfunction or illness in one family member affects other family members, because a family unit functions as an interconnected whole (Friedman, Bowden, & Jones, 2003). Health care providers understand that cancer and its treatment affect not only cancer patients but their families as well. Several studies have documented the effects that cancer can have on a patient's family. For instance, Davis-Ali, Chester, and Chesney (1993) studied the psychological impact of cancer on patients and their spouses. They found that patients and spouses worried equally about their own personal health, and that spouses worried more about patients' futures than the patients did themselves. In addition, patients and spouses reported participating equally in the treatment process, yet patients report receiving significantly more social support than do spouses. Davis-Ali et al. (1993) concluded that conceptually, cancer is a family disease, and suggested that health care providers and researchers need to reorient their thinking from the traditional conceptions of patients / spouse roles in illness to a more holistic perception of patients and spouses as jointly active participants in a stressful and challenging experience that affects both lives greatly.

In a study of the impact of surgery on head and neck cancer (HNC) patients and their caregivers, Watt-Watson and Graydon (1995) found that families with a HNC patient experienced reduced quality of life (QOL). In a longitudinal study, Hilton (1993) studied issues and challenges faced by families coping with breast cancer, interviewing 12 families with cancer patients at five time points (time of diagnosis; 2 to 3 weeks later; 2 to 3 months later; 7 to 8 months later; and 12 months after diagnosis or treatment), and an additional 23 partners of cancer patients at three or four time points. Three primary themes or domains of concern emerged: (a) taking care of the cancer medically; (b) effects on family patterns; and (c) managing other issues that the family faced, in addition to the cancer. The 'Family Patterns' domain reflected three aspects of family interaction, including family support behaviors, major marital discord, and shifting priorities. The 'Family support behaviors' domain reflected a number challenges that families face, such as the belief by some family members that many patients seemed to expect that the other family members would be attuned to their needs and would make meeting these needs a top priority; if this did not happen then problems emerged. In contrast, family members often reported that they did not know how to provide effective support or did not have the time to provide as much support as patients wanted or needed. Overall, the findings of this study confirmed that cancer has a significant impact on family relationships.

Overall, families of cancer patients have reported that they face many issues related to cancer and its treatment, including caregiving tasks and burden (Chen, Chu, & Chen, 2004; Nijboer, Triemstra, Tempelaar, Sanderman, & Van Den Bos, 1999; Nothouse, Schafer, Tipton, & Metivier, 1999), effects on family interactions (Chen et al., 2004; Harden, 2005; Hilton, 1993; Navon & Morag, 2003; Soothill, Morris, Thomas, Harman, Francis, & Mclllmurray, 2003), changes in family roles (Harden, 2005; Hilton, 1993; Northouse et al., 1999; Soothill et al., 2003), communication difficulties (Harden, 2005; Hilton, 1993; Nalbadian, Nikolaou, Nikolaidis, Petridis, Themelis, & Daniilidis, 2001;

Navon & Morag, 2003; Porter, Keefe, Hurwitz, & Faber, 2005), and financial and psychological stresses (Edward & Clarke, 2003; Fleming, et al., 2006; Hilton, 1993; Matthews, 2003; Northouse et al., 2002; Vickery et al., 2003). At the same time, as with other families, family members must cope with issues unrelated to cancer such as their own health problems, and taking care children or other family members (Chen et al., 2004; Soothill et al., 2003). Thus, cancer affects not only the QOL of patients but also has an impact on the quality of the family members' lives, and potentially the QOL for the family as a unit (family quality of life [FQOL]).

Edward and Clarke (2003) have argued that it is important for researchers and health care providers to be family-focused, as cancer affects not just the patient but the whole family. However, although the number of studies considering family caregivers as well as the cancer patient has increased, few studies in this area have focused on FQOL (i.e., aspects of life that are unique to family membership), but rather on the QOL of cancer patients or their families (Campbell et al, 2004; Segrin, Badger, Meek, Lopez, Bonham, & Sieger, 2005; Thornton, Perez, & Meyerowitz, 2004), or assessed the agreement of ratings between the patient and other family members (Deschler, Walsh, Friedman, & Hayden, 1999; Deschler, Walsh, & Hayden, 2004; Milne, Mulder, Beelen, Schofield, Kempen, Aranda, 2006; Sandgren, Mullens, Erickson, Romanek, & McCaul, 2004; Tang, 2006). These studies used QOL instruments developed for the general population (Campbell et al., 2004; Deschler et al., 1999; Deschler et al., 2004; Thornton et al., 2004), specific cancer patients (Milne et al., 2006; Sandgren et al., 2004; Thornton et al., 2004) or caregivers (Campbell et al., 2004) but are limited by the fact that the QOL questionnaires focused on individual QOL. That is, they do not focus on challenges faced at the family level.

Although some QOL questionnaires do include a family domain or a few items related to family issues, they do not examine family issues in depth. For example, the European Organization for Research and Treatment of Cancer Quality of Life Questionniares-C30 (EORTC QLQ-C30) (Aaronson et al., 1993) has a single item related to family, "Has your physical condition or medical treatment interfered with your family life?" The Functional Assessment of Cancer Treatment-General (FACT-G): version 4 (Functional Assessment of Chronic Illness Therapy, 2003.) includes a Social/Family Well-Being domain but has only five family-related items: "I get emotional support from my family;" "My family has accepted my illness;" "I am satisfied with family communication about my illness;" "I feel close to my partner;" and "I am satisfied with my sex life." Thus, although some QOL measures assess some family aspects of functioning, their assessment of family aspects is limited, and thus cannot guide in depth intervention to maintain or promote FQOL of families with cancer patients.

A further limitation in this area is that most studies that focused on the effects of cancer on the family have used interviews to collect the data (Hilton, 1993; Navon & Morag, 2003; Northouse et al., 1999). Clearly, interviewing is a very useful method to obtain in depth data but the time and training requirements limit the ability to collect large samples, and to apply the technique in clinical settings. Questionnaire administration, in contrast, is limited in its ability to ask probing questions but is much more easily implemented in clinics, and thus allows for collection of larger datasets.

A review of the literature was unable to find a FQOL questionnaire developed for use in heath care or cancer. Three studies that examined FQOL in (a) chronic illness (including cancer) (Anderson, 1993), and (b) breast, colon, uterine, prostate cancer patients (Mellon & Northouse, 2001; Mellon, Northouse, & Weiss, 2006) used the Quality of Life --- Parent Form as an instrument. The Quality of Life --- Parent Form was developed from Olson and Barnes (1992) questionnaire, which assesses the degree of subjective satisfaction with various domains of life (marriage and family life; friends; extended family; health; home; education; time; religion; employment; mass media; financial well-being; neighborhood/community). Although some of these domains are family-oriented, they fail to cover other important domains that specifically are affected by cancer and its treatment, such as family roles and family communication.

Murphy, Ridner, Wells, and Dietrich (2007) have suggested several characteristics that QOL measurement tools should possess. These include being easy to administer, easy to understand, easy to score, having high reliability, validity, and sensitivity, and most importantly, high clinical relevance. The Family Caregiving Alliance, National Center on Caregiving (2006) has suggested that family caregiver assessment should embrace a family-centered perspective, inclusive of the needs and preferences of both the care recipient and the family caregiver, and the assessment should directly link to a plan of care and provision of services, measurable intended outcomes. Thus, what is currently needed in the field of cancer and FQOL is a tool that assesses FQOL of family among families with a cancer patient, a tool that is focused on the effects of cancer and its treatment on family issues.

Purpose of the Study

The primary purpose of this study was to develop a Family Quality of Life Questionnaire for use with families with an adult cancer patient, to develop an instrument that would be practical for use both for research and for assessment by health care providers. This questionnaire would be able to be used in conjunction with individual QOL questionnaires to assess QOL both at the individual and family level. Based on the results of my literature review, the domains at which challenges might occur for families with cancer patients face included: (a) family interactions, (b) family roles, (c) family communication, and (d) family emotional support. Thus, this questionnaire focused on the impact of cancer and its treatment on these family domains; in addition, overall FQOL was assessed to obtain general satisfaction with family life. These family domains were preliminary, however, and part of the purpose of this study was to determine whether domains might be changed or new domains added, depending on the results of the scale development work. Once this preliminary instrument had been developed, initial psychometric properties (i.e., reliability and validity) were evaluated.

Research Questions

1. Are (a) Family Interaction, (b) Family Roles, (c) Family Communication, and (d) Family Emotional Support important central aspects of FQOL for cancer patients and their families?

2. Is FQOL, as assessed by a self-report questionnaire including the above domains, unidimensional or multidimensional?

3. What are the reliability and validity of the FQOL questionnaire?

Hypotheses

To answer Question #3 regarding the reliability and validity of the proposed FQOL questionnaire, the psychometric properties of the questionnaire were assessed, including internal consistency reliability, test-retest reliability, convergent validity and discriminant validity. The hypotheses of this study were as follows:

1. The internal consistency reliability of the proposed FQOL questionnaire would be high.
2. Convergent Validity
    a. The *Family Interaction* subscale of the proposed FQOL questionnaire would be positively and significantly correlated with the Family Interaction subscale of the Beach Center Family Quality of Life Scale.
    b. The *Family Interaction* subscale of the proposed FQOL questionnaire would be positively and significantly correlated with the Balanced Cohesion subscale of the FACES IV.
    c. The *Family Roles* subscale of the proposed FQOL questionnaire would be positively and significantly correlated with the Role-Physical subscale of the SF-36.
    d. The *Family Roles* subscale of the proposed FQOL questionnaire would be positively correlated and significantly with the Role-Emotional subscale of the SF-36.
    e. The *Family Communication* subscale of the proposed FQOL questionnaire would be positively and significantly correlated with the Family Communication Scale of Olson and Barnes.

f. The *Family Emotional Support* subscale of the proposed FQOL questionnaire would be positively and significantly correlated with the Emotional Well-Being subscale of the Beach Center Family Quality of Life Scale.

g. The *Family Emotional Support* subscale of the proposed FQOL questionnaire of cancer patients would be positively and significantly correlated with the Emotional Well-Being subscale of the FACT-G

h. The *Family Emotional Support* subscale of the proposed FQOL questionnaire of family members would be positively and significantly correlated with the Emotional Well-Being subscale of modified version of FACT-G for family members.

i. The total score of the proposed FQOL questionnaire of cancer patients would be positively and significantly correlated with the total score of the FACT-G.

j. The total score of the proposed FQOL questionnaire of family members would be positively and significantly correlated with the total score of modified version of FACT-G for family members.

k. The total score of the proposed FQOL questionnaire would be positively and significantly correlated with the total score of the Family Satisfaction Scale.

3. Discriminant Validity
    a. The total score of the proposed FQOL questionnaire would be more highly correlated with the Mental Health subscale than Physical Health subscale of the SF-36.
    b. The total score of the proposed FQOL questionnaire of cancer patients would be more highly correlated with the Social/Family Well-Being, Emotional Well-Being, and Functional Well-Being subscales than Physical Well-Being subscale of the FACT-G
    c. The total score of the proposed FQOL questionnaire of family members would be more highly correlated with the Social/Family Well-Being, Emotional Well-Being, and Functional Well-Being subscales than with Physical Well-Being subscale of the modified version of FACT-G for family members.

Significance of the Issue and the Study

Significance to Society

As a disease with a relatively high incidence and profound impact on people's lives, cancer has a significant effect on society. Cancer is the second most common cause of death in the US, exceeded only by heart disease (American Cancer Society, 2007). In 2007, the American Cancer Society estimated there were 1,444,920 new cancer cases, not including carcinoma in situ of any site except urinary bladder and basal and squamous cell skin cancers. About 559,650 Americans are also expected to die of cancer in 2007, more than 1,500 people a day. However, the 5-year survival rate of cancer is increased. The National Cancer Institute estimates that approximately 10.5 million Americans with a history of cancer were alive in January 2003 (American Cancer Society, 2007). Some of these individuals were cancer-free; however, others still had cancer or recurrence of cancer and may have been in ongoing treatment.

Since individuals of working age as well as the elderly are at heightened risk for cancer, cancer often results in lost productivity in the workplace, because cancer and its treatment have an impact on many patients during the prime of their economic productivity. Cancer invariably also affects the patient's family. National Alliance for Caregiving and AARP (2004) estimated that 44.4 million Americans provide care for adult members and friends who are disabled, or have illnesses or conditions requiring long-term care. Of this number, 8% reported providing care to cancer patients. These informal caregiving responsibilities overall (i.e., not only for cancer) result in $11.5 billion annually in lost productivity (Family Caregiving Alliance, National Center on Caregiving, 2006). Informal caregivers individually lose about $659,139 over a life time: $25,494 in Social Security benefits, $67,202 in personal benefits, and $566,443 in lost wages. Because cancer affects the productivity of society as well as family issues, national agencies such as Family Caregiving Alliance work to shape public policy to support family caregivers.

One of the important strategies reported by the National Consensus Development Conference held by Family Caregiving Alliance, National Center on Caregiving (2006) was an assessment that examined family caregivers and care recipients using a family focus. Thus, development of a FQOL questionnaire for families with cancer patients would be useful for family policy makers and health care providers, both to demonstrate the need for supportive policies as well as to determine the effects of policies in this population.

Significance to Health Care

In recent years, public health policy has directed treatment towards more holistic and global systems that consider individuals integrated into their family and community, with the goal of not just decreasing mortality but also of increasing QOL, decreasing health disparities, and promoting the health of people and communities. For instance, the goals of Healthy People 2010 are to increase quality and years of healthy life and to eliminate health disparities across sub-groups within the U.S. (U.S. Department of Health and Human Services, 2000). The American Cancer Society (2007) set the goal for 2015 to dramatically decrease cancer incidence and mortality rates while at the same time increasing the QOL for all cancer survivors. Although this goal focuses on cancer survivors, the American Cancer Society has recognized the importance of families and the impact on families of cancer. Thus, the American Cancer Society supports families of cancer patients in many ways by, for example, being a resource for families for information or support, developing policies for families of cancer patients, and providing research funding to studying QOL in family.

Increasing recognition of the importance of a family perspective has been given by health care providers because they understand that family is a core part of health care. The Family Caregiver Alliance, National Center on Caregiving (2006) reported that achieving quality of care and increasing QOL in cancer patients depends on embracing a family-centered perspective, and concluded that it is essential that the family be recognized, respected, assessed, and have its needs addressed. Assessing FQOL of families who have cancer patients is an essential component for determining and addressing the impact of cancer and its treatment on families.

Significance to the Discipline, Science, and Practice of Nursing

As a holistic profession, nursing focuses not only on patients but also on their families. According to the Nursing Social Policy Statement of the American Nurses Association, the recipients of nursing care are individuals, groups, families, and / or their communities (American Nurses Association, 1998). This policy was made explicit when the American Nurses Association established standards for clinical practice that includes both patients and families. According to these standards, nursing care is to be individualized to meet a particular patient's unique needs and situation, including awareness and respect for the patient's as well as the family's goals (American Nurses Association, 1998). Thus, nurses have a responsibility to care not only for patients but also for patients' families. In addition, the American Nurses Association and Oncology Nursing Society (1996) determined that, in oncology nursing, the "client" can include individuals, families, groups, and communities.

The practice of oncology nursing encompasses a number of roles, including direct caregiver, educator, consultant, administrator, and researcher. One of primary goals of oncology nursing is facilitation of optimal individual and family functioning throughout the cancer disease trajectory (American Nurses Association and Oncology Nursing Society, 1996). Thus, understanding FQOL, of what it consists, how it relates to cancer and its treatment, and how to maximize FQOL are important components in fulfilling nursing's role of facilitating optimal family functioning.

Awareness and conceptual understanding of FQOL can help nurses view health problems and patients more holistically, and examine the familial contexts of health problems. By understanding how cancer influences FQOL, nurses may develop better strategies to promote health by using important family resources, knowing where to intervene, and being aware of resources a family may need to support the patient (Mellon & Northouse, 2001).

Finally, the study of FQOL is important to nursing because, as Danielson, Hamel-Bissell, and Winstead-Fry (1993) stated, if professionals ignore the family, the health care system and the family may be at cross purposes. Cancer creates a stressful situation for the entire family and affects each family member (Ben-Zur et al., 2001), and a change in one family member affects all family members (Wright & Leahey, 1994). For health care providers and the patient's family to have a collaborative focus, it is essential to understand how the illness impacts the family, how the family understands, or misunderstands the illness, what stresses the family as well as the patient face. Consequently, a FQOL questionnaire for families with cancer patients can advance nursing knowledge of the impact of cancer on the QOL of patients and their families as an instrument of family research and as an assessment tool for clinical purposes, promoting the development of standards of care for clinical practice that will best serve the patient and family, broadly defined.

CHAPTER II

LITERATURE REVIEW AND THEORETICAL FRAMEWORK

Quality of Life

In his review of the history of the concept of QOL, Meeberg (1993) notes that the first use in an official governmental context of the phrase “quality of life” occurred in a speech by Lyndon Johnson at Madison Square Garden in October, 1964. More generally, the term “quality of life” first began to be used in the U.S. after the Second World War, to emphasize that there was more to having a “good life” than just being financially secure (Campbell, 1981, cited in Meeberg, 1993). This use probably reflects the history of the U.S. economy, which expanded rapidly after WWII and, as a result, financial security became easier to obtain, and people thus began to look beyond financial security to developing their QOL.

Since that time, QOL has been widely used in sociology and health care, with the meaning diverging somewhat across different academic disciplines. In sociology and the social sciences, QOL generally has referred to general life satisfaction or a sense of subjective well-being at individual or at community levels (Gerson, 1976). In health care too, researchers and clinicians have become interested in QOL, moving beyond not only mortality and survival rate of patients but also on ways to increase the quality of patients’ lives. QOL is one of the important outcomes in health care and is a major consideration (along with survival rates, etc.) when health care providers, patients, and their families make treatment decisions, especially with chronic diseases such as cancer. However, health care providers have concluded that sociology's definitions of QOL are too broad for health care's purposes and may fail to provide health care professionals with clinically relevant and interpretable information that can guide treatment decisions (Murphy, Ridner, Wells, & Dietrich, 2007). Thus, the term health-related QOL (HRQOL) has been developed for use in health care arena. However, the terms QOL and health-related QOL generally are used interchangeably, referring to the well-being of the individual patient or client broadly in regards to health and health problems, such as the side effects of treatments.

Although there is a relatively high level of interest by health care providers and health researchers on QOL, there is no consensus definition for QOL. The World Health Organization (1997) defined QOL as individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns. This is a broad concept affected in complex ways by the person's physical health, psychological state, level of independence, social relationships, personal beliefs, and relationship to salient features of their environment. Haas (1999) analyzed the concept of QOL and summarized the definitions and attributes of QOL, concluding that QOL (a) is multidimensional, (b) is an evaluation of an individual's current life circumstances, (c) is value-based and dynamic, (d) comprises subjective and / or objective indicators, and (e) is most reliably measured by subjective indicators by persons capable of self-evaluation.

Similarly, in the cancer area, Cella (1994) characterized QOL as subjective and multidimensional. Because it involves subjective experiences, Cella (1994) believes that QOL is best measured from patients' perspectives. Because it is multidimensional, its measurement requires inquiry about a range of areas of the patient's life, including physical well-being, functional ability, emotional well-being, and social well-being. Gotey and Moore (1992) defined QOL in head and neck cancer as a state of well-being in which an individual is able to perform everyday activities related to physical, psychological, and social well-being and patient satisfaction with function and / or control of disease, and / or treatment-related symptoms.

Thus, based on literature review, QOL in health care has two characteristics important for clinicians and researchers. First, QOL is multidimensional, and includes at least four core domains and other domains related to health and the impact of diseases and treatments on satisfaction of people's lives. The four core domains are: (a) physical, (b) functional, (c) psychological / emotional, and (d) social (Becker, Shaw, & Reib, 2005; Cella, 1994; Cooley, 1998; Gotey & Moore, 1992; List & Stracks, 2003; Portenoy, 1999; WHO, 1997). Secondary domains include: (e) spirituality (Cella & Tulsky, 1990; Haas, 1999; Porteney, 1999; WHO, 1997); (f) relationships with health care providers; (g) finances (Porteney, 1999); (h) the environment (WHO, 1997); and (i) global ratings of QOL (Cella & Tulsky, 1990). Second, it is generally accepted that QOL is comprised of both subjective and objective elements. Thus, patients and caregivers are the best source of information for their own QOL but other persons, such as caregivers and clinicians who are close with patients, also can provide important information regarding patients' QOL.

Family Quality of Life

These conceptualizations and definitions of QOL have focused on individual level. However, health care providers realize that the family plays a vital role in caring and supporting cancer patients. Health care providers also realize that cancer and its treatments do not affect only the QOL of cancer patients but also the QOL of their families. Thus, interest in FQOL of families of patients who have cancer has increased in research and clinical practice. Because FQOL is a new construct and has just recently started to develop in health care and cancer area, there were few studies about FQOL. In the present study, FQOL as conceptualized in sociology, special education, and health care were reviewed to better understand this phenomenon.

The Concept of Family

Before beginning to discuss the concept of FQOL, it is first necessary to consider the concept of the family. The English word “family” is derived from several languages. The Merriam-Webster dictionary (Gove & the Merriam-Webster Editorial Staffs, 2002) identifies the word family as coming from Latin, French, and Sanskrit. In Latin, family is *familia* and is defined as “servants of a household,” with the household thus including more than persons related by blood or marriage. In French, family is *famulus* and is defined as “servants” and “kin to,” with this latter term referring to marriage and blood kin. In Sanskrit, family is *dhaman,* defined as “dwelling place,” and *dadhati*, defined as “he put and places.” Most definitions in dictionaries identify the meaning of family as being related to people. For example, Webster’s Third New International Dictionary of the English Language Unabridged a Merriam-Webster (Gove & the Merriam-Webster

Editorial Staffs, 2002) defines family as a noun that refers to the basic biosocial unit in society having as its nucleus two or more adults living together and cooperating in the care and rearing of their own or adopted children. The Encyclopedic Dictionary of Sociology (Frank et al., 1986) defined family as “a set of persons related to each other by blood, marriage, or adoption who constitute a social system.” Stedman’s Medical Dictionary (Hensyl, 1990) identified family as “a group of blood relatives,” or, more strictly, the parents and their children. Thus, the meanings of family from dictionaries focus on people who are related by blood, marriage, or adoption.

Social and economic changes have influenced family structure, and current family structure differs from the past. At present, in the U.S. most families are nuclear families as opposed to extended families. Some couples do not marry but live together for extended periods, and many people remain single. Thus, the current meaning of family is broader than in the past. Stuart (1991) analyzed the concept of family and summarized the attributes of family, including (a) the family is a system or unit; (b) its members may or may not be related and may or may not live together; (c) the unit may or may not contain children; (d) there are commitments and attachments among unit members that include future obligations; and (e) the unit’s functions consist of protection, nourishment, and socialization of its members. In health care, family is defined as a social system or entity composed of a plurality of interacting persons (Thomas, 1982).

The family system may be defined as the relationship of the parts (Thomas, 1982), the units of which the family is composed, and the relationship between structure and function. Thus, from Thomas’s perspective about family, changes in the family system produce changes in the members of the system. In a family nursing textbook, Friedman et al. (2003) defined family as two or more persons who are joined together by bonds of sharing and emotional closeness and who identify themselves as being part of the family.

Because the meaning of family is very broad, the issues of how family should be defined or who are appropriate subjects for family studies (and hence who should be included in FQOL) merits some discussion. Feetham (1984) stated that the researcher may define family by the study subjects in terms of their functional relationships to each other. In addition, Friedman et al. (2003) stated that the only way of determining an individual's perceived family is to directly ask him or her. However, researchers must explicitly state the inclusion and exclusion criteria for 'family' (which could, however, be based on the subjects' definition), with patients or families determining who they consider to be in their family. For example, Poston, Turnbull, Park, Mannan, Marquis, and Wang (2003) defined family as including the people who think of themselves as part of the family, whether or not related by blood or marriage, and who support and care for each other on a regular basis.

Given the above discussions, in this study, family was defined broadly as a system comprising two or more persons who are joined together by bonds of sharing or emotional closeness, wherein each person identifies who are his or her family members. Cancer patients identified their families who care them and/or share cancer experiences with them, because both cancer patients and their family members who care, support, and share cancer experiences with patients receive the direct impact from cancer and its treatment on their FQOL as a family unit.

History of the Family Quality of Life Concept

The term FQOL or quality of family life has been used in family policy since the 1970s. Rodger (1975) stated that “to ask about a country’s family policy is to ask how State action and Government policies are actually affecting families and the quality of family life --- not just poor families, but all families in that country” (p. 113). In this paper, Rodger did not directly specify the meaning of quality of family life but rather connected it to increases in the economic viability of the family and promotion of family welfare. McDonald (1979) suggested that advocates and policy makers include enhancement of family well-being and QOL for families as a broad goal of family policies. However, although policy makers subsequently increasingly began to consider FQOL and suggest that it should be an outcome of family policy, they did not provide a definition of the term.

After its initial appearance in the policy arena, the concept of FQOL began to be used as a variable in sociology, special education, and health care. Sociologists have used the term quality of family life to refer to the general life satisfaction of the family. The first actual study that used this concept was conducted in 1988 to study marital quality, parental satisfaction, and life satisfaction (Pittman & Lloyd, 1988). Rettig and Leichtentrit (1999) next conducted a study focusing on family well-being. However, few studies focusing on FQOL have been conducted in sociology, and these tend to focus on family well-being broadly, without consideration of the health of families.

Historically, there has been more interest in FQOL in special education than in other disciplines and within the last decade; many studies have been conducted investigating FQOL in families with children with disabilities. Because this concept is new and relatively undefined, many of these studies have focused on how best to conceptualize FQOL and its domains (Brown, Anand, Fung, Isaacs, & Baum, 2003; Poston et al., 2003), with subsequent studies developing measures to assess FQOL in families with disabled children (Park et al., 2003). Current studies of FQOL in special education have begun to go beyond this, to identify variables that predict FQOL (Jokinen & Brown, 2005; Wang et al., 2004), and hence may explain its development.

In health care, the concept of family well-being was first raised in Thomas's article (1982) that identified the principal goal of the family as the development individual competence and to ensure family members' well-being. However, Thomas (1982) did not define of family well-being directly. He referred to the concept of wellness, that is more than the absence of disease, and he suggested that family well-being can be predicted from family structure, functional role processes, and vulnerability.

In nursing specifically, the term of FQOL has been used since 1990s. The concept of FQOL was first used empirically in Anderson's (1993) dissertation study of the relative contribution of illness-related stress and family system variables to FQOL during early chronic illness. Since then, there have been a few additional studies. This limited literature has focused primarily on chronic illnesses such as cancer (Mellon, 2002; Mellon & Northouse, 2001; Mellon et al., 2006) and mental disorders (Walton-Moss, Gerson, & Rose, 2005). However, in health care, the conceptual model and FQOL assessment instruments have been taken from other disciplines, especially sociology, rather than being developed specifically for health care. Most recently, however, there has been interest in the development of conceptual models of FQOL specifically for cancer patients and their families (Mellon & Northouse, 2001) although there has been little work on development of assessment instruments for FQOL in cancer patients.

Definitions of Family Quality of Life

In various academic domains, this construct has been referred to as both “Family Quality of Life” and “Quality of Family Life,” with the former tending to be used in health care and special education, and the latter being used in sociology. Both terms refer to the same construct, the QOL for the members of the family, and the quality of their life as a unit. In this study, for the sake of consistency, I generally refer to “Family Quality of Life”; when reviewing a particular study, I used the term that the author(s) of the study used, but it should be recognized that these terms are interchangeable.

Although the concept of FQOL has been used since the 1970s, few formal definitions of FQOL have been proposed. Rettig and Leichtentritt (1999) defined FQOL as a multidimensional well-being concept, involving the experiences and observations of several individuals within a family system, whose combined evaluations of family well-being are latent indicators of FQOL. FQOL has been explicitly operationally defined in only two studies. Anderson (1993) defined FQOL as the subjective assessment of the extent of satisfaction of how needs in multiple areas of life are met in the environment. However, this definition is very broad and not specific to the family level. Park et al. (2003) defined FQOL as the conditions where the family’s needs are met, and family members enjoy their life together as a family and have the chance to do things that are important to them. This definition goes beyond individual QOL to FQOL and shows that FQOL should be considered at the family unit, beyond individual QOL.

Based on critical analysis, three conceptualizations of QOL of families with a cancer patient can be distinguished. The first is the study of the QOL of family caregivers only (Borneman et al., 2003; Burn, 2003; Hwang et al., 2003; Weitzner, McMillan, & Jacobson, 1999). These studies used general QOL questionnaires and / or used QOL questionnaires developed specifically for caregivers (Borneman et al., 2003; Burn, 2003; Hwang et al., 2003; Weitzner et al., 1999). However, these studies focused on the individual rather than the family level, as they examined physical, functional, emotional, and social problems of family caregivers affected by cancer and the side effects of its treatment.

The second perspective focuses on domains of family life as a whole, including broad aspects of family life, such as housing (Mellon & Northouse, 2001; Mellon et al., 2006). Studies using this perspective have focused on the determinants influencing FQOL and collected data from both patients and their family caregivers in a dyad, using a QOL questionnaire based on a sociological perspective that examined broad domains of family life. Although these studies attempted to examine QOL at the family level, the domains upon which they focused do not specifically or distinctly assess the impact of cancer and its treatment on FQOL (e.g., they focused on satisfaction with education, but not on the potential effects of cancer on family roles). In addition, this second perspective does not provide useful information or suggest interventions to promote FQOL domains by the clinician.

The third perspective focuses on aspects of QOL that are unique to family life, such as family relationships, roles within the family, etc., parts of life that are inherently part of a family but not of an individual (Chen et al., 2004; Boyle et al., 2000; Harden, 2005;

Hilton, 1993; Matthews, 2003; Navon & Morag, 2003; Nijboer et al., 1999; Northouse et al., 1999; Soothill et al., 2003, Thornton et al., 2004). Most studies using this perspective collected data from both cancer patients and their family caregivers, and used open-end questions or in-depth interview to explore family life domains affected by cancer and its treatment. In the present study, because of its potential to add unique information and understanding, this third perspective was used, focusing on aspects of Quality of Life unique to family life.

Theoretical Framework

Because FQOL in families with a cancer patient is a relatively new construct, there is no specific framework that can be used. In this study, then, a more general Family Systems Theory was used, as a broad concept to understand the relation between individual and family levels of functioning. Conceptualizations of FQOL in sociology, special education, and health care were used to suggest broad FQOL domains. Finally, findings from empirical studies about the impact of cancer and its treatment on families were used to determine specific FQOL domains and generate items for each domain of this questionnaire.

Family Systems Theory

Understanding FQOL requires an understanding of family members individually, the family as a unit, and the relationship between the family and society or the community. Thus, Family Systems Theory seems likely to be a useful theory for understanding these different levels of family. Family Systems Theory is derived from General Systems

Theory, developed by Von Bartalanffy in 1950 (Friedman et al., 2003); it more recently has been influenced by the holistic paradigm and by cybernetic and communication theories (Friedman et al., 2003; Steinglass, 1984).

Family Systems Theory views the family as an interacting system. All parts of this system are viewed as interconnected or interrelated, with the whole greater than the sum of its parts (non-summativity). Understanding is possible only by viewing the family as a whole, by understanding the effects of the family as a whole has on each of its parts (the ripple effect), and vice versa. Causes and effects within the family are interchangeable (circular causality notion), and family systems are self-reflexive and goal seeking at the unit level. Family adaptation is the capacity of the family and its members to modify their behavior to the changing demands of the family's inner and outer worlds.

The family is an open system in that interacts with external as well as internal environments. In Family Systems Theory, the internal environment is comprised of subsystems or sub-units of the primary family system, such as subsets of family relationships; e.g., spouses, parent-child, sibling subsystems. The external environment is comprised of supra-systems, the larger environmental systems of which the family is a part, such as the family's culture reference group and community. Friedman et al. (2003) has suggested that if one wants to study the family using Family Systems Theory as a framework, then it is necessary to study the sub-systems and supra-systems of the family as well.

However, this is a high level theory that does not provide explicit guidance about how to study phenomena. And although the theory states that the whole is greater than the sum of its parts, it does not explicitly state how one should collect and analyze data to capture that whole. The theory does, however, provide a reminder of the importance of interactions, reciprocal effects, and the contextual factors of family, and guide family researchers. Thus, from Family Systems theory, FQOL is conceptualized as the QOL of a system, with the individual QOL of each family member representing a sub-system. Community and society are supra-systems, as shown in Figure 1. From this perspective, if we want to study FQOL we must to study not only the individual QOL of each family member but also family members' interactions as a family unit. However, because of limited time and resources, the present study focused on the relationship between a system and a sub-system only with the family system, and did not include the supra-system. That is, this study focused on FQOL domains related to the relationship of family as a family unit.

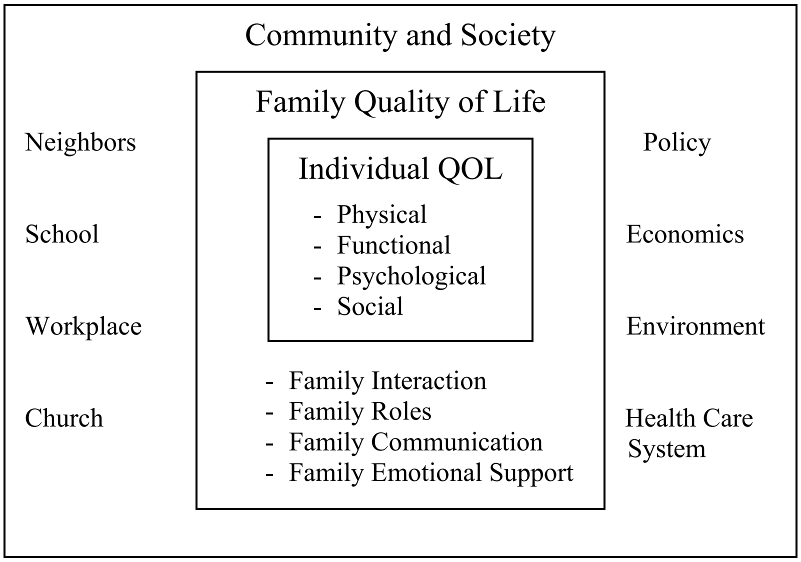

Figure 1. Family Quality of Life

Family Quality of Life Domains in Sociology, Special Education, and Health Care

Conceptualizations of FQOL domains vary across each area or discipline of study, with little or no consensus regarding what appropriate FQOL domains are. Although some studies have not explicitly identified FQOL domains, the FQOL domains in their questionnaires can be used to infer their perspectives about FQOL. Thus, FQOL domains and FQOL questionnaires were reviewed to identify FQOL domains. This literature review included four review articles (Caldwell, 2003; Smith-Bird & Turnbull, 2005; Summers et al., 2005; Thomas, 1982) and seven studies that identified FQOL domains (Anderson, 1993; Hoffman, Marquis, Poston, Summers, & Turnbull, 2006; Mellon & Northouse, 2001; Park et al., 2003; Poston et al., 2003; Pittman, & Lloyd, 1988; Rettig & Leichtentrit, 1999).

In sociology, Pittman and Lloyd (1988) used the following FQOL domains: (a) quality of the marital relationship; (b) parental satisfaction; and (c) life satisfaction. Rettig and Leichtentrit (1999) suggested using Foa's resource theory as indicators of FQOL, with these indicators being satisfaction in the following domains: (a) love; (b) status; (c) information; (d) money; (e) goods; and (f) services. Love was defined as an expression of affection, warmth, or comfort. Status was defined as an expression of evaluative judgment that conveys high or low prestige, respect, or esteem. Information was defined as advice, opinion, instruction, or enlightenment. Money was defined to include any form of currency that has some standard of value. Goods were defined to include tangible products, objects, or materials. Services included activities on the body or belongings of a person that often constitute labor for another. Although these FQOL domains did not include health, they cover FQOL domains that involve satisfaction in life and role, financial well-being, and social domain.

In special education, two groups have developed FQOL surveys involving explicit domains. These teams include the research group from the Beach Center on Disability from the University of Kansas, and a group of researchers from Australia, Canada, and Israel. The Beach Center developed FQOL domains and a FQOL survey based on Poston et al.'s (2003) and Park et al.'s (2003) work. Poston et al. (2003) studied domains of FQOL based on the perspectives of (a) family members of children and youth with and without disabilities, (b) service providers, and (c) administrators. Poston et al. (2003) concluded that the same questions used to structure an assessment of individual QOL also may be used for FQOL. To determine individual QOL, questions such as "For me to have a good life, how important is it for me to get the medical care when I need it?" were asked. In moving from an individual to a family unit for analysis of QOL, the same question was, for instance, modified to read "For my family to have a good life together, how important is it for my family members to get the medical care when they need it?" As this sample question indicates, from the perspective of Poston et al. (2003), FQOL represents a relatively straightforward transformation of individual QOL domains to consider all family members as the subject, in terms of what it takes for them to have a good life from their aggregated perspective. However, Poston et al. (2003) suggested that in contrast to individual QOL, FQOL addresses the impact of individual QOL on the family (i.e., the interactions and effects of individual members as they produce the aggregate of FQOL).

According to their findings, individual QOL domains for children with disabilities included satisfaction with:

- *Advocacy*: Advocacy role, advocacy activities, and facilitators of advocacy.
- *Emotional well-being*: Identity, respect, reducing stress, and choice.
- *Health*: Physical health, mental health, and health care.
- *Environmental well-being*: Home, school, work environment, and neighborhood and community.
- *Productivity*: Education, work, leisure, and personal development.
- *Social well-being*: Acceptance, relationships, and support.

In contrast, the FQOL domains included satisfaction in:

- *Daily family life*: Family care, daily activities, and getting help.
- *Family interaction*: Positive interactional environment, communication, supporting each other, and flexibility.
- *Financial well being*: Paying for basic necessities, paying for health care, paying for other needs, sources of income, and financial security.
- *Parenting*: Providing parental guidance, discipline, and teaching.

The results of this study indicated that the domains of individual QOL differ from the domains of FQOL and thus, measuring FQOL by using individual QOL questionnaires may fail to capture important FQOL domains. There have been three questionnaires that developed specific Family Quality of Life domains. First, Park et al. (2003) developed the Family Quality of Life Survey based on Poston et al.'s (2003) FQOL domains, which included: (a) family interaction, (b) parenting, (c) health and safety, (d) general resources, and (e) support for persons with disabilities. Second, based on studies of Poston et al. (2003) and Park et al. (2003), the Beach Center group identified FQOL domains and developed a FQOL survey for families who had disabled children, with the following domains: (a) family interaction, (b) parenting, (c) emotional well-being, (d) physical/material well-being, and (e) disability-related support (Hoffman et al., 2006; Smith-Bird & Turnbull, 2005; Summers et al., 2005). And third, a team of researchers from Australia, Canada, and Israel developed the Family Quality of Life Survey, which included the following domains: (a) health, (b) financial well-being, (c) family relationships, (d) support for other people, (e) support from services, (f) careers and preparing for careers, (g) spiritual and cultural life, (h) leisure, and (i) community and civic involvement (Brown et al., 2003). There are some similarities among domains between the Beach Center and Brown et al. (2003) FQOL domains, including health, financial well-being, family interaction, and support from services. Thus, these domains may be particularly important FQOL domains, at least in regards to families with children in special education services.

However, these domains may or may not be applicable to other populations, especially families who have cancer patients, in part because cancer patients often are adults, and because the challenges that cancer patients and families face are at least somewhat different from those of families of children with disabilities. In health care, Thomas (1982) used Family Systems Theory as a conceptual framework and proposed that several factors would underlie family well-being: (a) family structural components, including family stress, family satisfaction, family support, family cohesion, and family adaptation; (b) family functional role processes, including role conflict, role overload, role ambiguity, role nonparticipation, and role preparedness; and (c) family vulnerability, including psychosomatic symptoms and life satisfaction. Based on this conceptualization, Caldwall (2003) developed the Family Well-Being Assessment Tool, to measure perceptions of roles as a parent and child within the nuclear family; however, this tool was developed for use with families with children with a chronic illness (Caldwell, 2003).

In studies of families with an adult cancer patient, no questionnaire has been developed to assess FQOL, although three studies about FQOL in families with a chronically ill family member. Anderson (1993) focused on families with a member with cancer, and Mellon and Northouse (2001) and Mellon et al. (2006) used the Quality of Life---Parent Form (Olson & Barns, 1992) to measure FQOL among families with a member with breast, colon, prostate, and uterine cancer. This questionnaire has domains covering satisfaction with: (a) marriage and family life, (b) friends, (c) extended family, (d) health, (e) home, (f) education, (g) time use, (h) religion, (i) employment, (j) mass media, (k) financial well-being, and (l) neighborhood and community. However, this questionnaire was developed from a sociological perspective, so it does not focus on the impact of disease and its treatment as part of FQOL.

Based on critical analysis, the conceptual frameworks of individual QOL and FQOL do have some overlap in definitions and attributes. Both individual QOL and FQOL frameworks are multi-dimensional, focus on perceptions of well-being, and include both subjective and objective components. However, QOL and FQOL focus on different levels or aspects of life (i.e., the individual and the family, respectively). FQOL domains differ somewhat across disciplines and areas of study, although there are some common domains across disciplines including family interaction, health, roles, employment, financial well-being, emotional well-being, leisure, spiritual, community, support for others, support from services, and life satisfaction. Consequently, these domains appear to be central to FQOL, and were incorporated into the instrument developed in the present study.

The Impact of Cancer and its Treatment on Family Quality of Life

There is much evidence demonstrating significant impact of cancer and its treatment on families, in particular on family relationships. Navon and Morag's study (2003) found that the side effects of prostate cancer and hormonal therapy affected the relationships between patients and their spouses widely, including their daily life, leisure activities, sexual and emotional closeness, sincerity and communication, and the roles and relative status within the family. There is evidence that some families with cancer have experienced family relationship problems for at least a year after the beginning of treatment (i.e., from the time of diagnosis). Boyle et al. (2000) found that family caregivers of cancer survivors who had autologous bone marrow transplantation rated the social adjustment of family and coping with relationship changes as the first and second most significant challenges that they faced when the patient returned home and was attempting to re-establish daily life. The patients rated coping with family was one of the most difficult issues that they faced when returning home. Thornton et al. (2004) found that prostate cancer patients who had radical prostatectomy and their partners reported poorer relationship quality at one year post-surgery compared to pre-surgery. The findings of Hilton's longitudinal study (1993) in families with a member with breast cancer also indicated that problems with family relationships remained one year after diagnosis or surgery. However, no longitudinal studies about the quality of family relationships extending more than one year were found. Thus, we do not know how long the impact of cancer and treatment on the family lasts, though these one year results suggests that it may extend for a significant period of time.

Based on a review of the literature, the impact of cancer and its treatment on family relationships includes (a) *family interactions* (Chen et al., 2004; Harden, 2005; Hilton, 1993; Navon & Morag, 2003; Soothill et al., 2003); (b) *family roles* (Chen et al., 2004; Boyle et al., 2000; Harden, 2005; Hilton, 1993; Matthews, 2003; Navon & Morag, 2003; Nijboer et al., 1999; Northouse et al., 1999; Soothill et al., 2003, Thornton et al., 2004); (c) *family communication* (Harden, 2005; Hilton, 1993; Porter et al., 2005; Soothill et al., 2003); and (d) *family emotional support* (Borneman et al., 2003; Boyle et al., 2000; Harden, 2005; Hilton, 1993; Northouse et al., 1999; Segrin et al., 2005; Soothill, et al., 2003). Although some of these studies examined the effects on FQOL of specific types of cancer such as breast cancer (Hilton, 1993; Segrin et al., 2005), colon cancer (Nijboer et al., 1999; Northouse et al., 1999), gastrointestinal cancer (Porter et al., 2005) and prostate cancer (Harden, 2005; Navon & Morag, 2003; Thornton et al., 2004), or included multiple types of cancer (Borneman et al., 2003; Chen et al., 2004, Matthews, 2003; Soothill et al., 2003), results across the types of cancer were similar in areas of family interaction, roles, communication, and emotional support.

Family Interactions. Hilton (1993) investigated issues, problems, and challenges of 12 families coping with breast cancer, by interviewing the families first at the time of diagnosis and then 12 months after the diagnosis or treatment began. Hilton (1993) identified three categories of concerns related to family interactions, including (a) family support behaviors, (b) shifting priorities, and (c) marital discord. Hilton (1993) found that families often did not know how to provide effective support or did not have the time to provide as much as the family members wanted or needed. Family problems developed when cancer patients felt that their husbands did not support them or were not concerned as the patient felt they should be. In addition, one year after diagnosis, couples often were in conflict with each other because family members' expression of concern decreased after the early treatment period. In addition, in response to their increased awareness of the effects of cancer, families often shifted their priorities to reduce risk factors (e.g., diet, smoking, and stress) and to increase QOL of their families. However, some family members were unable to adjust to these changes and conflict developed in family. Although the findings of Hilton's (1993) study highlighted the importance of family support behaviors, this study did not identify the specific support behaviors that were important, with the exception of showing concern. However, in interviews with families who had prostate cancer, Navon and Morag (2003) found that supportive behaviors included (a) emotional expression through displays of affections, (b) concern about the patients' health, (c) time devoted to discussing their fears and hopes, and (d) their encouragement to participate in joint leisure activities, such as cooking a meal or reading a book together.

Marital and sexual relationships appear to be a major area of concern for cancer patients and their spouses or partners. Harden (2005) reviewed the literature about the couples' experiences with prostate cancer, and concluded that the side effects of urinary incontinence and sexual impotence can threaten male's self-image and create conflict in marital relationships. In addition, the side effects of cancer treatments may add to these problems. Navon and Morag (2003) studied the adverse impacts of hormonal therapy on the relationships of 15 advanced prostate cancer patients and their spouses, using in-depth interviews. Eight of their subjects reported that the changes in their personality and bodily appearance had created a physical and emotional distance between them and their spouses, with their partners refusing to have any physical contact with them, and some even fearing that the illness was contagious; some patients felt that a man lacking sexual capabilities was worthless, and cannot make any demands on his wife. Although the other seven participants reported that they were able to adjust by using non-coital sex or by trying to use sexual stimulation, this came at some cost since hormonal therapy reduces sex drive for all patients, and these patients thus were pushing themselves to perform sexually, for the sake of their relationship. More generally, cancer patients and their partners may differ in their sexual needs, which may increase stress on the relationship. Soothill et al. (2003) found that only 10% of cancer patients wanted professional help in regards to sexual whereas 50% of their partners wanted help in this area. This difference in perceived needs may increase problems if the needs of patients or their partners are out of balance. In addition, due to the chronic nature of cancer, it may affect the broader marital relationship as well. Hilton's (1993) longitudinal study found that some couples with breast cancer initially had been more in harmony but as time passed the differences and disturbances became greater and resulted in marital discord. Thus, the marital relationship is a key issue that health care provider should consider and assess in families with cancer, because marital satisfaction is a central element of QOL of cancer patients and their spouse (Chen et al., 2004) and protect stress related to cancer (Mellon et al., 2006).

In summary, an important component of family interactions involves family intimacy, behaviors that support partners and serve to maintain the family structure and functioning. In families with cancer, family supportive behaviors and the marital relationship are important aspects of family interactions that may be influenced by the cancer and its treatment. However, there are a number of limitations in this literature. Most studies (a) did not directly examine the impacts of cancer on the family interaction but rather relied on self-report, (b) used small sample sizes, and (c) only collected data from cancer patients and their spouses or partners but not other family caregivers. In addition, most studies used interviews to collect data, which although useful for exploring issues makes it difficult to collect larger samples.

Family Roles. Family roles are one area that researchers have studied in depth, because family members generally must change their roles to become caregivers for the patient. At the same time the family members need to maintain their same current roles, as well as possibly add more roles if patients cannot maintain their own roles. Thus, family members have responsibility for many roles. Based on a literature review, family roles that change in response to cancer include: (a) caregiving, (b) household work, (c) child care, and (d) working. If families are unable to adapt their roles and their attitudes towards the new responsibilities, burden or role strain can develop (Harden, 2005).

Ultimately, these challenges will affect family relationships and QOL of family members (Chen et al., 2004).

When a family member has cancer, other family members have to change their roles to be primary caregivers and spend a significant portion of them providing care for the cancer patient both during and after the treatment period. Chen et al. (2004) found that during the treatment period, the average duration of care of spouse caregivers of breast, head and neck, and esophageal cancer patients was 18.09 months. The average care intensity was 6.14 days per week, with 74.4% reported they provided care to patients seven day a week. Mean daily care responsibility was 20.29 hours per day, with 71.9 % reported caregiving responsibility for their sick spouses 24 hour per day. Not surprisingly, the tasks and responsibilities of family caregivers are related to the specific physical problems and functional abilities of the cancer patient. For instance, Thornton et al. (2004) found that prostate cancer patients who had radical prostatectomy were more limited in their role performance due to physical problems at 3 weeks postsurgery, and required more care from their partner. These patients functioning improved between 3 weeks and 1 year postsurgery (except for sexual and urinary functioning) and the care responsibilities of the partner also decreased (i.e., improved) after 3 weeks and 1 year postsurgery.

Northouse et al. (1999) interviewed 30 colon cancer patients and their spouses after treatment. They found that 57% of patients reported changes in their functional ability, especially in regards to managing their care (e.g., colostomy) and managing symptoms associated with their disease; 30% of patients reported changes related to health-related activities such as spending more time driving to medical appointments or taking medicines. Subjects reported that they had to spend time altering diet plans, driving to medical appointments and both direct (e.g., care of patients' colostomy) and indirect care (e.g., shopping for supplies). Family caregivers also had responsibilities not only for the cancer patients but also other family members, their own health problems (Chen et al., 2004), and other health problem of cancer patients (Hilton, 1993). The actual activities involved in caring for the patient often are difficult because family caregivers frequently must cope with physical and mental complications of the chronic illness (Boyle et al., 2000). These factors also affect QOL of family. Nijboer et al. (1999) found several factors related to reduced QOL, including low income, living only with the patient, a high level of patient dependency, a necessity for performing more care tasks, and the level of changes in activities.

Cancer also impacts on families in regards household chores and child care. Some cancer patients cannot perform household chores because of their physical and functional problems, and other family members thus must take on additional household responsibilities (Northouse et al., 1999). Soothill et al. (2003) studied unmet needs of cancer patients and their family caregivers. They found that 13% of cancer patients needed help with housework and 7% with child care; for family caregivers, 21% needed help with housework, and 15% with child care. Shifting household tasks not only affects other family members' burden but also the cancer patient's sense of self. Some patients feel that having other family members take over their domestic roles diminishes their worth in family, especially in regards to their children (Navon & Morag, 2003).

In addition, work-related issues in family can become major challenges if patients or family caregivers are working full time. Due to side effects of treatment as well as the direct effects of treatment, the amount of time that must be taken off for treatment (Hilton, 1993), and the multiple responsibilities in the family and at work (Boyle et al., 2000; Harden, 2005), some cancer patients have difficulty maintaining their occupational status. Further exacerbating the problem is the fact that loss of the ability to work may contribute to financial problems for cancer patients and their families. For example, in a study head and neck cancer patients and their families, one study found that 29% of patients reported financial problems (Relic et al., 2001). Another study reported that 41.5% of its participants reported they experienced limitations in regards to work or with household jobs, and 15.4% reported they were completely unable to work at a job or at home (Epstein et al., 1999).

Nalbadian et al.'s study (2001) found that one half of laryngectomized patients experienced significant changes in their financial situation, and related the worsening of their financial state to their inability to work. These results are comparable to a recent study that reported that 32.9% of long-term cancer survivors were unable to work, with 41.9% of the sample reporting a significant decrease in household income (Vartanian et al., 2006). The financial problems in family with a member with other types of cancers are similar to the problems of families with a member with head and neck cancer. For instance, Soothill et al. (2003) studied 233 paired breast, colorectal, lymphoma, and lung cancer patients and their family caregivers, and found that 40% of patients and 33% of caregivers needed help with financial problems. However, cancer-related financial problems do not occur just for lower-income families. Hilton's study (1993) found that among 12 families who had breast cancer, professional couples also reported financial concerns that were related to less money earned during the treatment and recuperation period, and other aspects of finances that may already have been a problem. Because of patients' inability to work and the resultant family financial problems, some family members may have to change their role to be the breadwinner when the cancer patient previously was the breadwinner. In addition to having to earn money for the family, some family caregivers may need to maintain their household responsibilities (e.g., chores) and as well add other roles, such as caregivers. Thus, role overload is a significant threat for the QOL of families.

In summary, the roles each member plays within the family are the important part of the family. When a family member has cancer, cancer patients and their family members have to shift or reorganize their roles to maintain their family functioning, which can be a significant source of stress. Based on literature review, it appears that caregiving, household chores, childcare, and work are central roles and responsibilities that are affected by cancer.

Family Communication. Communication is essential for family members to understand the needs and perceptions of each other, and also underlies emotional support for the psychological problems that may arise with cancer patients and their families. Soothill et al. (2003) found that 88.4% of cancer patients and their family caregiver rated honest information as an "important" part of family communication, and 48.1% rated someone with whom to talk as an important part of family communication. Although most cancer patients and their families understand the importance of family communication, studies have found that some families face significant difficulties with communication (Hilton, 1993). The major problems in this area are (a) a basic lack of communication (Hilton, 1993), (b) caregivers' reluctance to share feeling about patient's condition with the patient (Harden, 2005), and (c) concern leading to an excessive desire to protect the patients' feelings (Porter et al., 2005). Talking with people about the illness, who to tell or not to tell, when to tell, and how to tell, is difficult issue for cancer patients and their families, especially when it involves children (Hilton, 1993). In addition, a lack of common understanding between family members about communication often may be problematic. Hilton (1993) interviewed breast cancer patients and their families and found that difficulties about communication developed when patients, their husbands, or other family members wanted to talk but other family members did not want to talk or see the need for it. Although couples often had different individual styles, this generally was not a problem unless there was an accompanying feeling of nonsupport.

Only one study has directly assessed disclosure of emotions and attitudes, withholding of emotions and attitudes, and determinants associated with disclosure and holding back. Porter et al.'s (2005) study of gastrointestinal cancer patients and their spouses found that patients and spouses reported moderately high levels of disclosure and low levels of holding back, with patients reporting higher levels of disclosure than spouses. For patients, the top five areas of disclosure were (a) the patient's cancer treatment, (b) the patient's physical symptoms, (c) financial concerns, (d) the relationship with partner, and (e) job-related concerns. In contrast, the top five areas of non-disclosure were (a) the patient's negative emotions, (b) fear of disease progression and death, (c) patient's sexual function, (d) the relationship with other people besides the partner, and (e) the relationship with partner.

For spouses, the top five areas of disclosure were (a) the patient's cancer treatment, (b) the patient's physical symptoms, (c) the patient's negative emotion, (d) fear of disease progression and death, and (e) the relationship with partner. For the spouses, the top five areas of non-disclosure were (a) fear of disease progression and death, (b) the spouse's negative emotion, (c) the relationship with the partner, (d) the patient's sexual function, and (e) the patient's physical symptoms. The fact that concerns about disease progression were both a major area of disclosure as well as non-disclosure suggests that there is a bimodal distribution in regards to this construct. Among patients and spouses, low levels of disclosure and high levels of holding back were associated with poorer relationship functioning and increased psychological distress for both patients and spouses. Patients and spouse who are able to talk openly with each other about their cancer-related concerns have more positive relationships. Interestingly, when spouses reported higher levels of disclosure, patients reported having better relationships with their physicians and talked more openly with their health care providers, and spouses also reported being more involved in the patient's medical care.

When considering specifics type of cancer, communication problems are particularly prevalent among head and neck cancer patients, and particularly problematic because cancer patients often have particular social needs with to family members and significant others (Taylor, 2003). For adults, verbal communication is the most natural form of communication. Although some patients may experience only a temporary loss of the ability to speak, loss of speech is one of the most frightening aspects of head and neck cancer and its treatment for patients. The inability to speak is a major problem of larynx cancer patients. A patient undergoing total laryngectomy has permanently lost the natural organ for speech and will have to develop other forms of communication. Alternative forms of speech include esophageal speech, the use of a voice prosthesis, or the use of an external mechanical device, such as an electrolarynx. However, the successful use of such devices is not only difficult for many patients but also directly contributes to the development of negative attitudes and low self-esteem (Mood, 1997). Although patients can learn to communicate using alternative techniques, laryngectomized patients report difficulties in communicating within the immediate family environment, when using the telephone, and particularly when communicating with strangers. These communication difficulties do improve somewhat with time, beginning from the end of treatment (Nalbadian et al., 2001); Deleyiannis et al. (1999) found that their patients reported better communicative functioning two years post treatment.

In summary, family communication appears to play a vital role promoting family relationships and FQOL. However, there are limitations in the studies that have investigated family communication. Based on critical analysis, all of the studies in the area of family communication focused on willingness and comfort talking but no study examined the willingness and readiness of family members to listen, which is a critical aspect of family communication. Thus, areas where additional research is needed include study of (a) successful and effective communication in family, (b) the ability to show concern, sharing and to discuss the cancer experience, their needs, and their feelings, (c) congruence between family members in regards to communication, (d) problems of communication, and (e) the willingness and readiness to listen of family members.

Family Emotional Support. There is much evidence indicating that cancer patients and their families face psychological challenges in the diagnosis and treatment of cancer, as well as post-treatment adjustment, requiring family emotional support. Northouse et al. (1999) reported that during diagnosis phase, colon cancer patients expressed anxiety, fear, disgust, surprise, feelings of loss of control and shocked; spouses also expressed negative reactions including anger, blame, and worry about the ability of their spouses. Hutton and Williams (2001) found that head and neck cancer patients felt anxious about the loss of pleasure or interest in life, low mood, frustration, and self-consciousness regarding their voice or appearance. Northouse et al. (2002) also found that the FQOL for caregivers of recurrent breast cancer patients was lower than that for the normal population and even the cancer patients themselves. Although some studies found that emotional problems decreased over time (e.g., Lloyed et al., 2003), other studies have reported the emotional problems fluctuated or even increased over time. Hilton's (1993) longitudinal study followed patients from diagnosis to 12 months after diagnosis or treatment, and found that across the various timepoints, breast cancer and their families were worried, anxious, scared, depressed, and angry about their emotional/behavioral reactions or lack of reaction. Similarly, Derks et al. (2004) found that 12 months after treatment, head and neck cancer patients in their study still reported increased depressive symptoms. Thus, family emotional support to help with these problems is an important aspect of families with a member with cancer. Specific issues for which cancer patients and their families may need emotional support include cancer recurrence (Mellon et al., 2006; Northouse et al., 1999), the patients' health status (Harden, 2005) and uncertainty about the future (Harden, 2005; Northouse et al., 1999). These issues to some extent are specific to cancer, in particular its potential recurrent nature.

Cancer and its treatment result not only in psychological problems among the patients but also among other family members. Fleming et al. (2006) reported that advanced metastasis cancer patients' mental health and depression scores correlated with those of caregivers. Segrin et al. (2005) similarly found that the emotional well-being of cancer patients and their family caregivers followed similar trajectories. These studies confirm the reciprocal effects predicted by Family Systems Theory, and suggested that to fully understand the QOL of cancer patients, researchers must consider the larger interpersonal system surrounding the patient.

Family members not only experience many of the same psychological problems that cancer patients experience, but they also report that they need but lack emotional support (Borneman et al., 2003; Boyle et al., 2000; Northouse et al., 1999). Soothill et al. (2003), for instance, found that breast, colorectal, lymphoma, and lung cancer patients as well as their family caregiver reported unmet emotional needs and a need for help. For patients, 13 % wanted help in dealing with the unpredictability of the future, 9% wanted help with fears in general, 11% wanted help with distressing symptoms, 13% wanted help coping with sad feelings, 13% wanted help dealing with the feeling of others, 8% wanted help with loneliness, 20% wanted help with anger, and 10% wanted help with feelings of guilt.

For family caregivers, 23% reported needing help dealing with the unpredictability of the future, 23% needed help coping with fears, 25% needed help coping with distressing symptoms, 28% needed help dealing with sad feelings, 23% needed help in dealing with the feeling of others, 25% needed help coping with loneliness, 31% needed help dealing with anger, and 38% needed help coping with feelings of guilt. Thus, it appears that family caregivers actually have more unmet emotional needs than patients.

In summary, family emotional support is an important need for cancer patients' families as well as for the patients themselves, because cancer is a chronic illness that can recur and is strongly related with death in perceptions of patients and their families. Based on this literature review, cancer patients appear to get emotional support from their families and their report that they also need family emotional support but the families may lack emotional support. Thus, to maintain family function and family relationships, family emotional support should be examined and promoted.

Summary of the Theoretical Framework for This Study

Based on the literature review, the conceptual framework for this study was based on Family System theory, FQOL domains used in previous studies in sociology, special education, and health care arena, and previous studies about the impact of cancer and its treatment on families. In this study, family is defined as cancer patients and their family members who, as identified by the patient, share bonds of emotional closeness as well as the cancer experience with the patient. Thus, family members may include parents, the spouse, same or opposite sex partners, relatives, offspring, and / or friends. From the Family Systems theory perspective, the family is a unit. Thus, when a family member has cancer, the entire family also will be affected by the cancer and its treatment, with the family as a unit adapting and modifying their behaviors to promote their FQOL.

There are unique aspects to FQOL for families with a member with cancer. These include (a) the potentially recurrent nature of cancer and the fact that there can be a high degree of uncertainty about whether treatment was successful (i.e., whether the cancer will recur) that can extend for several years; (b) cancer's strong association with death; (c) the fact that treatment often is extended for a long period of time; (d) the fact that treatment itself often is associated with serious side effects; and (e) that for some forms of cancer such as head and neck cancer, even "successful" treatment may result in the patient having significantly reduced function.

The purpose of this study was to develop FQOL questionnaire for families with a member with cancer, with the assessment focused on specific family aspects potentially influenced by cancer and its treatment. Thus, FQOL was defined as the subjective satisfaction of the family in areas of life that are unique to families: family structure, family functioning, and family relationships. FQOL in this study thus is a construct that is subjective, multidimensional, and reflective of the family level. Four domains, including family interactions, family roles, family communication, and family emotional support were examined, because evidence suggests that these domains are affected by cancer and its treatment, and because evidence indicates these are areas for which families often need help; in addition, overall FQOL was assessed.

Critical Analysis of Relevant Literature

Because the primary purpose of this study is to develop a questionnaire to assess FQOL among families with a member who is a cancer patient, two main areas were critically analyzed, including (a) FQOL questionnaires in general, and (b) other family questionnaires related to domains of FQOL affected by cancer and its treatment. Because there are relatively few FQOL or other related questionnaires, questionnaires used in sociology, special education, and health care were reviewed. The inclusion criteria to select questionnaires were questionnaire that (a) assesses FQOL domains or the domains related to the impact of cancer and its treatment on families (family interaction, family roles, family communication, and family emotional support); (b) were at the family level, and (c) have acceptable reliability and validity and / or are standard questionnaires that are used widely. Five questionnaires met these criteria, including the (a) Quality of Life-Parent form, (b) Beach Center Family Quality of Life Scale, (c) the Family Quality of Life Survey, (d) Family Well-Being Assessment Tool, and (e) FACES IV.

The Quality of Life-Parent Form was developed by Olson and Barnes (1992). This self report instrument measures satisfaction within domains of the individuals' life experiences. It has 40 items rated on 5-point Likert response format (from dissatisfied to extremely satisfied) that assess various domains of life in 12 subscales: (a) satisfaction with marriage and family life (4 items); (b) friends (1 item); (c) extended family (1 item); (d) health (2 items); (e) home (5 items); (f) education (2 items); (g) time (5 items); (h) religion (2 items); (i) employment (2 items); (j) mass media (4 items); (k) financial well-being (6 items); and (l) neighborhood / community (6 items). Higher scores indicate greater satisfaction in the particular domain. Construct validity was established with factor analysis. Internal consistency reliability was at 0.92 in a sample of the general population (Olson & Barnes, 1992). In health care, this questionnaire was been used by Anderson (1993) to measure FQOL in families with a member with a chronic illness (including cancer) and by Mellon (Mellon & Northouse, 2001; Mellon et al., 2006) to assess families with a member with breast, colon, uterine or prostate cancer. In families with a chronic illness, internal consistency reliability was reported at 0.73 for the total samples, 0.72 for participants with a chronic illness, and 0.73 for their family members. In families with a member with cancer, internal consistency reliability has been reported at 0.94 in cancer patients and 0.95 for family members. Although this questionnaire has good validity and reliability and is easy to use, it includes many aspects of family life that do not relate to health. Thus, it may be useful to assess overall aspects of family life, but it may be less useful for use in medical practice, especially in regards to developing interventions or for providing health education for promoting FQOL in families with cancer.

The Beach Center Family Quality of Life Scale was developed at the Beach Center of University of Kansas to measure FQOL in families with disabled children for use in research, and for evaluation in service programs or by policy makers (Hoffman et al., 2006). This scale is well developed, with three phases involved its development: (a) conceptualizing and exploring the domains of FQOL by using grounded theory (Poston et al., 2003); (b) development of a preliminary survey by using exploratory factor and item analyses (Park et al., 2003); and (c) development of the Beach Center Family of Life Scale, using confirmatory factor analysis, with an examination of reliability and convergent validity (Hoffman et al., 2006). The Beach Center Family of Life Scale includes 25 items covering five domains of family life: (a) family interaction (6 items); (b) parenting (6 items); (c) emotional well-being (4 items); (d) physical / material well-being (5 items); and (e) disability-related support (4 items). It uses 5-point Likert response format rated on importance (from a little important to critically important) as well as satisfaction (from very dissatisfied to very satisfied). Convergent validity is supported by the Family Interaction subscale's significant correlation with the Family APGAR, a 5 item measure of family functioning. The Physical / Material Well-Being subscale was significant correlated with the Family Resources Scale of Dunst and Leet

(Dunst & Leet 1985; Hoffman et al., 2006). Three month test-retest reliability for both importance and satisfaction responses for each of subscale were computed in 280 families with a disabled child. For the importance subscale, the correlation between two time points was 0.54 for Family Interaction, 0.66 for Parenting, 0.69 for Emotional Well-Being, 0.41 for Physical / Material Well-Being, and 0.82 for Disability-Related Support. For the satisfaction subscale, the correlation between two time points was 0.74 for Family Interaction, 0.70 for Parenting, 0.75 for Emotional Well-Being, 0.77 for Physical / Material Well-Being, and 0.60 for Disability-Related Support. The Cronbach's alpha for the total scale was 0.88, for the Family Interaction subscale 0.90, for the Parenting subscale was 0.86, for the Emotional Well-being subscale 0.84, for the Physical / Material Well-being subscale 0.74, and for the Disability-related Support subscale 0.85 (Hoffman, et al., 2006). The test-retest reliabilities range from fair to excellent. However, in judging test-retest reliability, it is important to consider whether families' satisfaction or views on importance may have changed across the three month time period. For instance, the reason the test-retest reliability for the Family Interaction subscale, for instance, was relatively low may be because the actual levels of satisfaction changed across the three month time period. Thus, the test-retest correlations may not be appropriate as measures of reliability but better construed as measures of stability.

This scale was developed to assess FQOL in families with a disabled child. Some subscales, such as Parenting and Disability-Related Support, may not be appropriate to measure FQOL in families with a member with cancer, because cancer patients generally are adults. However, Family Interaction and Emotional Well-Being subscales may provide a good starting point for measuring FQOL of families with a cancer patient.

The Family Quality of Life Survey was developed by a team of international researchers (Brown et al., 2006). This survey assesses the degree to which family life is enjoyable, meaningful, and supported by the types of resources that are important to family members, as well as the struggles faced by families. The survey focuses on the QOL of families with one or more members have an intellectual disability. It is useful for practitioners and family members as an overall assessment of support needs and for program design, and for researchers as an instrument to measure FQOL of families with a family member with intellectual disability. It contains three parts providing both quantitative and qualitative information. The first part assesses general background information about the family. The second part contains nine sections addressing specific areas of family life: (a) health; (b) financial well-being; (c) family relationships; (d) support from others; (e) support from services; (f) influence of values; (g) careers; (h) leisure and recreation; and (i) community integration. Each of these 9 parts has 2 sections. Section A contains questions that gather general information and provide a context for the questions. Section B contains questions related to 6 key aspects of QOL domains: (a) importance; (b) opportunities; (c) initiative; (d) attainment; (e) stability; and (e) satisfaction. The final part assesses overall FQOL.

This survey is self-report, for the main family caregiver, or can be completed by a researcher or practitioner with the main family caregiver. It takes about one hour to complete the survey. The validity and reliability was assessed in 29 families with a child with an intellectual disability by Isaacs, Baum and Wang (2006). Construct validity was established with factor analysis. The Cronbach’s alpha for the total scale was 0.84, the Health subscale was 0.44, the Financial Well-being subscale was 0.57, the Family

Relationships subscale was 0.89, the Support from Others subscale was 0.84, the Support from Services subscale was 0.53, the Influence of Values subscale was 0.84, the Careers subscale was 0.92, the Leisure and Recreation subscale was 0.73, and the Community Integration subscale was 0.84. The Cronbach's alpha for each concept also was examined and was reported to be: 0.32 for the Importance subscale, 0.56 for the Opportunities subscale, 0.80 for the Initiative subscale, 0.42 for the Attainment subscale, 0.76 for the Stability subscale, and 0.45 for the Satisfaction (Isaacs, Baum, & Wang, 2006). However, this scale was developed to use in families with a member with an intellectual disability, and takes an hour to administer. Thus, it may not be appropriate to assess FQOL in families with a member with cancer. The scale does, however, have several domains of FQOL that will be useful to consider for assessing FQOL in families with a member who is a cancer patient.

The Family Well-Being Assessment Tool (FWA) was developed by Caldwell (2003) using the family well-being perspectives of Thomas (1982). The FWA is a norm-referenced cognitive assessment for members of a nuclear family in regards to their perceptions of the extent to which the following are present in family life: (a) family structural components --- family stress, family satisfaction, family support, family cohesion, and family adaptation; (b) family functional role processes --- role conflict, role overload, role ambiguity, role nonparticipation, and role preparedness; and (c) family vulnerability --- psychosomatic symptoms and life satisfaction. It has two versions: a short version consisting of 45 items and 10 subscales for children 9 to 18 years of age, and a longer of 57 items with 11 subscales for parents. The scale is self-report, rated on 6-point Likert response format (from strong disagreement to strong agreement), with a possible range of 11 to 66; low scores indicate well-being or low stress. The time required to complete the questionnaire is 15 to 20 minutes, and the tool has good validity and reliability (Caldwell, 2003).

The items were conceptually derived from the family well-being framework of Thomas (1982). Content validity was assessed by two specialists in family research, with their inter-rater agreement in regards to the validity for each of the subscales ranging from 0.9 to 1.0. Construct validity has been assessed. The FWA differentiates high well-being families from low well-being families (Caldwell, 2003). Internal consistency reliability for the total score was 0.89 for the children's version and 0.90 for the parents' version, based on 204 children and 185 parents (Caldwell, 2003). One to three weeks test-retest reliability (N=82) was 0.88. However, although the FWA has good reliability and validity, and covers many important FQOL domains, most its items focus on the roles of parents and children, not covering many other highly roles relevant for adults with cancer. In addition, some items measure QOL at the individual level rather than family level. Thus, to measure families with an adult member with cancer, items will need to be modified.

The FACES IV questionnaire contains 42 items for the Flexibility and Cohesion Evaluation subscale, 10 items for the Family Communication subscale, and 10 items for Family Satisfaction subscale. Olson, Gorall, and Tiesel (2004) recommended that researchers who want to use the FACES IV should use the entire FACES IV questionnaire Package with 62 items. FACES IV was developed from previous versions of the Family Adaptability and Cohesion Evaluation Scales (FACES I, II, and III; Gorall, Tiesel, & Olson, 2004). The Circumplex Model of Marital and Family Systems was used as the theoretical framework for this scale.

Cohesion is defined as the emotional bonding that family members have with one another, with specific indicators including (a) emotional bonding, (b) boundaries, (c) coalitions, (d) time, (e) space, (f) friends, (g) decision-making, (h) interests, and (i) recreation. Flexibility is defined as the quality and expression of leadership and organization within the family, family role relationships, and relationship rules and negotiation. The FACES IV measures these dimensions of family cohesion and family flexibility using six scales, including two "balanced" scales that assess balanced family cohesion and balanced family flexibility, two "unbalanced" cohesion scales reflecting disengagement and enmeshment, and two "unbalanced" flexibility scales reflecting families that are rigid or chaotic (Olson et al. 2004). Items are rated on 5-point Likert response format (from "does not describe our family at all" to "very well describes our family"). FACES IV has been found to be reliable and valid (Gorall et al., 2004). Face validity was established from item ratings provided by family therapists, and construct validity was established by factor analysis. Concurrent and discriminant validity were established through comparison with widely used family assessment instruments (i.e., the Health / Competence Subscale of Self-Report Family Inventory; the General Functioning Subscale of Family Assessment Device; the Family Satisfaction Scale) and through subject self-identification of problem status of their family system. Internal reliability in a general population sample for was: Balanced Cohesion = 0.89; Balanced Flexibility = 0.80; Disengaged = 0.87; Enmeshment = 0.77; Rigid = 0.83; and Chaos = 0.85. Although this questionnaire focuses on family cohesion and family flexibility generally, it contains items related to family interaction and family roles that can be modified for families with an adult member with cancer.

The Family Communication Scale from the FACES IV was derived from the Parent-Adolescent Communication scale (Olson & Barnes, 2004). Family communication is defined as the positive communication skills utilized in the couple or family system, and is viewed as a facilitating family alters their levels of cohesion and flexibility (Olson & Gorall, 2004). This scale contains 10 items rated on 5-point Likert response format (from "does not describe our family at all" to "very well describes our family"), with high scores indicating that a family has good family communication. The validity of the Parent-Adolescent Communication scale was established by using factor analysis, and internal consistency reliability was reported as 0.88 based on a national sample of 1,841 individuals (Olson & Barnes, 2004).

The Family Satisfaction Scale (FSS) from the FACES IV contains 10 items, based on a 14 item scale developed by Olson and Wilson in 1982 (Olson, 2004). Family satisfaction is defined as the degree to which family members feel happy and fulfilled with each other. Both the original 14 item scale and the revised 10 item scale were designed to assess satisfaction with various aspects of family functioning including family closeness, flexibility, and communication. It uses self-report, with ratings on 5-point Likert response format (from very dissatisfied to extremely satisfied), with high scores indicating that family members are happy about their family. The validity of the 14 item scale was established through factor analysis (Olson & Wilson, 1982). Construct validity was supported by a correlation with the Locke-Wallace Marital Satisfaction scale

(Olson, 2004). Internal consistency reliability for the 10 item FSS scale is 0.92, based on a sample of 1,253 family members (Olson, 2004).

The FACES IV covers several primary FQOL domains, including family cohesion, family flexibility, family communication, and family life satisfaction. However, the balanced and unbalanced scales tend to have items that are somewhat repetitive (in opposite directions), because the balanced and unbalanced are similar but opposite. However, the balanced scales of FACES IV, Family Communication, and FSS was useful as an initial basis for assessing FQOL of families with a member with cancer because these subscales are domains (i.e., such as family interaction, family role, and family communication) likely influenced by cancer and its treatment.

In summary, there are five questionnaires that assess FQOL or family domains related to the impacts of cancer and its treatment at family level. Although in general these questionnaires have good validity and reliability, there are three main limitations to their use for assessing FQOL of family with a member with cancer patient. First, some questionnaires (e.g., the Quality of Life-Parent form) measure broad domains of family life, and do not focus on the domains related to health. Thus, they may be useful for comparing the FQOL of general population families and families with a member with cancer, but may be less useful for clinicians in regards to helping to improve the FQOL of families with a cancer patient.

A second limitation, from the health care perspective, is that some questionnaires contain a relatively large number of items (Brown et al., 2006) or repetitive items to distinguish family types (Gorall et al., 2004). Although suitable for their initial purposes, they can be burdensome for participants. Finally, all of these questionnaires were developed for families in general (Gorall et al., 2004; Olson & Barnes, 1992), families with disabled children (Brown et al., 2006; Hoffman et al., 2006; Park et al., 2003), or families with a child with a chronic illness (Caldwell, 2003). No FQOL questionnaire has been developed that addresses the specific issues that families with a member with cancer face. These five questionnaires do, however, support the importance of family interaction, family roles, family communication, and family emotional support as central domains of families, and the subscales and items from these questionnaires may be modified so as to develop a FQOL questionnaire for families with a member with cancer, and to examine the construct validity of the new FQOL questionnaire.

Assumptions

The assumptions of this study were derived from a Family Systems Theory perspective.

1. The family and its members adapt or modify their behaviors in response to situational changes so as to maintain family structure, function and overall FQOL.
2. The family system is comprised of subsystems. Each member is the part of subsystems as well as the family system. Thus, individuals can report on FQOL.
3. Because of the subjective nature of FQOL, self-report is a primary method of gaining FQOL information.

Definition of Terms

In this study, there were two terms that needed to be defined: family quality of life and family.

Family quality of life (FQOL) was defined as the subjective satisfaction on the family in areas of life that are unique to families: family structure, family functioning, and family relationship. In this study, FQOL was defined as an individual’s subjective satisfaction with his or her family, in areas of life that are unique to families. Based on the results of the literature review, four sub-domains for the preliminary FQOL questionnaire were tentatively identified: (a) family roles, (b) family communication, (c) family emotional support, and (d) family interactions. The four sub-domains were defined as follows:

Family Roles are the family roles and household responsibilities that involve concrete tasks (e.g., cooking; house cleaning; childcare, taking family member who gets sick).

Family Communication involves the verbal sharing of opinions, ideas, concerns, plans, feelings, etc.

Family Emotional Support involves positive behaviors that have the express purpose of providing emotional support to family members. Family Emotional Support is a form of Family Communication, but it specifically focuses on emotional support. It is separated from Family Communication because of its importance in family life.

Family Interactions are behaviors and interactions among family members that serve to or reflect maintenance of the family structure and functioning, and that do not fit into any of the above three categories.

These were a priori dimensions. However, the dimensionality of the FQOL questionnaire was formally examined in Phase 3 of the study.

Family was defined as cancer patients and their family members who, as identified by the patients, share bonds of emotional closeness as well as the cancer experience with the patient. Thus, family members could include parents, the spouse, same or opposite sex partners, relatives, offspring, and / or friends.

CHAPTER III

METHODOLOGY (PHASE 1: ITEM GENERATION)

Research Design

The main objectives for Phase 1 were (a) to determine whether (a1) family interaction, (a2) family roles, (a3) family communication, and (a4) family emotional support are central domains of FQOL (Research Question #1), and (b) based on a literature review and qualitative interviews with cancer families to generate FQOL items for these domains.

Research Setting

The Phase 1 portion of this study was conducted through the Vanderbilt Cancer Clinic of the Vanderbilt Ingram Cancer Center (VICC), and with cancer families who met inclusion criteria of the study but not treated at the VICC, who were suggested and introduced by health care providers at Vanderbilt School of Nursing.

Sample

Criteria for Sample Selection and Inclusion

This study used a convenience sample that included cancer patients and their families. The sample sizes and inclusion criteria varied for each phase of the project (see details below). General inclusion criteria for cancer patients for Phase 1 and Phase 3 included:

(a) the patient was 18 years or older; (b) any local, advanced or metastatic cancer diagnosis that required more than simple a surgical procedure; (c) able to read, write, and speak English; (d) written informed consent; (e) an adult family member willing to participate in the study.

For Phase 1, cancer patients with breast, prostate, lung, gastrointestinal, or head and neck cancer were selected. These particular forms of cancer were selected because of their high incidence and their potential impacts on FQOL. For instance, side effects of head and neck cancer and its treatment often impact the function of organs used for speech; thus, this type of cancer can have highly significant effects on communication. Because of its physical location, breast cancer can have a significant affect on women's sexual identity and sexual functioning.

General inclusion criteria for family members for Phase 1 and Phase 3 included: (a) the family member was 18 years or older; (b) if family members had cancer, they were not receiving any active treatments for cancer; (c) able to read, write, and speak English; (d) written informed consent. The term family was defined broadly. Cancer patients identified family members who were over 18 years of age and were considered by the cancer patient as family members who cared, supported, and shared the cancer experience with them. Family members were not necessarily related to the patient by blood or marriage, and might or might not live in the same house with patients. Thus, family members included parents, spouse, same or opposite sex partners, relatives, offspring, and / or friends. The key defining characteristic was that they were significantly involved in each others lives.

Method for Subject Recruitment

For Phase 1, to ensure that participants selected for this part of the study had involved families, the principal investigator (PI) asked the oncologists and nurses at the VICC to identify cancer patients who always came with a family member who participated in decision making about treatment. After identifying such persons, the oncologists or nurses at the VICC and Vanderbilt School of Nursing (a) briefly explained the study to them, and (b) if they were interested, introduced them to the PI who explained the study in detail, answered all questions, invited them to participate in this study, and obtained written informed consent.

Human Subjects Protection

The study obtained approval from Vanderbilt IRB in each phase. Potential participants had the study procedures explained and the possible risks, which were relatively minimal (possible discomfort with some of the questions; loss of confidentiality). Participants were informed that they did not have to answer any questions that they did not want to answer and they were informed that their participation was voluntary and they could withdraw from the study anytime. Potential participants were also informed that the interviews would be audio recorded, that the PI would use codes number instead of their name, that the audiotapes would be transcribed and coded, and then they would be erased. All questions were answered before the potential participants signed the informed consents and they received a copy of the consent form. The interviews were done in a private room at the VICC, Vanderbilt School of Nursing, or their home, depending on the participants' convenience.

Data Collection Methods

Items were generated through a literature review, and through semi-structured interviews with patients and their families. The purpose of the interviews was to confirm that the four domains identified in the literature review (family interaction, family roles, family communication, and family emotional support) were central areas of FQOL. The purpose of the interviews also was to determine if there were other important effects of cancer and its treatment on the FQOL of families with a cancer patient. The semi-structured interview was developed based on the literature review (see Appendix A and B). The interview started with general questions, such as "Can you please tell me what it has been like for you to live with cancer?" and "What worries you most about having cancer?" For family members, the questions were "Can you please tell me what it has been like for you to live with a family member who had cancer?" and "What worries you most about [patient's name] having cancer?"

Then, the interview focused on the effects or changes caused by cancer on family interaction, family roles, family communication, family emotional support, and overall FQOL. The interview also assessed what family members wanted in regards to family interactions, family roles, family communication, family emotional support, and FQOL, as well as suggestions or advice for other patients and family members experiencing cancer. Example questions related to family interaction of cancer patients were "I'd like you to take a minute and think back over the time since you were diagnosed with cancer. In what ways, if any, have your interactions with your family members changed? How do you feel about these changes? How would you like these interactions to be?" Example questions related to family emotional support of family members were "What kinds of support have you received from your family? Do you feel like you have received the support you need from your family? Has this support been helpful? What other kinds of family support would be helpful for you?" Example questions of overall FQOL were "When you think about your family life, what parts are you most satisfied with? What factors have helped to maintain or improve your family quality of life?"

The interview was piloted with one cancer family to determine whether the questions were understandable, and some questions were modified or reworded to make them clearer. Then, fourteen cancer families were approached between August 9, 2007 and September 4, 2007. One family declined to participate in the study because they were too busy and one family was withdrawn from the study because the cancer patient forgot to bring his hearing aid with him and was not able to be interviewed by the PI. Twelve cancer families completed the interview (See Participant Characteristics, in *Results of Phase 1*). The 12 cancer patients and 12 family members were interviewed independently in order to make them feel more comfortable discussing their experiences, feelings, and perceptions. Ten families were interviewed in a private room at the VICC, one family was interviewed at a private room of the Vanderbilt School of Nursing, and one family was interviewed in their home. The interviews lasted from about 25 to 75 minutes and were recorded with permission of participants. Audiotapes from these interviews were transcribed by a transcriber experienced in medical and cancer patients' transcriptions. Prior to analyzing individual transcripts, each interview transcript was compared to the audiotape, and any discrepancies were corrected by the PI.

Data Analysis

Data from interviews were analyzed using content analysis (Downe-Wamboldt, 1992; Waltz, Strickland, & Lenz, 2005). Based on the prior literature review, four categories (family interaction, family roles, family communication, and family emotional support) were set a priori. No new categories were added based on the content of the interviews. Data from the interviews were content analyzed using qualitative data analysis software ATLAS.TI 5.2. To develop the coding manual, data from two transcripts were coded and categorized. Inter-rater reliability was examined by the PI and faculty adviser coding two transcripts independently. For these two transcripts the percentage of coding agreement across all of the codes was 78.4%. After completing these codings, the PI and faculty adviser modified the coding manual based on the sources of disagreement. Then, the PI and a college student coded three other transcripts independently and met after coding each transcript to clarify and modify the coding manual. The percentage for coding agreement for all of the codes for these three transcripts was 80.4%. After completing the inter-rater reliability assessment, the coding manual was finalized, and the PI coded the remaining transcripts.

CHAPTER IV

RESULTS (PHASE 1: ITEM GENERATION)

Overview. The first purpose of Phase 1 was to answer Research Question #1, which was: Are (a) family interaction, (b) family roles, (c) family communication, and (d) family emotional support central aspects of FQOL for cancer patients and their families? The second purpose of Phase 1 was to generate an initial item pool based on a literature review and qualitative interviews for the preliminary FQOL questionnaire. In this phase, 12 cancer families (12 cancer patients and 12 family members) were interviewed. Participant characteristics, results of the qualitative interviews, and results of the item generation are presented sequentially.

Participant Characteristics

Twelve cancer patients and 12 family members were interviewed. For cancer patients, average age of patients was 60.16 years old (SD = 10.88) and average education was 15.83 year (SD = 3.30). The majority of patients were male (58.33%), White (91.67%), and married (75%). One third of the patients worked full time (33.33%) or were retired (33.33%). Three patients had lung cancer, two had colon cancer, two had head and neck cancer, two had pancreatic cancer, one had breast cancer, one had prostate cancer, and one had breast and colon cancer. Most patients were in cancer stage IV (66.7%), were in treatment (83.33%) and had had two types of treatment (58.3%): (a) surgery and chemotherapy (33.3%) and (b) chemotherapy and radiation (25.0%). For details see Table 1.

For family members, the average age was 55.92 years old (SD = 10.74) and average education was 16.33 year (SD = 3.77). Most family members were spouses (66.67%), female (66.67%), White (83.33%), married (91.67%), with a yearly household income over $60,000 (41.67%), and employed full time (41.67%). For details see Table 1.

Table 1

Demographic Characteristics of the Participants

Demographic Characteristics	Patients		Family Members	
	n	**%**	**n**	**%**
Age	M = 60.16, SD = 10.88 (Range = 47-79 years)		M = 55.92, SD = 10.74 (Range = 42-75 years)	
Education	M = 15.83, SD = 3.30 (Range = 12-21 years)		M = 16.33, SD = 3.77 (Range = 12-21 years)	
Sex				
Male	7	58.33	4	33.33
Female	5	41.67	8	66.67
Race				
White	11	91.67	10	83.33
African American	1	8.33	2	16.67
Ethnicity				
Not Hispanic or Latino	12	100	12	100
Marital Status				
Married	9	75	11	91.67
Widowed	2	16.67	1	8.33
Divorced	1	8.33	-	-

Table 1, continued

Demographic Characteristic	Patients		Family Members	
	n	**%**	**n**	**%**
Employment				
Employed full time	4	33.33	5	41.67
Employed part time	-	-	1	8.33
Homemaker	-	-	2	16.67
Retired	4	33.33	3	25.00
On disability	2	16.67	-	-
Self employed	1	8.33	1	8.33
On sick leave	1	8.33	-	-
Yearly Household Income				
$10,000 or less	1	8.33	1	8.33
$10,001 to $20,000	-	-	-	-
$20,001 to $30,000	1	8.33		
$30,001 to $40,000	-	-	-	-
$40,001 to $50,000	1	8.33	1	8.33
$50,001 to $60,000	1	8.33	1	8.33
Over $60,000	1	8.33	5	41.67
No response	7	58.33	4	33.33
Types of Cancer				
Breast	1	8.3		
Colon	2	16.7		
Head and Neck	2	16.7		
Lung	3	25.0		
Pancreatic	2	16.7		
Breast and Colon	1	8.3		
Cancer Stages				
II	2	16.7		
III	1	8.3		
IV	8	66.7		
Cannot identify	1	16.7		
Cancer Treatments				
Chemotherapy	2	16.7		
Chemotherapy and Surgery	4	33.3		
Chemotherapy and Radiation	3	25.0		
Surgery, Chemotherapy, and Radiation	3	25.0		

Table 1, continued

Demographic Characteristic	Patients		Family Members	
	n	**%**	**n**	**%**
Phases of Treatment				
During treatment	10	83.3		
After treatment	2	16.7		
Relationship with the Patients				
Spouse			8	66.67
Parent			1	8.33
Daughter			2	16.67
Relative			1	8.33

Qualitative Results from Interviews

A primary purpose of the Phase 1 study was to determine whether *Family Roles*, *Family Communication*, *Family Emotional Support* and *Family Interaction* were, as suggested by the literature review, central domains of FQOL. To answer this question, twelve cancer families were interviewed. The content analysis was done within the four domains mentioned above, as they were set a prior as main categories. Themes of each domain were identified and developed independently by considering the numbers of codes and participants that mentioned content within these codes. This approach to the analysis of Phase 1 data allows for similar themes across multiple domains.

Family Roles

In this study, the *Family Roles* domain was defined as family roles and responsibilities that involve concrete tasks. Seven themes related to Family Roles important for FQOL emerged from the interviews: (a) taking care of the patient, (b) household chores, (c) taking care of children, (d) being responsible for making money ("breadwinner" role), (e) disagreements about roles, and (f) role overload.

Taking Care of the Patient. All 12 of the family members reported that after the patient was diagnosed with cancer their roles within the family had changed to include becoming a caregiver for the cancer patient. In fact, this caregiver role had become their top priority. A female family member stated that "*First priority. Oh yeah. I'll take care of him first and then I'll do my other - I'll do my work*." If the patient was married, spouses became the primary caregiver although patients usually had many family members assisting in this role. A female patient stated that "*My husband does most of the care giving, and so that's the difference now. I have so many members but he does the care giving."* For patients who were widowed or divorced, their adult children or relatives often became their primary caregivers.

Although most patents had a family member who was the primary caregiver, cancer families felt that they needed to work as a "family team" to help take care of the patient. A sister-in-law of a cancer patient stated that "*We all had to help. I mean it was a team effort - we had to drive so far for radiation that we actually had a schedule on who would take what day and you know, all their off time was taking to radiation or helping to take to the doctor or whatever*." The "team" also received help from children in the family. A male cancer patient stated that *"To give my wife a break now and then, our children - some of our children, daughters have brought me to chemotherapy or to radiation - primarily radiation. But they are all willing to help in any way they can."*

The things that family members had done to take care of patients included making appointments, coming with patients to see doctors or receive cancer treatments, finding information about cancer, picking up prescriptions, preparing medications, taking care of a wound or colostomy, and preparing food for the patient. A male patient talked about things that his wife had done for him and how it had affected her life:

> *It's really given her a lot to do. She manages the appointments. She masters the information, puts the physicians through their inquisitions, monitors the treatment and makes sure that things go right and catches the slip-ups and gets them corrected on the spot. So, it has really affected her life in many ways more than it has mine.*

Coming with patients to see a doctor or receive treatment were main care giving activities that family members wanted to do, if they were able. However, family members going with the patient to see a doctor or for a treatment depended on their work schedules. For some family members, this was easier because they had flexible jobs whereas for others it was much more difficult to get time off. The daughter of a patient who had a flexible job and came to the hospital with her father every appointment stated that "*I have a good job so I can take off when I need to take off. So I take off when he has an appointment*." In contrast, the husband of a patient stated how difficult it was for him to adjust his work schedule to come with his wife:

> *I - the one thing, you know, is not - I think when you are dealing with this if you depend on your job - some employers are not very friendly - you know, they might give you one or two times but - then otherwise, they be trying to look to get rid of you. So that needs to be addressed, you know - how to protect - you know, because in most cases you got the spouse who has to continue to work to provide for the family and if they are having to take off a lot - that can you know cause a lot of problems for your employer which I think is one of the biggest things that really needs to be addressed. Ah - that's about the only thing I can say that, you know, I have had to try to adjust my schedule to - working at night, you know, you don't get no sleep like I come in today, I have got to go back to work at 6 so I won't even get any sleep. I will be up for over 24 hours, so.*

For families who did not live with the patients, they often made changes in their accommodations to help take care of the patients. Some family members who lived far from the patient would come to stay with the patient for a period of time to provide help, especially during cancer treatments. Other families decided to move so that it would be more convenient to take care of the patient. One family member moved to live near a patient's home in order to help take care of the patient, and a cancer patient moved to live with her daughter because the daughter wanted to help take care of her. None of the family members felt that being a caregiver was a burden, they generally felt glad to help the cancer patient: "*You know, which means it may mean changing a couple of things to help the other one out. But you know, when you love someone, you are willing to do that.*" "*I want to do that. That is what I feel like I am a part of. I want to be part of his life in every aspect, and I feel like that, that is what we do.*"

Household Chores. Eight of the 12 families stated their household chores had changed since the patient was diagnosed with cancer and had begun treatment. The major reason for the changes was that patients could not do the chores themselves as they had done previously because of their physical condition. A male patient stated that "*I am a good cook and I love to cook but I usually don't do a lot of cooking when I'm in that low blood count area because I don't have the strength and stamina to just set up at the stove for an hour and prepare a meal.*" Families arranged household chores in different ways depending on the family structure. If patients lived with family members, family members, especially spouses, would take over the majority of household chores or "*get it done*" for the patient. If the patient had minor children living with him or her, the children often helped with the household chores, although because of their age they could not always do a good job. For patients who lived alone and had to do household chores themselves, they often changed the ways they did the chores. An example was this was the husband of a patient who changed his responsibilities for the chores and how the children had helped him in this:

> *I mean we both shared the household chores but more so when she got cancer - then you know, I became the main one who is doing that and you know, I get the kids to help too… The kids they do help. Like I said, they will help with laundry, washing clothes - they don't do such a great job and you know so you want to make sure you want try to do that. But I have then fold the clothes and stuff. They do - you know, wash the dishes and take out trash and stuff. So - they do help with that part of it. And vacuum sometimes. But sometimes you still have to go behind them and stuff and you know stay on them about things but you know, they try to do their part as much as they can.*

An example of a male patient who lived alone was:

> *I usually do most all of that myself. I just don't do it all in one day, you know. I will dust a little this day and I'll run the vacuum cleaner another day, maybe even use two days to run the vacuum cleaner through the house complete. And I have a lady friend who comes in and does some of that for me now. She is a good, good friend and we see a lot of each other. We think a lot of each other.*

In contrast, four families stated that their household chores had not changed because of the cancer and its treatments. The reasons the household chores had not changed included: (a) the patient still had energy to do things, (b) the patient wanted to continue in her female role as a wife and a mother, (c) the family had always hired other people to do the household chores, and (d) the spouse of the family member with cancer had done the household chores prior to the cancer.

Taking Care of Children. Taking care of children typically became more difficult for cancer families who had young children in school. The difficulty was even greater when the family members worked full or part time and the patients were in treatment. All three of the families who had children in school with family members still working mentioned significant difficulty in taking care of the children. However, it was important to them that their children were able to maintain the same schedules and join in activities as they had previously, so the families had to "*work around the schedules*" or if they had other family members who lived near them, the family members would manage to help take care of children. The wife of a patient stated that "*Soon as the chemotherapy - well, I mean at a very concrete level, you know, it changes scheduling, so for example, when I was choosing which days my younger daughter would stay for her after school program at school, you know, that becomes one of them as something to, you know, to schedule around."*

In contrast, two families with young children but with a family member who was retired or a family member who was a homemaker mentioned that they did not have any serious problems taking care of their children. The husband of a patient stated that: "*I have been retired for a few years. Yeah. So I am there to help her which makes - it's nice. I help - I do, you know, most of the housework and cooking - a lot of the cooking and running our daughter here and there, you know, so she (the patient) can rest and it's been good for us for me to be there. It has worked out fine.*"

Being Responsible for Making Money ("Breadwinner" Role). For some families, cancer did not affect their financial situation but for other families, where both the patient and spouse were working, cancer impacted their financial situation. This was especially problematic if the patient could not work and had to go on disability. Seven patients and five family members who were breadwinners mentioned that they were financially secure and that they felt fortunate for this. In contrast, one patient and two family members mentioned that they had financial problems because the cancer patient could not work and the medical care was expensive. The ways that families tried to solve these financial problems included: (a) changing their life styles and (b) setting priorities for their expenses. Usually, patients were the first priority for their families. The husband of a patient stated that *"There are so many hidden costs and things that come with dealing with that… lose of income, especially with you both working and then you know, your partner is not able and I wouldn't you know want her to try to go back to work and do anything. I just - so yeah your life style would change significantly. You know, especially when you know, two parties are working."* He also discussed his family's financial difficulties involving medical expenses, health insurance, and other bills but that the patient remained the first priority for his family regardless of whether other bills might be paid late. He stated that:

> *So, that's one of our biggest costs, you know, paying for medicines. It went from like paying I would say two hundred, now we might spend on the average three hundred to three fifty to four hundred dollars for medicines and some of those medicines…Some medications…insurance not cover that because it is so expensive and so when we bought it, you know, I spent like two hundred fifty dollars, you know, probably for a weeks medicine for her, but you know, you can only do that for so long and you know, you make a decision where well, do I pay this bill or get that medicine. It is not even an option for me. It's like you know, I know she worries about that sometimes, you know, and that's why I work two jobs. I am going to try and do what I can for her first and if a bill was behind, then I be behind, you know. But I rather try to take care of her first. And so the kids - sometimes I try to do as much as I can for them but there are times when they have to learn to do without, you know. I know that she doesn't like that but you know, that is just where I have to make a choice. And she comes first.*

Disagreement about Roles. Three patients and six family members reported that disagreements around roles sometimes occurred in their families. Two of the main disagreements involved (a) family members wanting to "*protect*" patients but patients wanting to maintain their independence, and (b) family members who tried to help the primary family caregiver to a degree that was seen as excessive. A male patient explained the disagreement between he and his wife regarding her tendency to be too protective:

> *My wife is very protective. She tries to take care of more than she needs to take care of - and I am trying to preserve some of my contributions to the household too. So the light work she doesn't fuss about. I do a little cleaning up, dishes, cleaning bathroom or vacuum. Things like that are no problem. I think we are beyond the point of being concerned about heavy lifting, mostly because of the surgeries. She was overly protective that - both the abdominal surgery and the implanting of the portal. I think she was afraid it was going to pop out if I did anything (laughs) even though the surgeon said it was fine.*

A female family member discussed how her children had stepped in and offered to help her, but that this was more than she wanted: *"I think my kids felt, in a way, obligated and ah - but well, I need to make sure mom is okay and I need to do this and I need to do that. And finally I told them, I said you know, I am independent. They were like little mothers themselves. So you want to say - wait a minute now, you know, I need my space too."*

Role Overload. Role overload involved caregivers experiencing excessive emotional or physical strain because of the level of responsibility they felt in their role as caregiver. Families discussed two main types of role overload. The first occurred when a family member was diagnosed with cancer, and other family members would take on the caregiver role in addition to their normal roles and responsibilities. Family members talked about their experience in needing to balance their roles and responsibilities in taking care of the patient to which they often referred as "*a full time job*" with their other roles and responsibilities. For families with children and caregivers who worked full or part time, it was especially difficult to balance all of their roles and responsibilities simultaneously. The caregivers tried the best they could. The wife of a patient stated that taking care of the patient was a full time job. Although she did not take care of her husband all the time, this was on her mind all the time: "*It's a full time job because it is always in your mind. You know, it's very seldom you know that it is not somewhere in your mind.*" She also described how difficult it was to balance all of her roles and responsibilities:

> *I feel like I have to find ways to - I have to work harder to balance out everybody's needs…I think in some ways the biggest thing is just trying to balance out you know, everybody's needs. I mean I do feel bad sometimes when, you know, my older daughter will say like can we go to Wal-Mart or something? For example… now I am much more likely to say you know, not tonight, I'm tired. But then I don't know if that is such a bad thing because I guess that's a way I am taking care of myself is just you know setting some of those limits a little bit more. I don't always do that, sometimes I'll - you know. But I think in some ways a worry is I want to make sure that I am still taking care of them, that not all my caretaking energy is being focused on (name of patient) or something that I worry about sometimes. I guess I just worry about there being enough of me for everybody. For (name of patient), for them, for work.*

A second aspect of role overload that families discussed involved the multiple roles that being a family caregiver of a cancer patient required. Because of medical expenses, families were under pressure to generate a substantial amount of money while at the same time they needed a job that would allow them to take care of the patient as well. Thus, to be both a breadwinner and caretaker at the same time was a difficult situation for families who had low income and were not financially secure. The husband of a patient explained his work situation:

> *With the cost increase with the medicines and then I have had to, you know, like one of the jobs I had - you know I make good money but it - I had to make a choice, you know, it's like - family, you know being able to take my wife to get her to the doctor and so - you know, I have had to change jobs because of that because you know, I am putting her first. And so - yeah, some employers, you know, they are not friendly toward wanting to allow you to take off and you know, on a regular basis, so I did the best thing I could - just you know, move on and find a job where I don't have that as bad, so that's why I try to work more at night and then there's on the weekend where I am working, you know, in the day too, so you know - ah - you just do what you have to. Wherever you can fit - open time up to earn extra money and stuff.*

Eventually many family members become overwhelmed, and they discussed feeling tired and not taking care of themselves. The husband of a patient mentioned how he felt overwhelmed he was by the situation:

> *After a while I think it will get the better of you. I mean, it's being going on 3 years, so you get a little tired too, but you realize you know, that you are doing everything you can and try to keep your spouse positive and stuff. But yeah, at times you get a little tired… I think that most spouses they just you know, deal with it and just try to focus on taking care of their spouse and try to keep things running, just sometimes they start thinking about what - how they are trying to do all this stuff, it can be a little overwhelming for them… Work. You got work. Kids. And you know bringing her back and forth to the doctor, so social life is kind of nonexistent for me. You know - it's - it would be nice, you know, to let off some steam once in a while where maybe you can go bowling or something like that, but it just - no time. That I have been able to keep her first and you know, like I said, have had to change around things so…you know.*

In summary, it is clear that Family Roles are greatly influenced by cancer and its treatment. Family members who become caregivers for the cancer patient must add this role to their pre-existing roles and responsibilities. There are many shifts in roles as cancer patients' functional abilities are reduced. Family Roles became more difficult for nuclear families that do not have other family members living near by, or that have young children and both adult family members working. To maintain adaptive family roles, family members needed to work as a "team" and find "balance" in their roles in order to avoid role conflict and role overload.

Family Communication

In this study, the *Family Communication* domain was defined as the verbal sharing of opinions, ideas, concerns, plans, and feelings. Based on the interviews, six subthemes regarding the importance of Family Communication for FQOL emerged: (a) openly discussing cancer and its treatment, (b) talking about how one is doing and what is happening, (c) sharing feelings, (d) talking about positive things as well as cancer, (e) discussing the future, and (f) keeping communication open.

Talking Openly about Cancer and Its Treatment. Eleven families stated that talking openly about cancer and its treatment was important for them. The extent to which families felt they could talk openly about cancer and its treatment depended on the phase of cancer and the family member who was involved in the discussion. This was especially true when it involved telling children about the cancer diagnosis and its treatment. The diagnosis phase was the most difficult time for cancer families in regards to talking about cancer. Many patients and family members stated that it was very difficult at first for them to talk about the cancer diagnosis, with many families stating that they needed a period of time to get over their initial shock. One male patient stated that he had problems talking about his diagnosis for a month. The wife of a patient stated that it took her about three weeks before she was able to say the word "*cancer*." After this first period, however, most patients and family members were able to talk with other family members or other people more openly about the cancer, its treatment, and the side effects.

A male patient explained about how difficult it was for him to talk about cancer at first, but after that initial period he was able to talk about the cancer more openly:

> *At first it was, yeah. More I guess more embarrassed. I was more embarrassed than I should have been, and that took me a little while to get over and the other thing was how was I going to handle it. I had to work that out in my mind before I could talk about it to other people, and so I had to get that worked out also. So - and once those two things were worked out and then I don't care who knows and if I tell them, you know, I'll tell them. If they ask, they ask, you know. I try to be pretty open with them.*

After cancer families had progressed beyond the diagnosis phase and had begun receiving treatment, they tended to talk more openly about cancer, treatment, and its side effects. Family members believed that talking openly about cancer helped patients get through cancer better than trying to hide it. For some families, talking about cancer and its treatment occurred on a "*regular basis*." A female patient who was receiving chemotherapy stated that "*You know, there is a whole lot of conversation about cancer in my life at this point.*" Family members reported that they felt good if the patient was the person who began the discussion about cancer. The daughter of a patient discussed how she "*felt better*" when her father was willing to talk about his cancer although it was painful for her. She stated that:

> *Well, it helps because it is better to say everything than not address it. You know, when you don't talk about it, it is like a fear. So when you do talk about it, it makes you feel better even though the end is the same. It makes you feel better that he is willing to talk. Because*

> *I don't want to talk about it - I don't want to force him to talk about it. Who wants to talk about their death, you know. So when he talks about it, it makes me feel better even though it's a horrible conversation. It makes me feel better that he's not - you know- too afraid to talk about it. So - it's weird. It's really weird.*

For families who had children, telling the children about patients' diagnosis was particularly difficult because they wanted to protect their children from the reality of the cancer. Ultimately, all of the families who had children decided to tell them about the cancer because they believed this was part of trust. However, the level of information about the cancer and its treatments differed depending on the children's ages and personalities. The husband of patient explained how he told his children about cancer:

> *We have talked to the children about it, you know - the 7 year old, I mean, we put it in terms where she can kind of understand for her age group, but the teenagers yes, they are aware that, you know, she has cancer and that this can get worse before it gets any better and you know, if - at best we hope to try to keep it from spreading worse, you know.*

Talking about How One is Doing and What is Happening. All families mentioned that after the initial diagnosis and reactions to this news, the topics of family conversation turned to focus on how the patient and family caregivers were doing and what was happening, if there was any news. A male patient stated that "*It has definitely changed from what it was, yeah. It is - most of your conversations now, with your spouse, are devoted to, you know, cancer, how we're doing and stuff like that. And business is kind of secondary to it. So it has definitely changed.*" "*How you're doing and what is going on*" became the first questions that cancer families asked the patients and the primary family caregiver. The wife of a patient stated that "*They are - I mean, every time we talk they always want to know what's going on and how he's doing and actually that is one of* *the first things they ask about."* Knowing about what was happening with the patients helped family members feel less concern. It also made the patients felt good that their family members were concerned about them. A male patient explained that his family that always asked him about what was going on with him and he always told his family members about his situation because he realized that his family members were concerned about him. He explained that:

> *I let them all - I am sure that they all know exactly what's going on. I give them that information but they - you know - they are concerned about how I feel, my day to day feelings, you know. How much strength I have got and that kind of thing.*

Sharing Feelings. Ten patients and eight family members mentioned that "*how do you feel*" had become one of the most important questions when a family member had cancer, and it represented family members sharing feelings with each other. A female patient stated that "*With my siblings and my parents - yeah, it's better than it was but you know - so. It changes everything. It does. It changes how they look at you and what the conversations are about. It always starts with so, how are you feeling?"* It is evident that having someone with whom people can talk and listen and share feelings is important for patients and family members. Families reported they learned that it was important for them to share their feelings about cancer and death with the family member who had cancer and other family members. The daughter of a patient described her family's experience with cancer, and how that made her wants to talk about cancer and share her feelings with her mother more openly:

> *When my dad was sick, we expected him to live. They thought he would live a year. Maybe a little bit longer. They thought it was probably a slow grower but it turned out to be very aggressive. But anyway at that time, and we didn't talk about death. We*

> *didn't talk about how he felt. And when my sister was sick. You know, she was young and she was a very pretty girl and you know, it was disfiguring her cancer. And we didn't talk about it and I think we learned from those two experiences that you need to talk about it. You need to communicate. You need to tell people how you feel. You know, how you feel about death. And you know - I remember asking my dad one day how he felt about it and he said it was the biggest challenge he had ever faced in his life. Well, that was about the only time we ever talked about it… I think we thought there would be plenty of time in the future. Sometimes it's too late to ask them… I know, a lot of time my mother doesn't want me to be down so she will - but I know she is - but we will talk about it and you know - think that is just the best way to do it. It is to just make sure everybody is open and communicates, not try to hide things.*

Although families reported that sharing feeling was important to them, two patients and four family members reported that it was difficult to share their feelings with the family. The main factors that made it difficult to share their feelings were personality, wanting to protect feelings of family members, and concerns about death. Personality was one of the main factors that families mentioned as underlying this problem. The wife of a patient stated that "*He and I don't - he has never been a big talker anyway. I'm - I have always been a rather solitary person and don't - and find it very difficult to share things with anyone*." The way that she dealt with her feeling was "*I just let it go and try to bring it up again later. Sometimes it works, sometimes it doesn't. Sometimes we will have a nice - a good conversation about it and other times it's just I don't want to talk about it*." Wanting to protect the feelings of patients or other family members was an interest competing with the desire to share feelings with the family. A female patient stated that "*They (her family members) don't really like to talk too much about it I don't think. It kind of hurts*." Sharing feelings about cancer also was difficult because of cancer's connection to death, but these issues were on the minds of patients and family members.

A male patient explained how his wife talked with him about her concerns sometimes, but that she still did not mention her worry that he might die:

> *A couple of times in those instances when she gets upset. She hasn't actually articulated any concerns about mortality and those kinds of things. I am sure that's here, just hasn't come out explicitly - it's there, kind of implicit. I think it is a reasonable thing to be worried about.*

Talking about Positive Things as well as Cancer. Four patients and four family members also stated that it was important for them to talk about positive topics and not only about the negative aspects of cancer. Focusing on the negative was discouraging to patients and family members and made them worry more or "*made them get sick*." A female family member reported that when her family member with cancer heard someone say something negative, it upset the patient "*I don't like it when - there are some times when it was - there are really negative people and you can tell when he has talked to them because then he gets a little bit negative. So, it's like I have got to boost him up*." Therefore, they wanted their family members and others to keep a positive perspective. A male patient explained:

> *I'm so sorry you have got cancer or how long have you got to live. Tell me about this - I really don't want to hear all of that, quite frankly. So I just don't - I don't want people's sympathy… Death is not a thing that I have any fear of and we never talk negative, not because - mainly because we - We don't avoid the subject. We don't talk negative because we don't think that way. You know, we just don't think negatively... we don't go around negative. We just don't do that. That's accomplishes absolutely nothing.*

Discussing the Future. Five patients and three family members mentioned that the future was an important topic that they needed to discuss in their families. Discussing the future was a difficult topic because, for cancer patients, the future is often linked to death.

Four families, however, especially those with patients in cancer stage IV, stated that they felt it was important to have a conversation about their feelings with the patient because the patient was facing a significant likelihood of death in the near future. A female patient stated that "*Communication that helps you prepare for future issues is the main thing. I told him (her husband) I am not going to be there one day*." Two families mentioned that their family had started to have conversations related to patients' funerals and wills. For example, the daughter of a patient explained:

> *It made us have to start talking about a lot of things that we never talked about before. Like his will and you know, what he likes to do now, you know. So - it - I guess it made us get more involved in his business. You know, before, he was sick I didn't have to ask him about his business at all. It wasn't any of my business to ask him that and now I have to be more - I have to ask him more things about his - you know, for instance, his health care or - you know, check on him and see how he is doing all the time. Then we have to talk about things like his will and things like that. That before I wouldn't have to talk about. So - and that way it has changed.*

Keeping Communication Open. Six patients and eight family members stated that it was important for them to keep communication open. Keeping communication open was important because it helped the family members feel less concerned about the patient. A male patient stated that he sent an email updating his family about his medical condition every month to keep communication open, because he realized that his family members were concerned about him. "*I send out a - at least a monthly medical update on myself to my members, to my family, to my friends. Just so - there is nothing to hide. I am not trying to hide anything so I feel like it is my obligation to keep people informed because they are concerned.*"

Keeping communication open helped the patients feel more secure. A female patient stated that it was important to keep communication open because *"Keeping the communication open so you can get answers and you can ask questions and be able to feel more secure with - and stay happier… and that's why I call them (her family members) and talk to them, you know, try to keep communication both ways."*

In summary, although cancer is a difficult topic for almost all families to discuss, cancer families often stated that talking openly about cancer and its treatments helped both patients and family members get through the cancer experience. Important aspects of *Family Communication* included talking about how the patient and family caregivers were doing, what was happening with the patient, how the patient was feeling, and discussing the future, which were seen as important because they helped family members feel less concern by bringing their concerns out in the open. Maintaining a positive attitude and keeping communication open also were seen as useful for families and strengthen their relationships. Thus, *Family Communication* is an important aspect of FQOL that helps families maintain and/or strengthen their relationships and prepare for the future.

Family Emotional Support

In this study, the *Family Emotional Support* domain was defined as positive behaviors with the explicit purpose of providing emotional support to family members. Eight subthemes for *Family Emotional Support* emerged: (a) being physically around the patient, (b) "being there" emotionally, (c) caring about each other, (d) checking in on the patient, (e) showing concern, (f) providing encouragement, (g) showing support, and (h) expressing love.

Being Physically Around the Patient. Three patients and six family members stated that being around the patient was one of the ways that they showed and provided support. The reasons that family members wanted to be around the patients were (a) it provided the patients with support; (c) they had strong desire to take care of patients, and (c) they were uncertain how much longer the patient would be alive. The wife of a patient reported that she would rather be with her husband than go out with her friends, because she wanted to support her husband and she was uncertain how much longer he would be alive:

> *I think another thing that makes me see people less is that this makes me feel like I want to be home. Like I want to be available at home and I mean that in a couple of ways - like you know, just in case he needs something or you know, let's say it was - let's say it's a night when my daughters are with their father. At this point I just wouldn't think of saying well, I' going to go - I am going to go out with the girls tonight. You know, partly because - I mean he can take - even when he is not feeling well he can take care of himself. I mean, he would be happy for me to do that but it is partly, you know, I still want to be around and available and the other thing is that I feel like, you know, he and I have so little time as it is just by ourselves and then there is this part in the back of my mind saying, you know, who knows how much time we'll have in total. So, I think that keeps me from seeing people too.*

An example of the husband of a patient that wanted to be with his wife all the time because he had strong desire to take care of her was:

> *I feel a real strong need to be with her. I don't want her very far from me. I don't. I don't know why that is, I just feel like I want to be - when she goes away for 2 or 3 hours, or 4 or 5 hours with her sisters, it just kind of - kind of bothers me a little bit. I don't know - I just - I guess it's because I have the strong will to be*

> *there with her, you know, and try to take care of her the best I can.*

Being There Emotionally. Ten patients and 11 family members mentioned that "*being there*" emotionally was one of the most important ways they saw to support each other. Although not all family members were responsible for taking care of the patient, if the patient realized that the family member was there for them emotionally, this helped support the patient emotionally. A female patient said about her family members "*A couple of them, they don't care give. They just - they are there. I don't know if it's a good thing but ah just being there for each other and we're just talking helps a lot. And to me, that's been my life thing.*"

Although most of families reported family members were there for them emotionally, two families reported that family members failed to be there emotionally. They stated that some family members said they would be there but in reality they were not present when the patients or the primary family caregivers needed them. The husband of a patient explained:

> *I think overall you have a lot of people, especially on her side of the family that say they will be there and they are not there really because, you know, they have got their own lives too and you know, it makes it a little harder because you don't really have that full family support other than your spouse and you know, your kids, trying to work things out. So - that is what makes it the most difficult, you know - not having enough family support and in some cases they just are unable to - you know- I think some people talk a good talk.*

Caring about Each Other. Two patients and five family members mentioned that caring about each other and expressing this feeling was an important aspect of support. Families reported that "*a good support system of people who care for each other in the* *family*" was an important basis for emotional support. Caring about each other helped to hold the family together as they go through a difficult time. The wife of a patient stated that caring about each other was one of the most important things that held her family together:

> *What can hold us together? I think everybody just has to trust that even though day to day things might not always be great that, you know, we love each other and we care about each other and that we are going to be okay. And you know, I really - I mean I really believe that in life whatever happens you are going to be okay. It could be horrible in the meantime but that, you know, ultimately things will be all right. So, I think everybody - just - I think what holds things together is when everybody trusts that everybody is doing the very best that they can. And that they care about each other.*

Checking in on the Patient. Four patients and four family members mentioned that their family members always checked in on them, and that this felt supportive to them. A female patient stated "*My family members also try to make sure that I get the chance to get out and to do and for them to watch okay, you know, I didn't see you yesterday but we talked on the phone today, you know*." Besides checking in on patients, family members also would check in on family caregivers as well. A female family member said "*My daughter checks on me every night, you know, wants to make sure I'm okay*."

Showing Concern. Nine patients and 11 family members mentioned that showing concern was one important way that family members could be supportive. Knowing that their family members are concerned serves as emotional support for patients. A male patient stated that "*I get support from them, just in the knowledge that they are concerned about me. That's support.*"

Children showed their concern to the patients in their own way, depending their age. If they were grown up and did not live with the patients, they would show concern by calling the patients often. If they were still young and lived with the patients, they would show concern through positive behaviors. The wife of a patient described how her 10 year old daughter showed concern for her stepfather:

> *It's really interesting. So, my younger daughter shows her concern in trying to make him feel better. So, you know, bringing him little things or she sends - it was so sweet, I guess it was 2 night ago, he was feeling very tired and he was lying down in bed. She went over to him and she gave him a kiss on the cheek.*

Providing Encouragement. Two patients and seven family members mentioned that directly providing encouragement was an important support for them. Patients reported that they needed encouragement from their family members to "*make them get through cancer*," "*not be afraid with cancer*," and "*keep their spirits high*." Given the nature of cancer, it is inevitable that the mood of family members and patients go up and down, and when a patient has a down time, it is important for family members to encourage and cheer the patient up. The husband of a patient mentioned how he encouraged his wife to continue her cancer treatment:

> *Because as they get worse, in some cases, the chemotherapy doesn't work, then you know, they go through different mood swings and you know, they are fighting for their life, so you want to try to encourage them on one hand and then it can also wear down the party - you know, your spouse or whatever - they can get a little tired too, but you know, you try to encourage your spouse to go through the treatments and hope for… The best thing I can do is just, you know, try to encourage her that you know, you have been able to make it this far and a lot of the things… I just let her know that you know, I am here for her and you know I try to do what I can.*

In turn, patients also encouraged their family members. Several family members reported that the patient's personality was itself encouraging for them. Patients who were positive, strong and cheerful helped to cheer up family members. Thus, the way patients dealt with cancer affected how their family members coped with cancer. A husband stated that his wife, who had cancer, had helped him be strong and provided encouragement:

> *Because my wife is so positive, I just - I just look at amazement at her the way she handles this. I just can't - I can't imagine it. And it just helps me tremendously because I support her, of course, all the way. And it helps me too to be strong because of her.*

Showing Support. All patients and family members stated that showing support was one of the most important emotional supports they received. Psychological support from their families helped patients and family members get through the cancer experience "*a tremendous amount*." All patients and family members mentioned that their families had shown emotional support for them. For some patients, the support they received from their families was sufficient such that they did not need emotional support from outside the family. A male patient stated that "*I am the one who has got support here (from his family). So I have no room for any more*." For family members, all of them reported that their family members showed them support in their fight with cancer. Patients realized that their family caregivers needed to receive supports as well they did, because their family caregivers could become overwhelmed with their roles and responsibilities. Thus, patients tried to show support for their family caregivers. A male patient said about his wife:

> *I think she needed more support than I did. She felt not lost but just overwhelmed and it was because, you know, we had just*

> *bought the business. We run a business and moving and now this - this cancer and I think she needed more psychological help than I did.*

Because of physical problems, some patients had limitations on their ability to show support for their family members. Their family members, however, understood these limitations. A wife stated that:

> *As much as he is capable of. I mean, you know, realistically he just doesn't have, right now, you know, the energy and just the kind of emotional resources, you know, to be as supportive as he has been, you know, before the cancer. So, I feel like I know that he is being as supportive as he is possibly can but ah - yeah, but I would say that that has changed because, you know, I can remember times before when you know, he could take on that caretaker role, and he still does sometimes. The other night, I mean, I did kind reach my breaking point and you know, he said, you know, just go lay down and then I'll wait for you and we will have supper together and so. It's not like he never supportive. But, you know, I guess I just don't - I don't expect as much right now. I just try to be realistic.*

In addition to the patient, other family members provided support for primary family caregivers. Four family members reported that they received support from their children, cousins, and other relatives. An example of how a 10 year old daughter showed support to her mother who took care of her stepfather was:

> *She will say to me things like you look tired. Or you know - can I get you a drink of water? Or you know - and so I think at the level that she's at, she does understand. She may not understand the full extent but she understands that there is, you know, there is a big medical problem and that it takes a lot of energy to take care of it and that it makes (husband's name) feel really crummy sometimes and that it makes mommy tired. Ah - and so to that extent I think she really does try - you know, appropriate for her age---10 years old or even more than you would expect... It is helpful and it may not be helpful in a material way but it is really helpful in an emotional way.*

*Expressing Love***.** One patient and eight family members said that expressing love for each other was an important way that the family supported each other. Family members mentioned that telling patients that they loved them or expressing love through hugs were important ways that they provided support. For example, the wife of a patient stated:

> *I think the ways I support him are like just doing all the things that I do to help him with his medical care and then just telling him I love him a lot. You know, because the thing I want him - I think the thing I want him to understand is that this doesn't change my feelings in any way at all, you know. I mean, it's not like why did you have to go and get cancer?*

In summary, cancer families need emotional support from their families to help them cope with the cancer and its treatments. Based on the interviews, the most frequent ways that families provided emotional support for each other were by being present physically and emotionally, showing concern and love, and providing encouragement. All family members needed emotional support at some time during the cancer experience, although the focus was support for the patient and his or her family caregiver.

Family Interaction

In this study, *Family Interaction* was defined as behaviors and interactions among family that serve to or reflect maintenance of the family structure and function, and that do not fit into the family roles, family communication, and family emotional support domains. Thus, *Family Interaction* tends to involve general behaviors or interactions that family members engage in with each other. Positive family interactions that cancer families reported had helped their families maintain family structure, functions, and relationships were selected as themes. Five subthemes were: (a) the importance of contact with family members, (b) involvement in family activities, (c) helping and supporting each other, (d) becoming closer, and (e) physical intimacy.

*Importance of Contact with the Family***.** Ten patients and eight family members stated family members contacted each other more often than in the past since the patient had been diagnosed with cancer. Although some families stated that they were inherently a close knit family, cancer still made their families contact each other more often. The frequency of contact with patients had changed significantly from having contact every few weeks or months to every few days or everyday. The ways that family members used to contact patients and each other included phone calls, email communication, and visits. Phone calls were the most common way for family members who did not live with the patient to keep in contact. A female family member said that *"Before he had cancer, Ah, maybe 2 times a week. I mean we talk and if we needed to, but it's an everyday now, how are you doing and you know, make sure that he is okay because he does live by himself."* Three patients and a family member also mentioned that they used E-mail communication, in addition to phone calls, to stay in contact with each other because it was convenient for them to send an email to many family members.

Twelve patients and 10 family members also mentioned that their family members came to visit more often than in the past. One main reason was because they were concerned that the patient might die soon. A wife discussed her daughter-in-law, saying "*We have seen more of her. I mean, we saw her on a pretty regular basis anyway but she is an only child and she loves her father (the patient) and she's - she knows she is going to lose him and she is not happy about that, of course. So she comes and visits when she can."*

Involvement in Family Activities. Six patients and seven family members stated that their families came together or joined in family activities more often than in the past. The activities that were mentioned included playing games, taking a trip, eating out, or getting together for important occasions. Involvement in family activities made family members appreciate and strengthened their family relationships. A male patient stated that:

> *We have some family get together. We were together on the 4th of July weekend and all. And all but two of my grandchildren were in attendance. And all of my great grandchildren. I have 4 great grandchildren. And I had a good time. I had a good time visiting, I always do.*

*Helping and Supporting Each Other***.** All cancer patients and family members reported that they helped each other, especially in the areas that cancer patients typically were unable to do by themselves because of the cancer (e.g., driving). When patients and/or their primary family members needed to go see the doctor or get treatment, other family members played a vital role in helping them. For example, if patients and primary family members ran their own business, other family members came to help take care of their business when patients and primary family members need to go to the hospital. Children also helped support family function in the ways they could. Although family members had to do many things for patients, family members were willing to help and be available anytime and for anything that patients needed. Thus, helping and supporting each other in general maintained family function and "*made a big difference*" for them. The wife of a cancer patient stated that:

> *The treatment more than anything because it takes us away from the business. We have to find someone to watch the business while we're gone because someone has to be in the office from 9 until 5. … You know - to watch (their business). We're in Murfreesboro and she (a patient's daughter) is already here (Nashville). She has*

> *come down and helped me at - in our business. She has come and helped me several times doing things down there and that's been a big help. And that makes a big difference.*

*Becoming Closer***.** Although cancer is fundamentally a negative event, eight patients and 10 family members stated that their families had become closer because of the cancer. The two main reasons family members stated that they had became closer were that (a) they wanted the cancer patient to become better, so family members had more connections to find ways to "beat cancer," and (b) they wanted to "rebuild" their families because of their concerns that they were going to loss a family member to cancer. An example of how this closeness develops was described by a sister-in- law of a patient:

> *We are a lot closer because I think, you know, before you hear that or before you have cancer everyone is going their separate ways. Everyone is independent, everybody is, you know, happy go lucky, and then cancer hits you like an animal coming down and all of a sudden everybody is dependent on everybody for support. In a good family everybody takes their part. And I am satisfied now that they realized how close we have got to be.*

An example of family members becoming closer because of their concerns that the patient was going to die was stated by a female patient:

> *I do see a lot of improvement in my family members together, working together and getting things done and trying to get things done, sometimes accomplished… It's (cancer) brought us together and it - also at times we fight. We also fight over it. We fight over certain things. But I think that it's - it's a medium there that where we are not hurting each other like we did before. We realized that we have got to stop at this point and do something else. You know, there have been more apologies and more things going back and forth and stopping and just - stop holding a grudge, you know and things like that… I have got 10 brothers and sisters… I think that in a lot of ways that has helped rebuild my family from that point of view… All the family members got together and there were a couple of them we hadn't talked to much and everything. It has gotten to where we are talking to each other more because we need - realize that one of us is not going to*

> *be there.*

Physical Intimacy. Physical intimacy was one of the important parts of the family life of a couple. Six patients and six family members explained that they had not been physically intimate or had a sexual relationship with their spouses since they were diagnosed with cancer. The underlying problems included (a) the patient not being interested in sex because of feeling sick or tired, or because (b) that they had some physical problem related to cancer treatment, such as after-effects of a hysterectomy where they did not have normal hormone levels. A female cancer patient stated that *"There was a lot of times that, as far as having sexual relations with my husband, the desire was not there."* However, few spouses mentioned that the lack of a sexual relationship bothered them but rather most spouses mentioned that they tried to "*work through it*" because they understood that physical intimacy was part of their relationship. Several patients and their spouses discussed different ways that had responded to this problem, including discussing it with each other, not focusing on or thinking about physical intimacy, and doing something else that showed their love and strengthened their relationship, such as hugs, kisses, and holding hands. The husband of a cancer patient explained how he maintained physical intimacy:

> *Ah - and I think you know, just the bonding like you may - for her - having a hug or a kiss is something once in a while, you know, lets her know that you still love her and stuff and you are not putting pressure on her that - you know, you got to have sex. Like I said, that is just something that you got to put out of your mind and you know, just focus on, you know, what you have got to do for your family.*

To summarize, patients and family members often felt that cancer had some positive effects on their family interactions, especially in that it had helped to "*rebuild*" or “*reconnect*” their families. Because of the cancer, family members contacted and helped each other more, joined in family activities more frequently, and felt that they had become emotionally closer. Although many patients had difficulties in regards to physical intimacy or sex, their spouses accepted the problems and showed their love and affection in other ways.

Overall Family Quality of Life

It should be evident from this review of the patients’ and family members’ discussion of these various domains of Family Quality of Life, many of these domains are not distinct. Expressing love is a form of emotional support, and emotional support is a way of showing concern. In addition, there is some overlap between themes across domains. For example, keeping in contact, a theme from the Family Interaction domain, may also be considered “being there” for the patient in the Family Emotional Support domain.

Thus, there is a strong general component to Family Quality of Life, which can be thought of as overall FQOL. In the interviews, in discussions about overall Family Quality of Life, three subthemes emerged: (a) impact of cancer on the family, (b) satisfaction with the family, and (c) how families attempted to maintain or improve their satisfaction with their family.

Impact of Cancer on the Family. All of the patients and family members said that cancer not only affected the patient but also all of the family. On specific area that several families mentioned affected by the cancer was their emotions. As a family member described, cancer was "*an emotionally draining disease for the family*." An example provided by the wife of a patient was:

> *I think just seeing him go downhill was hard (tearful). He has always been a such a strong person and seeing him be broken. I thought it was going to be his trial but it was both of us. I thought I was going to be there just here to help him through it and I didn't realize how it was going to affect me…I feel like it definitely affected me emotionally… I feel like we are kind of drifting in life right now, and I don't like that feeling.*

Satisfaction with the Family. Eleven patients and 12 family members reported that despite the cancer, overall they were satisfied with their FQOL. The main factors that made patients and family members feel satisfied with their FQOL were their success in their personal life and career, and strong family relationships. Three patients who reported always having a good attitude and satisfaction in their life mentioned that cancer had not affected their FQOL. A male patient stated that he always had been satisfied with his family life and that cancer did not affect this for him "*I have never been dissatisfied so I - it's just not - you know - the cancer has had no effect on that at all. None*." Some patients and family members reported that they were satisfied in their FQOL because they were successful in their careers and life. An example of a male patient described how he felt successful and satisfied in both his professional and personal life, despite the cancer:

> *From a business standpoint and from a personal standpoint, I have enjoyed a very successful career. I accomplished everything I wanted to accomplish and in our private life, years ago I finally found the right woman in my wife I am very satisfied in that. And ah for years my relationship with my daughter was not the best, but in the last five or six years it's gotten to be real good and I'm appreciative of that. So - but ah - overall I think I've got a pretty well rounded success rate.*

Having strong relationships in the family was one of the keys for families to being satisfied with their FQOL. Several families mentioned that they felt satisfied with their

FQOL because they were confident that their family was a unit and they were all together. Thus, it made them felt satisfied in the family life. An example of how patients were satisfied with their family as unit was described by a male patient was: "*That we have peace among our family, that there is not dissension. We have, you know, we have some little dissension. You can't have a perfect situation, but our family has come together now as a unit better now than they ever had.*"

Although almost all patients and family members stated that they were satisfied with their FQOL, they did say that they would be even more satisfied if their family member did not have cancer, although they accepted the cancer situation. For example, the wife of a patient stated: *"I think I am pretty satisfied with everything right now. I'd be more - I'd be happier if he wasn't sick, but he is and there is nothing we can do about it. So, we make the best of it."*

How Families Attempted to Maintain or Improve their Satisfaction with their Family. Because cancer directly affects the family, several cancer families felt that if they could overcome the cancer, it would help to improve their FQOL. Two patients and two family members said that the patients feeling better or not having any side effects would improve their FQOL. An example of "*getting well*" as the best way to improve FQOL was stated by a male patient:

> *Getting well. That would be the only thing. If I got well, that would improve. That would improve certainly things for her and certainly things for me. Because I think if I were to die as a result of this, it would be a lot harder on my wife - far more difficult for my wife than for me. Of course, I won't have to worry about that because I'm dead. But ah - it would be much rougher on her.*

In summary, based on the results of these interviews, it is clear that cancer affects not only patients but also all family members and their FQOL. Families must learn as a family, rather than as individuals, how to face, cope, and live with cancer.

Conclusion

Overall, the results from a content analysis of the interviews supported the hypothesis that these four domains are central aspects of FQOL for cancer families. It was expected that there would be substantial overlap among the domains of FQOL, in particular among the subdomains within each of these four primary domains. For instance, within the *Family Emotional Support* domain two sub-domains were Expressing Love and Showing Concern. But expressing love is a form of emotional support, and emotional support is a way of showing concern, and thus these subdomains to some extent overlap. However, the purpose of the subdomains within the four domains was not to identify discrete categories but rather to provide structure within a particular category for reporting results.

In addition, there may be some overlap between themes across domains. For example, "keeping in contact," a theme from the *Family Interaction* domain, also might be considered "being there" for the patient, a theme from the *Family Emotional Support* domain. This reflects the reality that there is a strong general component to FQOL, which can be thought of as overall FQOL. A decision was made to maintain these distinctions in the qualitative analysis, because it would be easier to collapse similar domains if future empirical analysis warranted scale consolidation or reduction.

Item Generation

The initial item pool was developed by identifying codes that were high in frequency and high in number of participants that talked about those codes in each of four categories: (a) Family Interaction, (b) Family Roles, (c) Family Communication, and (d) Family Emotional Support (See Table 2 for details). In addition, some codes that were low in frequency were still considered if they were supported by the literature review. One code (taking care of pet) also considered although it was low in the number of codes and participants because only one family of the 12 families interviewed had pets.

Table 2

Frequency of Codes and Participants Who Talked about Those Codes in Each Category

Categories and Coding	Number of Codings		Number of Participants	
	Patients	Family Members	Patients	Family Members
Family Interaction				
- Available anytime or for anything needed	9	12	5	6
- Contact / Call often	28	40	11	11
- Get closer	24	17	8	9
- Good relationship	17	19	9	10
- Helping each other	28	27	10	9
- Join family activities	11	18	6	7
- See family (visit, go out, etc.)	24	24	12	10
- Sex	11	10	8	7
- Willing to help	10	10	4	5
Family Roles				
- Affects working / performance at work	6	5	3	4
- Breadwinner / Financial	21	18	8	6

Table 2, continued

Categories and Coding	Number of Codings		Number of Participants	
	Patients	Family Members	Patients	Family Members
- Comes with patient to see doctor	14	25	8	9
- Comes with patient to treatment	12	30	9	11
- Household chores	55	35	12	12
- Meal planning	4	6	3	4
- Role overload	10	11	3	4
- Disagreement about roles	3	11	3	5
- Schedule (stressful to manage complex schedule)	9	11	5	6
- Take care of children	10	18	2	6
- Take care of patients	19	61	6	11
- Take care of pets	1	2	1	1
Family Communication				
- Keep communication open	18	10	6	8
- Not talk negatively	9	11	4	4
- Person with whom one talks, and who is ready to listen	3	1	2	1
- Talk about diagnosis / cancer	15	17	7	9
- Talk about feelings	19	18	10	8
- Talk about future issues	8	3	5	3
- Talk about how one is doing	9	13	7	6
- Talk about what is going on	8	8	6	5
- Talk openly	25	28	11	11
- Talk to family more	19	6	5	3
Family Emotional Support				
- Be around patients / Spend time with patients	4	12	3	6
- Be there for each other	18	28	10	11
- Care about each other	3	10	2	5
- Checking on patient	8	8	4	4
- Show concern	25	33	9	11
- Encouraging	6	18	2	7
- Show support	30	53	12	12
- Tell or show love	2	14	1	8

The FQOL questionnaire was developed from this initial item pool. As a result of discussions with committee members and experts, it was decided that the questionnaire should focus on the satisfaction with rather than the amount of the various aspects of FQOL. This is consistent with the definition of FQOL used in this study. The preliminary questionnaire contained 41 items, with (a) Family Interaction (9 items), (b) Family Roles (9 items), (c) Family Communication (10 items), (d) Family Emotional Support (8 items), (e) Family Quality of Life sub-domains (4 items) and Overall Family Quality of Life (1 item).

To obtain additional input on the preliminary items, after discussion with the dissertation committee, the PI presented the preliminary FQOL questionnaire to the Pain and Management Research Team of the VICC for their comments, because the research team contained oncologists, nurses, researchers, and other health care providers who are cancer experts with extensive experience in cancer research. As a result of this meeting, several items that were redundant and / or not important for most types of cancer were deleted and wording of some items modified.

This next preliminary version of the FQOL questionnaire contained 37 items and was divided into three parts: (a) general FQOL questions, (b) cancer specific FQOL questions, and (c) questions directly focusing on FQOL sub-domains and overall FQOL. There were 21 general FQOL items comprised of (a) Family Interaction (5 items), (b) Family Roles (4 items), (c) Family Communication (5 items), (d) Family Emotional Support (7 items). There were 11 cancer specific items comprised of (a) Family Interaction (1 item), (b) Family Roles (5 items), (c) Family Communication (4 items), (d) Family Emotional Support (1 item).

The items directly assessing FQOL sub-domains contained 4 items, and overall FQOL was one item. The preliminary questionnaire used a 5 point rating scale (Not At All, A Little, Somewhat, Quite a Bit, and Very Much), with two versions: (a) one for cancer patients, and (b) one for family members. The cancer patient vs. family member versions contained the same items for general FQOL, FQOL sub-domains and overall FQOL questions. There were slightly different wordings for cancer specific questions so that they were appropriate for patients vs. family members.

CHAPTER V

METHODOLOGY (PHASE 2: ITEM REVIEW)

Research Design

Content validity is an important aspect of measurement development because it assesses the relevance of potential items, and the extent to which the potential items represent the domains to be covered by the instrument, which allows for the interpretation of scores when the measure is used (Waltz, Strickland, Lenz, 2005). Content validity generally is based on experts' judgment regarding the extent to which items represent and cover the domain of interest (Lynn, 1986; Waltz et al., 2005).

The purpose of Phase 2 was to examine the content validity of the preliminary FQOL questionnaires developed in Phase 1. This initial item pool was examined and reduced based on content validity ratings of cancer experts.

Research Setting

In Phase 2, cancer experts at several different institutions were invited to be consultants of the study. These institutions included the VICC, Vanderbilt School of Nursing, the Maury Regional Hospital, University of Michigan School of Nursing, and University of Rochester Medical Center and School of Nursing.

Sample

Criteria for Sample Selection and Inclusion

For Phase 2, experts with a minimum of five years of experience working with cancer patients were invited to be consultants to examine content validity of the preliminary FQOL questionnaires.

Method for Subject Recruitment

For Phase 2, the PI, the faculty adviser, and dissertation committee members selected health care providers who met the criteria. The PI contacted the experts in person, or via telephone or email and invited them to examine the content validity of the preliminary questionnaire.

Human Subjects Protection

The research methodology, all questionnaires, and letter of invitation used in Phase 2 were reviewed and received approval from the Vanderbilt Institution Review Board. When the PI invited experts, the PI explained the purpose of the study and of Phase 2, and invited them to be consultants to examine validity of the preliminary FQOL questionnaires. Experts were informed that their participation was voluntary and if they were interested they should sign the consent forms and return a copy to the PI with the completed questionnaires. A copy of informed consent was included for their records. The role of experts in this study was not to rate their own FQOL but rather to rate the relevance, clarity, and sufficiency of the preliminary FQOL questionnaires' items and provide suggestions and comments to improve the items and format of the questionnaires.

Data Collection Method

The procedures used to examine the content validity in this phase were based on recommendations of Waltz et al. (2005). Phase 2 was conducted from May 6, 2008 to June 4, 2008. Experts received a packet of questionnaires in person or by mail and a stamped and envelopes to return the questionnaires. The packet of questionnaires included (a) the objective of the study, (b) the preliminary FQOL questionnaires for cancer patients and for family members as developed in Phase 1, and (c) the preliminary questionnaire modified to examine content validity. This latter version of the questionnaire used a 4-point Likert format following Waltz et al.'s suggestion (see Appendix C). Experts were asked to rate: (a) the relevance of each item in regards to FQOL; (b) the clarity of each item; and (c) the sufficiency of the sub-domains (family interaction, family roles, family communication, and family emotional support) and the FQOL construct. Experts were also asked whether the questionnaires should include satisfaction and the importance of each item. In addition, several opened-ended questions were included for experts' suggestions and comments about the format and the items.

Data Analysis

Data were analyzed using SPSS version 15 to examine the frequency, mean, and standard deviation of each item. Items that seven or more experts rated as lacking relevance, sufficiency or clarity were modified or dropped (Waltz et al., 2005). In addition, mean ratings for each item were used as criteria for modifying or dropping items, as shown in Table 3.

Table 3

Criteria for Decision about Items based on Experts' Suggestions during Phase 2

Criterion	Interpretation	Decision
Mean clarity or relevance rating above 2.5	High relevance / High clarity	Not necessary to modify the item, except if the experts' suggestions would increase item relevancy or clarity
Mean clarity or relevance rating between 2.00 - 2.50	Moderate relevance / Moderate clarity	Possibly modify the item, following the experts' suggestions.
Mean clarity or relevance rating below 2.00	Low relevance / low clarity	Necessary to modify the item, following the experts' suggestions or drop the items.

CHAPTER VI

RESULTS (PHASE 2: ITEM REVIEW)

Overview. The main purpose of Phase 2 was to examine the content validity of the preliminary FQOL questionnaires developed in Phase 1. Ten cancer experts served as consultants who evaluated the content of the items and the preliminary FQOL questionnaire.

Participant Characteristics

Eleven cancer experts with at least five years of experience with cancer patients were invited to participate in Phase 2. One cancer expert did not return the package of questionnaires. Therefore, 10 cancer experts (3 oncologists, 6 nurses including nursing faculty and researchers, and nurse practitioners, and 1 psychologist) signed the consent forms and returned the preliminary questionnaires with their evaluation of the measures for content validity.

Results

The relevance and clarity of each item as well as the sufficiency of the items to represent FQOL were examined. In addition, the modifications for final items for the FQOL questionnaire to be used in Phase 3 are reported.

For the general FQOL questions, mean relevance of the items ranged from moderate (M = 2.10, SD = 0.99) to high relevance (M = 3.00, SD = 0.00), and mean clarity of the items ranged from low (M = 1.56, SD = 1.24) to high clarity (M = 2.78, SD = 0.44; see Table 4).

Table 4

Means and Standard Deviations for Relevance and Clarity Ratings for the General FQOL Questions

How satisfied are you with…	Relevance		Clarity	
	M	SD	M	SD
Family Interaction				
1. How available family members are when someone in the family needs something.	2.80	0.42	1.80	0.79
2. The contact family members have with each other	2.60	0.70	2.00	1.16
3. The help my family members give each other.	2.50	0.71	2.00	0.71
4. How involved family members are in activities together.	2.30	0.82	2.11	0.93
5. My sex life with my partner. *If you prefer not to answer, please check this box* ☐	2.30	1.06	2.56	0.73
Family Roles				
6. How available family members are to care for someone who gets sick.	2.90	0.32	2.56	0.53
7. The help family members give each other with household chores.	2.80	0.42	2.67	0.50
8. The sharing of responsibility for taking care of the children or pets. *If your family does not have children or pets, please check this box* ☐	2.80	0.63	2.78	0.44
9. Our family's financial situation.	2.70	0.68	2.33	1.00
Family Communication				
10. The discussions and solutions to our problems with which we come up as a family.	2.90	0.32	1.56	1.24
11. How openly my family talks about important things.	3.00	0.00	2.25	0.71

Table 4, continued

How satisfied are you with…	Relevance		Clarity	
	M	SD	M	SD
12. How openly family members express their feelings.	2.89	0.33	2.75	0.46
13. How positively my family talks with each other.	2.44	1.01	1.89	1.17
14. How openly my family discusses the future.	2.56	0.73	2.50	0.54
Family Emotional Support				
15. How often family members are there for each other.	2.90	0.32	2.22	0.83
16. How much my family cares for each other.	2.78	0.44	2.00	0.93
17. How often my family checks on each others' health and other needs.	2.10	0.99	2.11	0.93
18. How concerned my family is for each other.	2.80	0.42	2.44	0.53
19. How much my family encourages each other.	2.60	0.97	2.33	0.50
20. How much my family supports each other.	2.89	0.33	2.13	0.84
21. How family members show their love for each other.	2.40	1.08	2.33	1.00

For cancer specific FQOL questions, the mean relevance of the items ranged from moderate (M = 2.40, SD = 0.84) to high relevance (M= 3.00, SD = 0.00) and the mean clarity of the items ranged from low (M = 1.89, SD = 1.27) to high clarity (M = 2.67, SD = 0.50; see Table 5). The sufficiency of the general and cancer specific FQOL questions was high (M = 2.60, SD = 0.52), as shown in Table 6. Agreement with the suggestion to add importance ratings along with satisfaction ratings in the preliminary questionnaire was moderate (M = 2.11, SD = 0.78). However, some cancer experts expressed concern about the burden to the participants if they were asked to rate both aspects.

Table 5

Means and Standard Deviations for Relevance and Clarity Ratings for the Cancer Specific FQOL Questions

How satisfied are you with…	Relevance		Clarity	
	M	SD	M	SD
Family Interaction				
1. How close my family is to each other because of my cancer. *For Family Member version*: How close my family is to each other because of the cancer.	2.40	0.84	1.89	1.27
Family Roles				
2. How available family members are to go with me to the doctor. *For Family Member version:* How available family members are to go with the patient to the doctor.	2.90	0.32	2.67	0.71
3. How the members of my family balance their own responsibilities with their need to help take care of me. *For Family Member version:* How the members of my family balance their own responsibilities with their need to help take care of the patient.	2.90	0.32	2.11	0.78
4. How well members of my family are able to change their roles to respond to my illness. *For Family Member version:* How well members of my family are able to change their roles to respond to the patient's illness.	2.50	0.97	2.33	0.71

Table 5, continued

How satisfied are you with…	Relevance		Clarity	
	M	SD	M	SD
5. The ability of my family to adjust to my activity level because of my cancer. *For Family Member version:* The ability of my family to adjust to the patient's activity level because of his / her cancer.	2.50	0.71	2.00	0.87
6. How well my family members are able to balance the time demands of their own schedules and the time required to help me. *For Family Member version:* How well my family members are able to balance the time demands of their own schedules and the time required to help the patient.	3.00	0.00	2.44	0.73
Family Communication				
7. The openness with which my family talks about cancer.	2.80	0.63	2.22	1.09
8. Family discussions about cancer, medical treatments, and their side effects.	3.00	0.00	2.33	1.12
9. The openness with which family members express their feelings about my situation. *For Family Member version:* The openness with which family members express their feelings about the patient's situation.	2.80	0.63	2.44	0.73
10. The frequency with which family members ask me how I am doing.	2.60	0.70	2.44	0.88
Family Emotional Support				
11. The amount of time that my family spends with me.	2.50	0.71	2.67	0.50

Table 6

Means and Standard Deviations for Sufficiency Ratings

Domain	Sufficient	
	M	SD
General and Cancer Specific Questions	2.60	0.52
Overall Domains and Overall FQOL	2.60	0.70

For FQOL sub-domains and overall FQOL questions, mean relevance of the items was high (M = 2.70 - 3.00, SD = 0.48 - 0.00) and mean clarity of items ranged from low-moderate (M = 2.00, SD = 0.67) to high (M = 3.00, SD = 0.00; see Table 7). The sufficiency of the FQOL sub-domains and overall FQOL questions was high (M = 2.60, SD = 0.70; see Table 6).

Table 7

Means and Standard Deviations for Relevance and Clarity Ratings for the Overall FQOL Domains and Overall FQOL

How satisfied are you with…	Relevance		Clarity	
	M	SD	M	SD
1. Interactions in your family.	2.70	0.48	2.00	0.67
2. Distribution of responsibilities in your family.	2.80	0.63	2.40	0.70
3. Communication among members of your family.	3.00	0.00	2.80	0.42
4. The emotional support that people in your family give each other.	3.00	0.00	3.00	0.00
5. Overall, how satisfied are you with your family life?	2.90	0.32	2.90	0.32

Based on these data, items were reviewed and then modified as necessary to increase their relevance and clarity. In addition, four items (three general FQOL questions and one cancer specific FQOL question) were deleted because of redundancy with other items, as suggested by experts' recommendations. One item was moved from the general questions to the cancer specific questions. Following the suggestions of several of the experts, the overall FQOL question was separated from the FQOL subdomain questions. The wording in the items was changed from the first person to the second person (from "my" to be "your"). For example, "My sex life with my partner" was changed to be "Your sex life with your partner." Consequently, the next version of the questionnaires had four parts with a total of 33 items, including (a) 17 general FQOL items, (b) 11 cancer specific FQOL items, (c) 4 FQOL sub-domain items, and (d) one overall FQOL question. Following the experts' suggestions, the difficulty level of the language was reduced to the 6th grade level through consultation with a Medical Center Editor. Finally, two cancer specific FQOL items that asked about the openness of the family in regards to talking about cancer, and the treatments and their side effects were combined because they focused on essentially the same topic with in cancer families' communication. One cancer specific FQOL item that asked about time that the family spent with the patient was moved to the general FQOL questions because the item focused on family life in general rather than on cancer specific issues. Thus, the final preliminary version of the questionnaires had 4 parts with a total of 32 items, including (a) 18 general FQOL items, (b) 9 cancer specific FQOL items, (c) 4 items directly assessing the FQOL sub-domains, and (d) 1 overall FQOL item. See Appendix D for complete details regarding item reduction and modification.

Based on these changes, these preliminary versions questionnaires were pilot tested with two cancer families (2 cancer patients and 2 family members), one family member, and three non-patients. The pilot participants were asked to report on the importance of the FQOL domains covered by the items, on the clarity of the items, and the time burden of the questionnaire since in this version they were asked to rate both their satisfaction and the importance for them of the domain covered in each item. Each pilot participant rated a random subset of the items because the purpose of this pilot test was to obtain in-depth reactions to the wording of each item and the questionnaire format. After the participants finished these ratings, they discussed them with the PI in detail, their understanding of the meaning of them items, how difficult it was for them to rate both the importance and satisfaction, what format for the questionnaire they thought would be easiest for people to answer, and their comments and suggestions for modifying the wording of the items. Two non-patients and one family member also asked to read all items of the preliminary FQOL questionnaire. All participants reported that the items covered the important areas of FQOL and were clear. However, five participants (two cancer patients, two family members, and one non-patient) stated that rating both the satisfaction and the importance for each item was confusing. In addition, using both ratings increased the amount of missing data and resulted in an excessive amount of time required for participants to complete the questionnaire. Consequently, the FQOL questionnaires used in Phase 3 maintained all items but had participants only rate their satisfaction (see Appendix E and F).

CHAPTER VII

METHODOLOGY

(PHASE 3: ITEM SELECTION AND PSYCHOMETRIC EVALUATION)

Research Design

The main objectives for Phase 3 were to answer Research Question #2 (i.e., determine whether Family Quality of Life, as measured by the FQOL questionnaire, was unidimensional or multidimensional), and Research Question #3 (i.e., assessing the reliability and validity of the FQOL questionnaires). Towards these ends, a group of cancer families were administered a series of questionnaires, and quantitative data analyses were used to answer these research questions.

Research Setting

In Phase 3, several institutions and methods were used to recruit cancer patients and their family members. Cancer patients and their family members were recruited from the VICC, the Maury Regional Hospital, and the American Cancer Society's Memorial Foundation Hope Lodge (Hope Lodge) in Nashville, TN. In addition, the study was advertised by a mass email communication at Vanderbilt Medical Center, on a website related to cancer, and flyers distributed around Vanderbilt Medical Center, Vanderbilt University, and Gilda's Club in Nashville.

Sample

Criteria for Sample Selection and Inclusion

The inclusion criteria for cancer patients and their families for Phase 3 were the same as the inclusion criteria for Phase 1 (See Phase 1 for details).

Method for Subject Recruitment

For Phase 3, cancer patients and their families were recruited at three sites: (a) Vanderbilt Ingram Cancer Center (VICC), (b) Maury Regional Hospital, and (c) the Hope Lodge. For the VICC and the Maury Regional Hospital sites, staff oncologists or nurses (a) identified cancer patients who are appropriate for inclusion in the study, (b) briefly explained the study to them, and (c) if patients were interested, introduced them to the PI who explained the study in detail, answered all questions, invited them to participate in this study, and obtained informed consent. If the patient came to VICC or the Maury Regional Hospital with a family member, the family member also was invited to participate in the study. If the patient did not come with family members, the PI asked the patient to identify a family member who might be interested in being involved in the study, and obtained permission to contact this family member by phone and send the questionnaires via mail. In addition, some cancer patients asked to take questionnaires with them to complete at home or for their family members to complete at home. In these cases, the PI gave them the packages of questionnaires and a stamped, self-addressed envelope to return the questionnaires to the PI.

Hope Lodge in Nashville, Tennessee is an NGO that provides accommodations for cancer patients and their families who are receiving cancer treatment from hospitals in Nashville but who live too far to drive and receive their treatment without an overnight stay. Accommodations are provided free of charge. For the Hope Lodge site, after receiving permission for the study, the PI publicized the study by posting flyers on the bulletin board at Hope Lodge. The flyers identified the dates and times the PI would be at Hope Lodge to recruit participants. If patients and their families were interested in the study, the PI explained the study in detail, answered all questions, invited them to participate in this study, and obtained informed consent in a private room that Hope Lodge provided for the study. If the patient did not come with family members, the PI asked the patient to identify a family member who might be interested in being involved in the study, and obtained permission to contact the family member by phone and send the questionnaires via mail. Some patients wanted to take the questionnaires for their family members to complete at home. In these cases, the PI gave them the packages of questionnaires and a stamped envelope in which to return the questionnaires to the PI.

Cancer patients and family members who learned about this study via email, flyers or a website related to cancer (e.g., http://news.canconnect.org) and wanted to participate in the study contacted the PI via email or phone. The PI determined whether the patients and their family members were appropriate for inclusion in the study. If they met the inclusion criteria, the PI (a) explained the study to them in detail, (b) answered all questions, and (c) invited them to participate in the study. If they were interested in participating, the PI sent them the packet of questionnaires through postal mail, including a stamped envelope in which to return the questionnaires to the PI.

Human Subjects Protection

The study received approval from the Vanderbilt IRB in for each phase and from the Maury Regional Hospital IRB for Phase 3. Potential participants had the study procedures explained to them and possible risks, which were relatively minimal (possible boredom with the questionnaires, discomfort with some of the questions, loss of confidentiality). Potential participants were informed that their participation was voluntary and they could withdraw from the study anytime. They also were informed that the PI would not share their data with their family members and their questionnaires would be coded by identification number rather than their name. Potential participants were given the opportunity to ask questions, all of which were answered. If potential participants were interested in participating in the study, they signed an informed consent. For the participants at the VICC, the Maury Regional Hospital and the Hope Lodge, this process took place in a private room or in a private location that allowed confidentiality to be maintained. For the participants who received the informed consent and package of questionnaires by mail, this process was conducted via the phone or email. A copy of the consent form was given to all participants for their records.

Data Collection Method

Procedures

In this phase, data were collected between September 3, 2008 and January 31, 2009. The subscales, items and format of the proposed of FQOL questionnaire developed in Phases 1 and 2 were administered to cancer patients and their family members. Cancer patients and their family members responded to the FQOL questionnaire individually. In addition, they individually answered several other questionnaires to examine validity of the FQOL questionnaire. Cancer patients and/or family members were given and completed the packet of questionnaires separately at the VICC, the Maury Regional Hospital, the Hope Lodge, or at their homes. Reminder letters or emails were sent to the cancer families who did not return the questionnaires. Of 197 families that were approached, 151 cancer families completed and returned questionnaires to the PI (76.65%). For 10 of the 151 cancer families, two family members in addition to the cancer patient were interested in participating in the study and completed the questionnaires; however, data from only one family member per family was analyzed. The criteria to select the family member were (a) primary caregiver, (b) number of hours they reported that they took care of the patient, and (c) living with the patient.

Forty-six cancer families that were approached declined to participate or withdrew from the study (23.35%). Of the 46, 15 declined to participate in the study, citing various reasons such as having no time, not being interested in the study, or their medical condition. Three families were interested in the study and contacted the PI but did not meet the criteria of the study because the patients had died. Twenty families were interested in the study and took the packet questionnaires back home or the PI sent the packet of questionnaires to them by mail but did not return the questionnaires. Eleven patients returned the questionnaires, but their family members did not. Seven family members returned the questionnaires, but the cancer patient withdrew or did not.

To examine test-retest reliability, 58 cancer families were randomly selected and asked to complete the FQOL questionnaire two to four weeks after the first administration. The second administration was conducted at home and participants returned the completed questionnaire by mail. A reminder letter was sent to them if they did not return questionnaires. Forty-eight patients and 47 family members returned the second questionnaires. However, only 41 patients (71%) and 40 family members (69%) completed the second questionnaires within the two to four weeks used to examine the test-retest reliability.

Measures

One of the purposes of Phase 3 was to examine the reliability and validity of the FQOL measure. Towards this end, participants completed a packet of additional questionnaires as well as the FQOL questionnaire. The additional measures included the SF-36, the FACT-G, the Family Interaction and Emotional Well-Being subscales of the Beach Center Family Quality of Life Scale, the Balanced Cohesion subscales of the FACES IV, the Family Communication Scale, and the Family Satisfaction Scale.

The FQOL Questionnaire. This is the questionnaire developed during Phase 1 and 2 to examine FQOL among adult cancer families (see Appendix E and F). It uses a 5-point Likert response format (Not At All, A Little Bit, Somewhat, Quite a Bit, and Very Much) to measure satisfaction with the four domains of FQOL. It contains 4 parts with a total of 32 items (see Results section of Chapter VI for more detail). Mean scores were calculated for the (a) total FQOL score, (b) general FQOL score, (c) cancer specific FQOL score, (d) four FQOL sub-domains (if the results from factor analysis confirmed the four sub-domains), and (e) overall FQOL assess by the single item. Higher scores indicate higher FQOL.

The Medical Outcomes Study 36-Item Short-Form Health Survey (SF-36®, version 1). This is a general QOL survey that is used widely in the general population and patients, including cancer patients (see Appendix G). It contains 36 items with eight QOL scales: (a) Physical Functioning (PF); (b) Role-Physical (RP); (c) Bodily Pain (BP); (d) General Health (GH); (e) Vitality (VT); (f) Social Functioning (SF); (g) Role-Emotional (RE); and (h) Mental Health (MH). Higher scores indicate higher QOL. The scales can be combined to generate two summary scores: Physical Component Summary (PCS) and Mental Component Summary (MCS). The Physical Component includes the Physical Functioning, Role- Physical, Bodily Pain, and General Health subscales; the Mental Component includes the Vitality, Social Functioning, Role-Emotional, and Mental Health subscales. This survey has undergone extensive psychometric testing and has been found to have high reliability and validity. Construct validity was established using factor analysis, and by the measure's ability to discriminate between patients based on severity of medical and psychiatric conditions in a sample of the 3,445 patients (heart disease, hypertension, diabetes, and depression; McHorney, Ware, & Raczek, 1993). In a sample of the 3,445 patients McHorney, Ware, Lu, and Sherbourne (1994) found internal consistencies as follows: PF 0.93; RP 0.84; BP 0.82; GH 0.78; VT 0.87; SF 0.85; RE 0.83; and MH 0.90. Campbell et al., (2004) reported the internal consistency among prostate cancer patients was 0.91 for PCS and 0.79 for MCS. In addition, Thornton et al. (2004) reported the internal consistency for all subscales was adequate ($\alpha > 0.68$) for prostate patients and their partners.

In the present study, the SF-36 was scored using the standard recommended scoring methods for Version 1 (Ware, Kosinski, & Keller, 1994), so all scales ranged from 0 (lowest possible QOL) to 100 (highest possible QOL). For the cancer patients in this study, the Cronbach's alpha coefficients for the eight SF-36 scales and the PCS and MCS were adequate ($\alpha \geq 0.80$; Table 8). For family members, the Cronbach's alpha coefficients for the eight SF-36 scales the PCS and the MCS were ≥ 0.78 (see Table 8).

Table 8

Internal consistency (Cronbach's Alpha Coefficient) for the measures used to validate the Preliminary FQOL Questionnaire

Measurements	Patients	Family Members
SF36		
Physical Component Summary (PCS)	0.94	0.93
Physical Functioning scale (PF)	0.93	0.93
Role-Physical scale (RP)	0.92	0.82
Bodily Pain scale (BP)	0.90	0.88
General Health scale (GH)	0.82	0.84
Mental Component Summary (MCS)	0.89	0.92
Vitality scale (VT)	0.87	0.84
Social Functioning scale (SF)	0.80	0.78
Role-Emotional scale (RE)	0.82	0.86
Mental Health scale (MH)	0.84	0.87
FACT-G		
Physical Well-Being subscale (PWB)	0.89	0.85
Social / Family Well-Being subscale (SWB)	0.71	0.80
Emotional Well-Being subscale (EWB)	0.71	0.67
Functional Well-Being subscale (FWB)	0.87	0.88
Total scale of the FACT-G	0.91	0.91
Beach Center Family Quality of Life Scale		
Family Interaction subscale	0.90	0.92
Emotional Well-Being subscale	0.81	0.87
Flexibility and Cohesion Evaluation Scales (FACES IV)		
the Balanced Cohesion subscale	0.89	0.94

Table 8, continued

Measurements	Patients	Family Members
Family Communication Scale		
Total scale of Family Communication Scale	0.94	0.95
Family Satisfaction Scale		
Total scale of Family Satisfaction Scale	0.95	0.96

The Functional Assessment of Cancer Treatment-General (FACT-G). This is an instrument used to assess health-related QOL in cancer patients. Now in its fourth version, it uses a 5-point Likert response format and contains 27 items in four subscales: Physical Well-Being (PWB), Social / Family Well-Being (SWB), Emotional Well-Being (EWB), and Functional Well-Being (FWB) (see Appendix H). Reliability and validity have been documented. In Cella et al.'s (1993) study of Version 2 of this questionnaire, internal consistency for the total score among breast, colorectal, and lung cancer patients was 0.89 and 3 to 7 day test-retest reliability was 0.92. Convergent validity, divergent validity and the ability to discriminate between patients based on disease stage, performance status rating, and hospitalization status also have been documented (Cella et al., 1993). Rose and Yates (2001) reported reliability in HNC patients at three time points: first week of treatment (T1), last week of treatment (T2), and one month after treatment (T3). Internal consistency for PWB was 0.79 (T1), 0.83 (T2), and 0.85 (T3); for SWB 0.69 (T1), 0.60 (T2), and 0.75 (T3); for EWB 0.70 (T1), 0.51 (T2), and 0.70 (T3); for FWB 0.86 (T1), 0.68 (T2), and 0.81 (T3). In the present study, the FACT-G version modified by Northouse (2005) for family caregivers of breast cancer patients was used to measure family members' own QOL (see Appendix I). The standard recommended scoring for the FACT was used in this study, so that higher scores reflect higher QOL. In the present study, for cancer patients, Cronbach's alpha coefficients for PWB, FWB and the total score were adequate ($\alpha > 0.86$); the SWB and EWB scales had lower Cronbach's alpha coefficients ($\alpha = 0.71$; see Table 8). For family members, Cronbach's alpha coefficient for all scales except EWB were adequate ($\alpha \geq 0.80$; see Table 8).

The Beach Center Family Quality of Life Scale. This scale was developed from the Beach Center of University of Kansas to measure FQOL in families who had a disabled child. It uses a 5-point Likert response format. Hoffman et al. (2006) reported internal consistency for the total scale was 0.88, for the Family Interaction subscale it was 0.90, and for the Emotional Well-being subscale it was 0.84. Test-retest reliability and convergent validity are adequate (Hoffman et al. 2006). In the present study, the satisfaction ratings from the Family Interaction (6 items) and Emotional Well-Being (4 items) subscales were used, with higher scores reflecting higher satisfaction in family interaction and emotional well-being (see Appendix J). In the present study, Cronbach's alpha coefficients for the Family Interaction and the Emotional Well-Being subscales were > 0.80 for cancer patients and family members (see Table 8).

The Flexibility and Cohesion Evaluation Scales (FACES IV). In this study, the Balanced Cohesion subscale (7 items) was used to assess family interaction and bonding that family members have with one another (see Appendix K). The FACES uses a 5-point Likert response format. Face, concurrent and discriminant validity and internal reliability have been reported for the general population (Gorall, Tiesel, & Olson, 2004), and the internal consistency for the Balanced Cohesion subscale has been reported to be 0.89

(Gorall, Tiesel, & Olson, 2004). The summed score was used in this study, with higher scores reflecting higher levels of positive family interaction. In the present study, Cronbach's alpha for the Balanced Cohesion subscale of cancer patients was 0.89 and for family members it was 0.94 (see Table 8).

The Family Communication Scale. This questionnaire was revised from the Parent-Adolescent Communication scale by Olson and Barnes (2004) (see Appendix L). It contains 10 items rated on a 5 point Likert response format, with the summed score ranging from 10 to 50. High scores indicate higher levels of adaptive family communication. The validity of the Parent-Adolescent Communication scale was established using factor analysis, with the internal consistency reliability estimated at 0.88 based on a national sample of 1,841 individuals (Olson & Barnes, 2004). No studies using this questionnaire with cancer patients were found. In the present study, Cronbach's alpha for the Family Communication Scale of cancer patients was 0.94 and for family members it was 0.95 (see Table 8).

The Family Satisfaction Scale (FSS). This scale assesses satisfaction with various aspects of family functioning, including family closeness, flexibility, and communication (see Appendix M). It contains 10 items, based on a 14 item scale developed by Olson and Wilson in 1982 (Olson, 2004). It is a self-report questionnaire, using a 5-point Likert response format, with higher scores indicating family members are happier with their family. The validity of the 14 item scale has been established through factor analysis (Olson & Wilson, 1982). Construct validity was supported by a correlation with the Locke-Wallace Marital Satisfaction scale (Olson, 2004). Internal consistency reliability for 1,253 family members for the 10 item FSS scale was 0.92 (Olson, 2004). No studies using this questionnaire among cancer patients were found. In the present study, Cronbach's alpha coefficient for the Family Satisfaction Scale of cancer patients was 0.95 and for family member it was 0.96 (see Table 8).

Data Analysis

SPSS version 15 was used to produce descriptive statistics, Cronbach's alpha coefficients, Pearson correlation coefficients, t-tests for dependent correlations; AMOS (version 7) was used to conduct confirmatory factor analyses. Internal consistency reliability, convergent validity, and discriminant validity were tested following the results of a confirmatory factor analysis indicating that the FQOL questionnaire contained the four subscales proposed. Cases with missing data were dropped in each analysis.

Psychometric Evaluation

Assessing the structure of the FQOL questionnaire. Factor analysis often is used to test the validity of the structure of constructs, so that the researcher can decide how items should be grouped together into subscales and which items should be dropped from the instrument entirely (Munro, 2001). Confirmatory factor analysis is a theory-driven method (Aroian & Norris, 2001) used to examine whether a specified set of constructs is influencing responses in a predicted way (DeCoster, 1998). In this study, confirmatory factor analysis was used to test Research Question #2 as to whether the preliminary FQOL questionnaires were unidimensional or multidimensional. Assuming that the measures were not unidimensional, Research Question #1 asked whether the central domains underlying participant responses on the FQOL were (a) family interaction, (b) family roles, (c) family communication, and (d) family emotional support. These four domains were selected based on the literature review and previous studies. The results of Phase 1 and 2 supported the proposed domains. Based on results from Phase 2, the FQOL questionnaire contained two parts: The general FQOL questions and the cancer specific FQOL questions, with four domains underlying each part.

The models hypothesizing four domains for the general FQOL questions and cancer specific FQOL questions were tested using confirmatory factor analysis separately. To examine Research Question #2 (whether the FQOL questionnaire was unidimensional), four models were proposed a priori and tested, including (a) a four domain model for the general FQOL questions, (b) a four domain model for the cancer specific FQOL questions, (c) a single, general factor model for the general FQOL questions, and (d) a single, general factor model for the cancer specific FQOL questions (see Figures 2 to 5). The hypothesis was that the FQOL questionnaire would be multidimensional and contain four domains: Family Interaction, Family Roles, Family Communication, and Family Emotional Support.

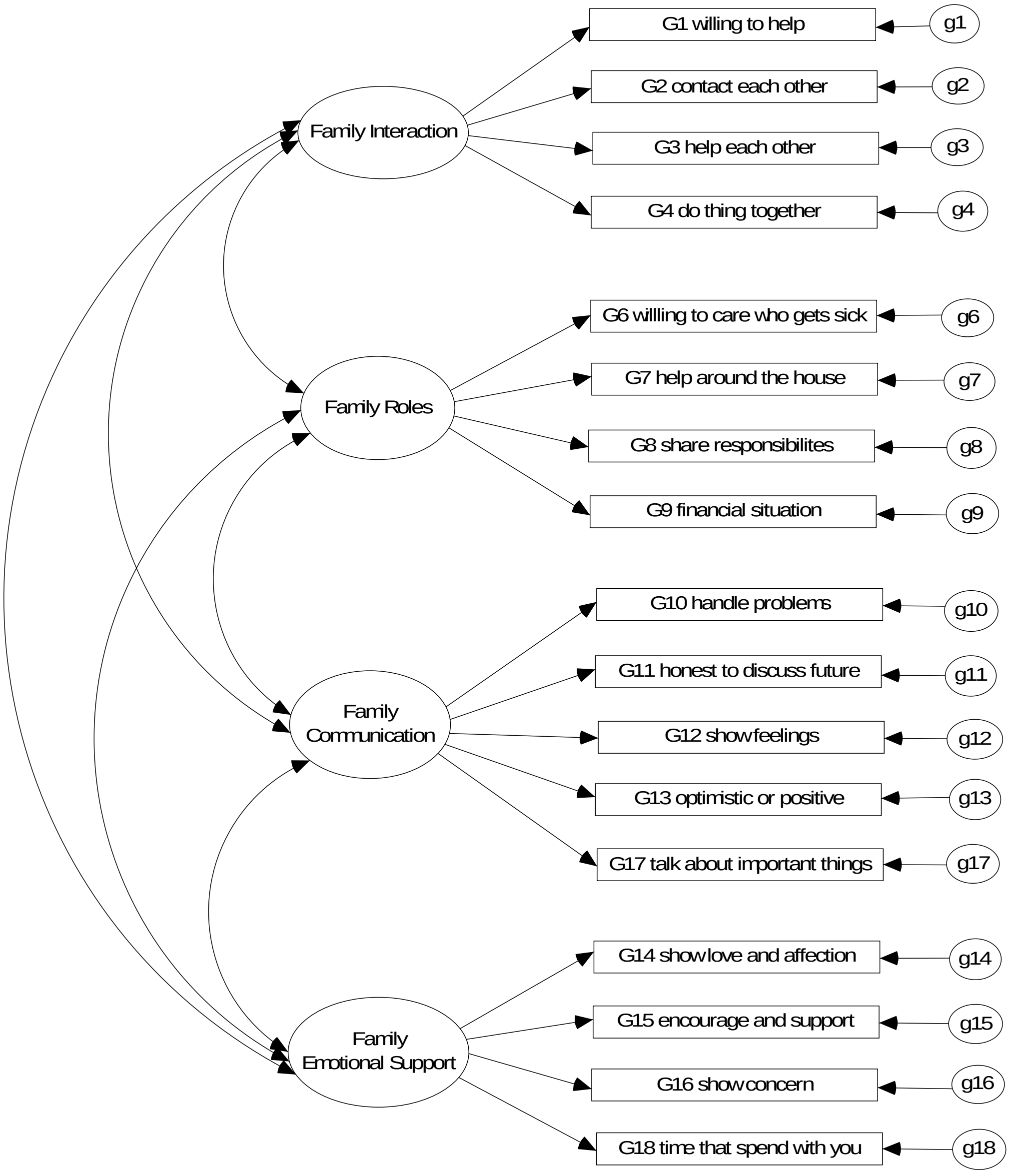

Figure 2. Four Domain Model for General FQOL Questions

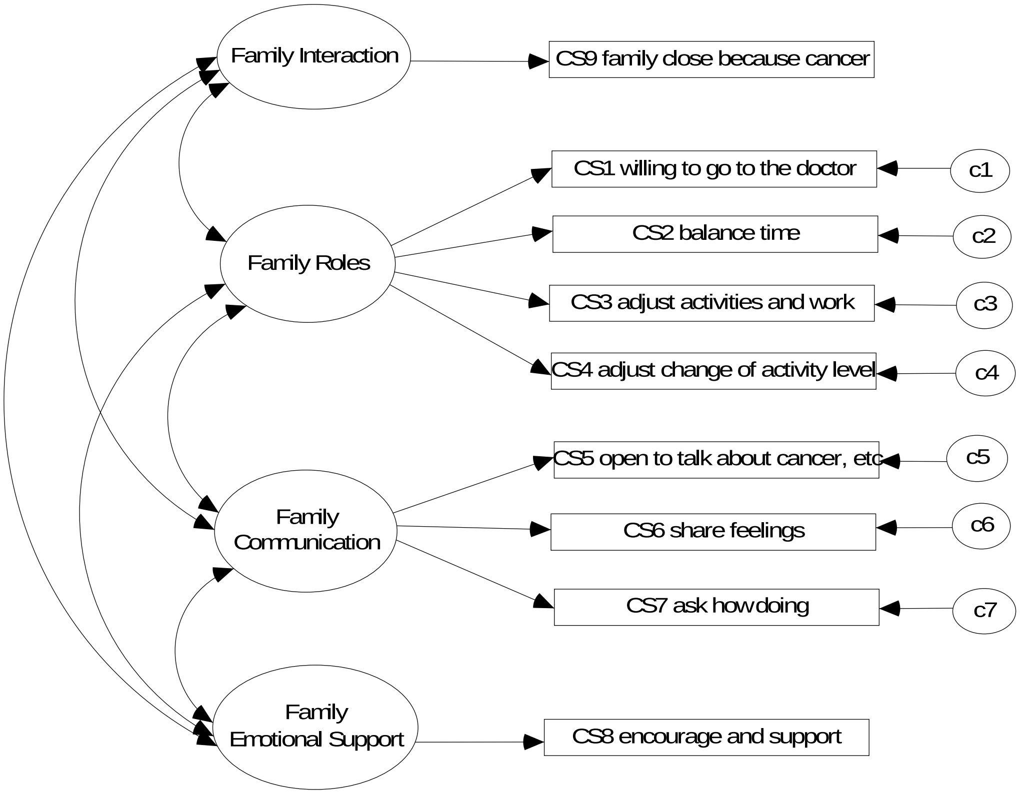

Figure 3. Four Domain Model for Cancer Specific FQOL Questions

In Figures 2 and 3, Family Interaction, Family Roles, Family Communication, and Family Emotional Support represent latent constructs or domains of FQOL correlated with each other. G1 to G18 (except G5) in Figure 2 and CS1 to CS9 in Figure 3 are the items from the FQOL questionnaire, loading on appropriate domains. Although item G5 from the general FQOL questions was one of the items in Family Interaction domain and is considered an important aspect of the FQOL construct, it was not included in these models because the participants were given the option of not answering this question, which dealt with physical/sexual intimacy. Thus, this item was separated from the model as a single item. The measurement errors (g1 to g18, except g5, in Figure 2 and c1 to c7 in Figure 3) represent exogenous (to the model) factors influencing the observed scores on the items that are unknown or not included in the model, such as age and emotional state (e.g., depressed; anxious). However, in the four domain model for the cancer specific FQOL questions, items CS8 and CS9 did not have measurement errors because the factors they defined had only single items.

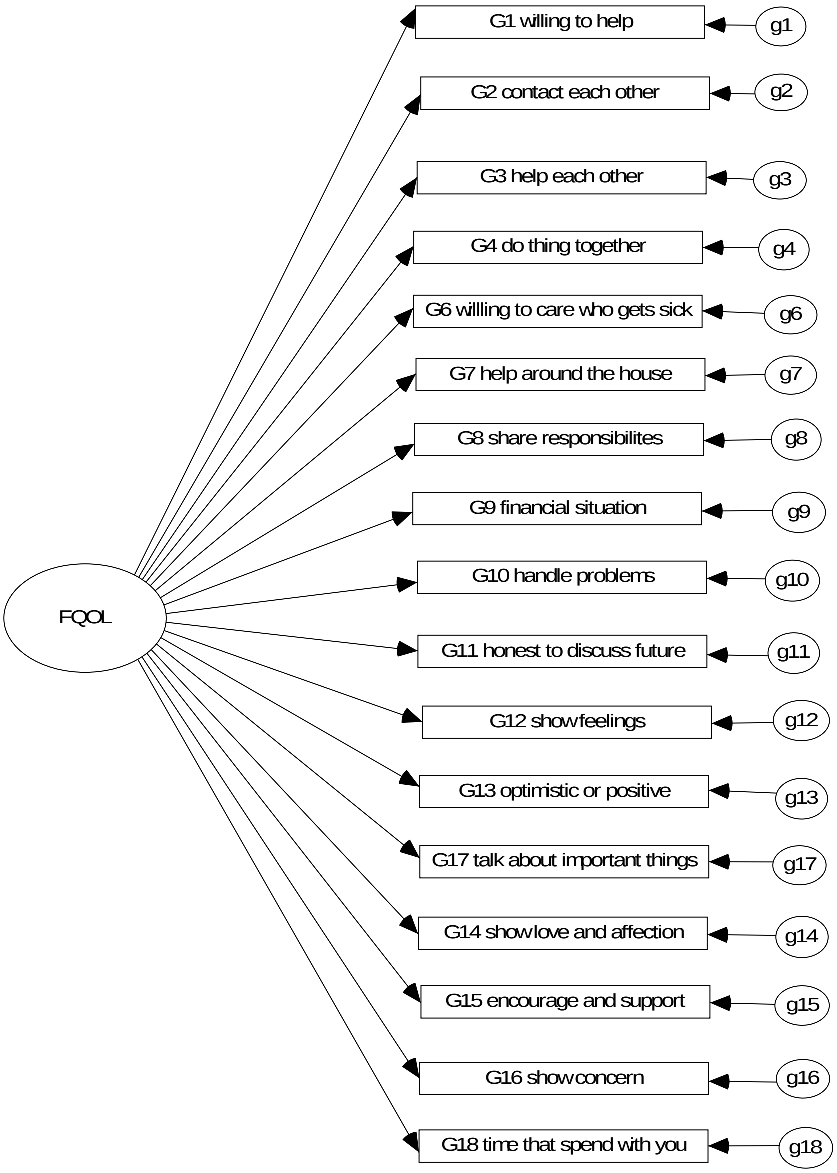

Figure 4. One Domain Model for General FQOL Questions

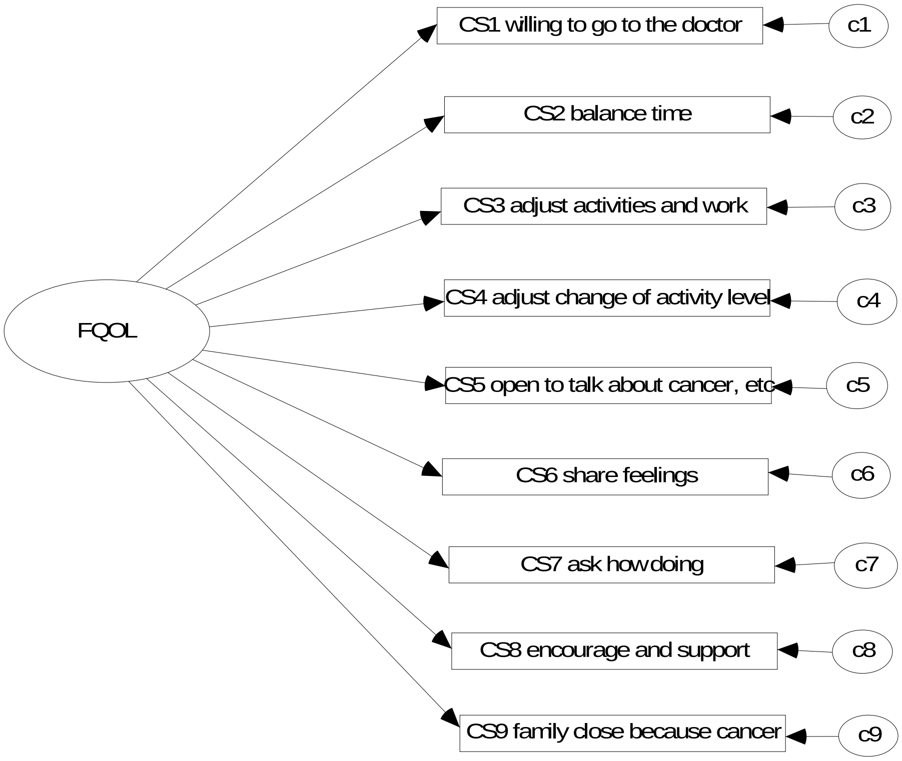

Figure 5. One Domain Model for Cancer Specific FQOL Questions

In Figures 4 and 5, the latent construct represents general FQOL. G1 to G18 (except G5) in Figure 4 and CS1 to CS9 in Figure 5 represent the FQOL items for the cancer specific FQOL questionnaire. The g1 to g18 (excluding g5) in Figure 4 and c1 to c9 in Figure 5 represent measurement errors.

When conducting the confirmatory analysis cases with missing data were deleted. Multivariate outliers in the FQOL questionnaires were examined using Mahalanobis distance. Parameters in the models were estimated using maximum likelihood. Model fit was evaluated considering several statistics, including the chi-square goodness of fit, the comparative fit index (CFI), Tucker - Lewis index (TLI), and the Root Mean Square Error of Approximation (RMSEA). The criteria for acceptable model fit were RMSEA values close to 0.6 or below, and CFI and TLI close to 0.95 or above (Hu & Bentler, 1999). The chi-square statistic was not used as part of the criteria to assess absolute model fit because it is highly sensitive to sample size and well fitting models can produce significant chi-squares (Albright & Park, 2008; Aroian & Norris, 2001); however, tests of difference between models used the chi-square differences to evaluate the statistical significance of model differences.

Internal Consistency Reliability. Internal consistency reflects the degree to which each item in a multiple item scale is related to the other items in the scale (Murphy et al., 2007). A low alpha suggests that some items are not measuring the same thing, and that the scale is measuring multiple constructs (Bjordal et al., 1999). Nunnally (1978) recommended that a newly developed instrument should have alpha of ≥ 0.70. In this study, internal consistency reliability of the FQOL questionnaires was assessed using Cronbach's alpha coefficient. Cronbach's alpha coefficient of total score and each subscale derived from the results of the factor analysis were examined.

Test-Retest Reliability. Test-retest reliability reflects the stability of an instrument, the extent to which individuals who take instrument twice receive the same scores. Thus, a stable instrument will show a large correlation between administrations, if the underlying state remains stable (Murphy et al., 2007). The closer the coefficient is to 1.00, the more stable the instrument is presumed to be (Waltz et al., 2005). The second administration generally should not occur within less than 2 weeks after the first (Knapp & Brown, 1995; Waltz et al., 2005). In this study, test-retest reliability across 2 to 4 weeks for the FQOL questionnaires was assessed by using Pearson correlations. Test-retest coefficient reliability was expected to be moderate to high (0.5 - 0.8).

Convergent Validity. Convergent validity implies that different measures of the same construct correlate highly with each other (Waltz, Strickland, & Lenz, 2005). In this study, convergent validity was assessed by examining correlations between each domain and the total score of the FQOL questionnaire with subscales and total scores of other questionnaires assessing similar constructs. It was hypothesized that (a) Family Interaction subscale would be significantly positively correlated with Family Interaction subscale of the Beach Center Family Quality of Life Scale and Balanced Cohesion subscale of the FACES IV; (b) Family Roles subscale would be significantly positively correlated with Role-Physical and Role-Emotional subscales of the SF-36; (c) Family Communication subscale would be significantly positively correlated with the Family Communication Scale; (d) Family Emotional Support subscale would be significantly positively correlated with Emotional Well-Being subscale of the Beach Center Family Quality of Life Scale and Emotional Well-Being subscale of the FACT-G; (e) the total scale of the FQOL questionnaire would be significantly positively correlated with the total score of the FACT-G and the Family Satisfaction Scale. However, testing these hypotheses was dependent on the results of a confirmatory factor analysis indicating that the FQOL questionnaire contained the four domains as proposed.

Discriminant Validity. Discriminant validity implies that measures of different constructs should have lower correlations with each other than with measures of the same constructs (Waltz et al. 2005). In the present study, because FQOL domains involve emotional, social, and functional domains more than physical domains, it was hypothesized that (a) the total score of the FQOL questionnaire would be more highly positively correlated with the Mental Component Summary (MCS) than Physical

Component Summary (PCS) of the SF-36; and (b) the total score of the FQOL questionnaire would be more highly positively correlated with the Social/Family Well-Being, Emotional Well-Being, and Functional Well-Being subscales than Physical Well-Being subscale of the FACT-G.

CHAPTER VIII

RESULTS

(PHASE 3: ITEM SELECTION AND PSYCHOMETRIC EVALUATION)

Overview. The main purposes of Phase 3 were to answer Research Question #2 (Is the FQOL questionnaire unidimensional or multidimensional) and Research Question #3 (what is reliability and validity for the FQOL questionnaire). In this phase, 151 cancer families (151 cancer patients and 151 family members) completed the FQOL questionnaire and other questionnaires. Forty one patients and forty family members also completed the FQOL questionnaire at the second administration within 2 to 4 weeks to assess test - retest reliability.

Participant Characteristics

One hundred and fifty - one cancer families (151 cancer patients and 151 family members) completed the questionnaires and their data were analyzed. For cancer patients, the mean age was 56.99 years (SD = 13.92) and mean education was 14.01 years (SD = 2.61). Most of patients were White (96.0%), married (76.2%) and the majority were male (56.3%). Approximately 1/3 of patients were retired (34.4%) with a median yearly household income of approximately $50,000 (see Table 9). The mean age for family members was 54.15 years (SD = 14.08) and mean education was 13.98 years (SD = 2.56). Most of family members were spouses (64.2%), female (70.2%), White (94.7%), married (82.8%), and slightly less than half were employed full time (42.4%). Most of family members lived with patients (78.8%), and were primary caregiver (84.8%; see Table 9). The mean number of hours per week that they spent taking care of the patient ranged from zero to 168 hours (M = 27.43, SD = 36.49). Half for the family members themselves had significant medical problems (51.0%); the five most frequent medical problems of family members were (a) high blood pressure (49.4% of those with medical problems), (b) bone and joint problems (25.6%), (c) arthritis (24.7%), (d) diabetes (18.2%), and (e) high cholesterol (10.4%) (it should be noted that some family members had more than one medical problem).

Table 9

Demographic Characteristics of the Participants

Demographic Characteristics	Patients		Family Members	
	N	**%**	**n**	**%**
Age	M = 56.99, SD = 13.92 (Range = 18-91 years)		M = 54.15, SD = 14.08 (Range = 20-84 years)	
Education	M = 14.01, SD = 2.61 (Range = 6-21 years)		M = 13.98, SD = 2.56 (Range = 8-21 years)	
Sex				
Male	85	56.3	45	29.8
Female	66	43.7	106	70.2
Race				
African American	5	3.3	6	4.0
Asian	1	0.7	2	1.3
White	145	96.0	143	94.7
Ethnicity				
Hispanic or Latino	1	0.7	2	1.3
Not Hispanic or Latino	150	99.3	149	98.7

Table 9, continued

Demographic Characteristics	Patients		Family Members	
	N	**%**	**n**	**%**
Marital Status				
Single	10	6.6	10	6.6
Single, living with partner	1	0.7	2	1.3
Married	115	76.2	125	82.8
Widowed	8	5.3	7	4.6
Separated	3	2.0	-	-
Divorced	14	9.3	7	4.6
Employment				
Employed full time	37	24.5	64	42.4
Employed part time	6	4.0	12	7.9
Homemaker	9	6.0	15	9.9
Retired	52	34.4	40	26.5
On disability	31	20.5	7	4.6
On sick leave / On leave to take care patient	1	0.7	1	0.7
Self employed	5	3.3	4	2.6
Student	1	0.7	1	0.7
Unemployed	9	6.0	7	4.6
Yearly Household Income				
$10,000 or less	10	6.6	8	5.3
$10,001 to $20,000	13	8.6	10	6.6
$20,001 to $30,000	12	7.9	10	6.6
$30,001 to $40,000	12	7.9	12	7.9
$40,001 to $50,000	15	9.9	13	8.6
$50,001 to $60,000	13	8.6	18	11.9
Over $60,000	48	31.8	54	35.8
Prefer not to answer	28	18.5	26	17.2
Relationship with the Patients				
Spouse			97	64.2
Partner			2	1.3
Parent			15	9.9
Children			26	17.2
Relative			9	6.0
Friend			2	1.3

Table 9, continued

Demographic Characteristics	Patients		Family Members	
	N	**%**	**n**	**%**
Primary Caregiver				
Yes			128	84.8
No			23	15.2
Live with Patients				
Yes			119	78.8
No			32	21.2

For the cancer patients, cancer types were categorized based on the U.S. Cancer Statistics Working Group (2007) classifications (see Table 10). The most frequent locations for the cancer were in respiratory system (18.5%), in specific areas of the head and neck (e.g., nasal cavity, larynx), or the lungs. Time since the diagnosis (to the point of data collection) ranged from 10 days to 226 months (mean = 35.37 months, SD = 42.64. One third had recurrent cancer (33.8%) and nearly half had metastasized cancer (43.0%). The majority (60.9%) of patients were in treatment when they participated in this study. One third of patients were post-treatment, with time since the end of treatment ranging from 2 days to 192 months (mean= 36.49 months, SD = 48.92). The most frequent type of treatment involved three forms of treatment, patients had surgery, chemotherapy, and radiation, which 24.8% of the sample received. Over half had other medical problems (60.3%) in addition to cancer including (a) high blood pressure (39.6%), (b) bone and joint problems (23.1%), (c) arthritis (15.4%), (d) heart disease (13.2%), and (e) diabetes (11.0%); some patients had more than one of these diseases. About one third of patients had no restriction in activities (37.1%) but about two third of patients had some problems in their daily activities (62.9%).

Table 10

Medical Characteristics of the Patients

Medical Characteristics	n	%
Type of Cancer		
Brain	5	3.3
Breast	18	11.9
Digestive system	16	10.6
Endocrine system	5	3.3
Genital system	14	9.3
Leukemias	8	5.3
Lymphomas	11	7.3
Myeloma	4	2.6
Mesothelioma	1	0.7
Oral cavity and pharynx	22	14.6
Respiratory system	28	18.5
Skin	9	6.0
Soft tissue	2	1.3
Urinary system	5	3.3
Bone and Joint	3	2.0
Recurrence of Cancer		
No	100	66.2
Yes	51	33.8
Metastasis of Cancer		
No	86	57.0
Yes	65	43.0
Phases of Treatment		
Diagnosis	6	4.0
During treatment	92	60.9
After treatment	53	35.1

Table 10, continued

Medical Characteristics	n	%
Cancer Treatments		
One treatment		
Chemotherapy	22	15.2
Immunotherapy	1	0.7
Radiation	1	0.7
Surgery	4	2.8
Two treatments		
Chemotherapy and Radiation	29	20.0
Chemotherapy and Stem cell transplant	8	5.5
Chemotherapy and Molecule target drug	1	0.7
Surgery and Chemotherapy	29	20.0
Surgery and Hormonal therapy	2	1.4
Surgery and Radiation	4	2.8
Radiation and Hormonal Therapy	1	0.7
Three treatments		
Chemotherapy, Radiation, and Immunotherapy	2	1.4
Surgery, Chemotherapy and Radiation	36	24.8
Surgery, Hormonal therapy, and Chemotherapy	1	0.7
Surgery, Hormonal therapy, and Radiation	2	1.4
Four treatments		
Surgery, Chemotherapy, Hormonal therapy and Radiation	2	1.4
Other Medical Problems		
No	60	39.7
Yes	91	60.3
Top Five [1]		
High blood pressure	36	39.6
Bone and joint problems	21	23.1
Arthritis	14	15.4
Heart disease	12	13.2
Diabetes	10	11.0

Table 10, continued

Medical Characteristics	n	%
Level of Activities		
No restriction	56	37.1
Can do Light house work or light office activities	52	34.4
Cannot carry out house work activities	22	14.6
Spend more than 50% in a chair or a bed	21	13.9

Notes: 1= % of top five of other medical problems from the total of 91 patients who had other medical problems and some patients had more than one disease.

Correlation Analyses

Before conducting the confirmatory factor analysis, the correlations between the total scores for the general FQOL questions and the cancer specific FQOL questions were computed. These scores were highly correlated for the cancer patients and for the family members ($r = 0.82$, $p < 0.01$; $r = 0.81$, $p < 0.01$, respectively; see Table 11). The fact that these two scores are so highly correlated suggests that a general factor underlies them. Nonetheless, it was decided to conduct the confirmatory factor analysis of the general and the cancer specific questions separately because separate models were set a priori.

Table 11

Pearson Correlation Coefficients between the Total Scores for the General FQOL Questions and the Cancer Specific FQOL questions, for the Cancer Patients and Family Members

FQOL Questions	Cancer Patients		Family Members	
	N	r	N	r
General - Cancer specific FQOL questions	151	0.82**	150	0.81**

** $p < 0.01$

In addition, the correlations between the total scores of (a) general and (b) cancer specific FQOL questions, and (c) the total FQOL score for the cancer patients with those for family members were examined by using Pearson correlations. Correlations for all three comparisons were significantly positively correlated in the low to moderate range ($r = 0.47$, 0.42, and 0.46, $p < 0.01$, 0.01 and 0.01, respectively). See detail in Table 12. Thus, separate confirmatory factor analyses were conducted for the cancer patients and family members.

Table 12

Pearson Correlation Coefficients between Total Scores for the General and Cancer Specific FQOL Questions, and Total FQOL score, for Cancer Patients and Family Members

FQOL Questions	N	r
General FQOL Questions	151	0.47**
Cancer Specific FQOL Questions	150	0.42**
Total Scale	151	0.46**

** $p < 0.01$

Confirmatory Factor Analyses

To answer Research Question # 2, confirmatory factor analysis was used to assess four a priori models: (a) a model with four domains (family interaction, family roles, family communication, and family emotional support) for the general FQOL questions, (b) a model with four domains for the cancer specific FQOL questions, (c) a model with a single general factor for the general FQOL questions, and (d) a model with a single general factor for the cancer specific FQOL questions, as described in Chapter 7 and as shown in Figures 2 to 5. The hypothesis was that the FQOL questionnaire would be multidimensional with four underlying domains. These four models of cancer patients and family members were examined separately and these findings were presented in order. Cases that had missing data were deleted from the analysis and multivariate outlier cases were examined by considering Mahalanobis distance with $p < 0.001$. For the general FQOL questions, seven patients and seven family members were multivariate outliers, and for the cancer specific FQOL questions, six patients and seven family members were multivariate outliers. However, the results of confirmatory factor analysis chi square goodness of fit and other fit statistics with and without the multivariate outlier cases were not significantly different (see Table 13). In fact, when the multivariate outlier cases were deleted for the cancer specific FQOL questions, the chi square goodness of fit increased. Consequently, to maximize the number of cases analyzed, the multivariate outlier cases were not deleted for the analyses presented below.

Table 13

Comparison of Chi Square Goodness of Fit for Data with and without Multivariate Outlier Cases

Cases	n	χ^2 Four Domain Model	χ^2 Unidimensional Model
General FQOL Questions			
Patients, with outlier cases	148	292.798 (df = 113, p = 0.000)	490.553 (df = 119, p = 0.000)
Patients, without outlier cases	141	284.898 (df = 113, p = 0.000)	466.206 (df = 119, p = 0.000)
Family members, with outlier cases	149	302.764 (df = 113, p = 0.000)	460.251 (df = 119, p = 0.000)
Family members, without outlier cases	142	296.384 (df = 113, p = 0.000)	480.167 (df = 119, p = 0.000)

Table 13, continued

Cases	n	χ^2 Four Domain Model	χ^2 Unidimensional Model
Cancer Specific FQOL Questions			
Patients, with outlier cases	149	104.125 (df = 23, p = 0.000)	219.563 (df = 27, p = 0.000)
Patients, without outlier cases	143	112.993 (df = 23, p = 0.000)	184.598 (df = 27, p = 0.000)
Family members, with outlier cases	148	124.522 (df = 23, p = 0.000)	291.713 (df = 27, p = 0.000)
Family members, without outlier cases	141	143.850 (df = 23, p = 0.000)	350.387 (df = 27, p = 0.000)

Results for the Confirmatory Factor Analysis of General FQOL Questions with the Cancer Patients

Of 151 cancer patients, three patients had missing data in the general FQOL questions, so the final sample included 148 patients.

Model with Four Domains for the General FQOL Questions. As shown in Figure 6, the four domains were highly correlated with each other (r ranged from 0.72 to 0.92). For the Family Interaction factor, standardized regression weights ranged from 0.68 to 0.90 and the R^2 for each item ranged from 0.46 to 0.82. For the Family Roles factor, standardized regression weights ranged from 0.46 to 0.85 and the R^2 for each item ranged from 0.22 to 0.73. For the Family Communication factor, the standardized regression weights ranged from 0.70 to 0.85 and the R^2 for each item ranged from 0.49 to 0.73. For the Family Emotional Support factor, standardized regression weights ranged from 0.75 to 0.93 and the R^2 for each item ranged from 0.56 to 0.87. The goodness of fit statistics indicated inadequate fit, with the chi square goodness of fit highly significant ($\chi^2 = 292.798$, df = 113, $p < 0.0001$) and other goodness of fit statistics also indicating inadequate fit (CFI = 0.905, TLI = 0.886, RMSEA = 0.104).

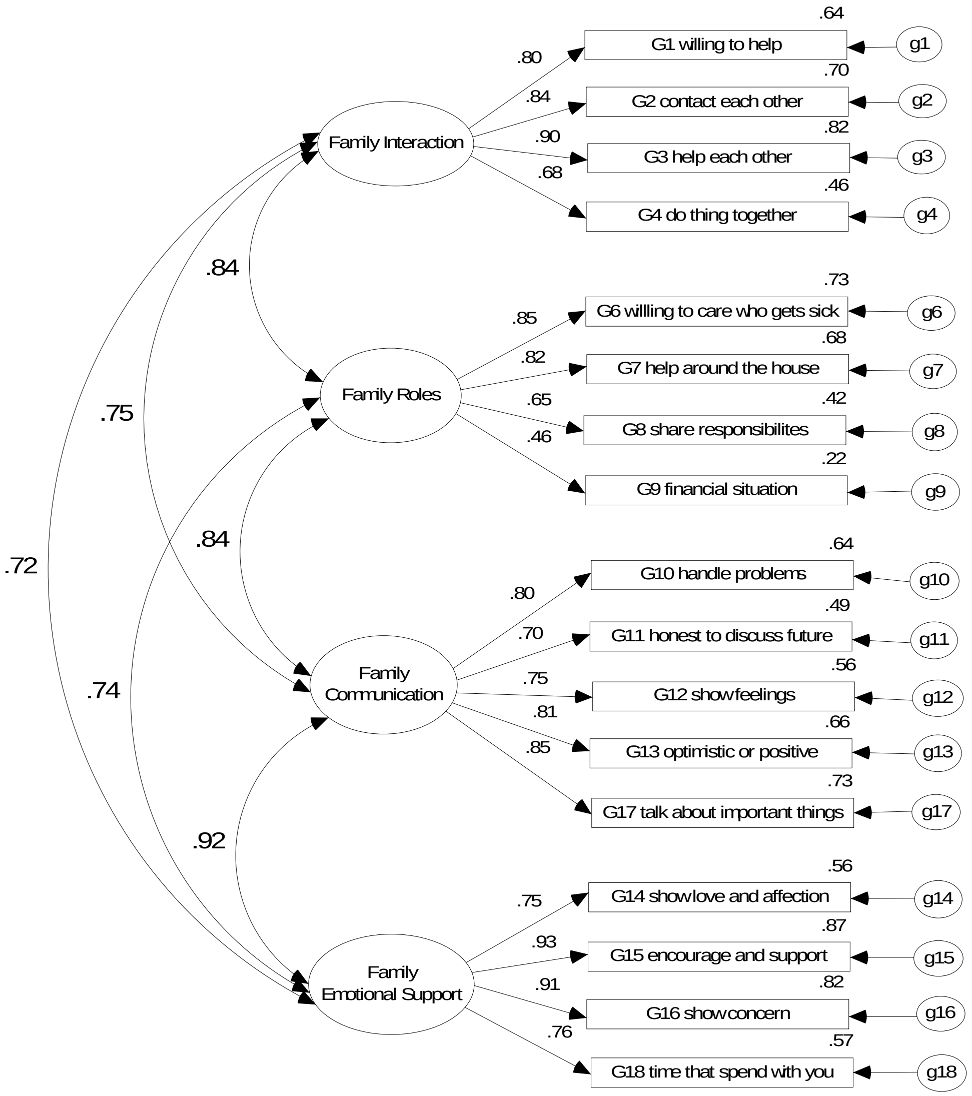

Figure 6. Model with Four Domains for the General FQOL Questions for Cancer Patient

Model with a General Factor for the General FQOL Questions for the Cancer Patients. A unidimensional model for the general FQOL questions was analyzed, as shown in Figure 7. Standardized regression weights between the FQOL factor and each item ranged from 0.42 to 0.86 and the R^2 for each item ranged from 0.18 to 0.74. The goodness of fit statistics indicated a poorer fit as compared to the four domain model. The chi square goodness of fit statistic was highly significance (χ^2=490.553, df = 119, p < 0.0001) and other goodness of fit as well indicating poor fit (CFI = 0.804, TLI = 0.776, RMSEA = 0.146).

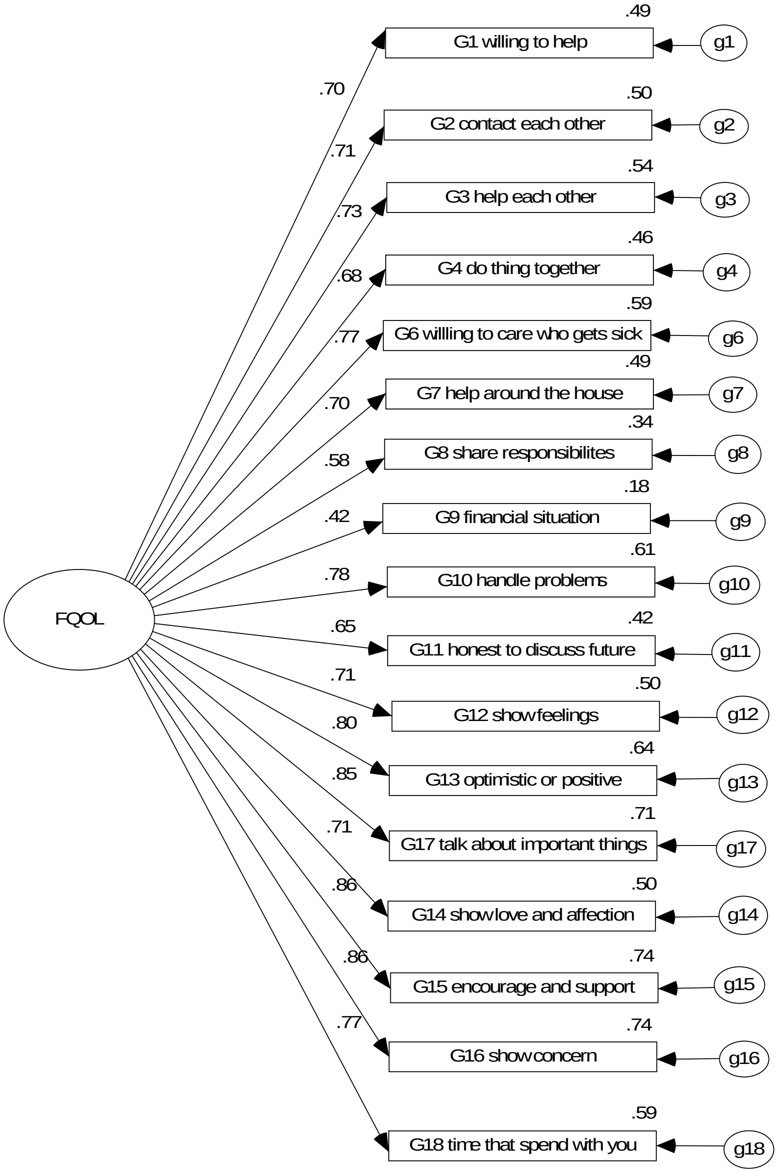

Figure 7. Single Factor Model for General FQOL Questions for Cancer Patients

Comparison of the Two General FQOL Questions Models. The chi square difference was used to examine the difference between the four domain and unidimensional model for the cancer patients' data. This difference was significant (χ^2, 197.775 df = 6, $p < 0.0001$) (see Table 14). Thus, although neither model described the structure for the general FQOL questions well, the four domain model provided a better fit than the unidimensional model.

Table 14

Comparison of the Chi Square Goodness of Fit statistics for the Four Domain versus Unidimensional models for the General FQOL Questions for the Cancer Patients

Models	n	χ^2	χ^2 of test difference
Four domain model	148	292.798 (df = 113, p = 0.000)	197.775 (df = 6, p < 0.0001)
Unidimensional model	148	490.553 (df = 119, p = 0.000)	

Results for the Confirmatory Factor Analysis of Cancer Specific FQOL Questions with Cancer Patients

For the 151 cancer patients, two had missing data in the cancer specific FQOL questions, so only 149 patients were analyzed.

Model with Four Domains for the Cancer Specific FQOL Questions. A model of four domains of cancer specific questions was analyzed, as shown in Figure 8. The four domains were moderately to highly correlated with each other (r ranged from 0.66 to 0.74). For the Family Interaction and Family Emotional Support factors, standardized regression weights and R^2 were not computed because both of these factors had only a single item. For the Family Roles factor, standardized regression weights ranged from 0.82 to 0.93 and the R^2 for each item ranged from 0.68 to 0.87. For the Family Communication factor, standardized regression weights ranged from 0.64 to 0.86 and the

R^2 for each item ranged from 0.41 to 0.74. The goodness of fit statistics indicated an inadequate fit, with a significant chi square (χ^2=104.125, df = 23, p < 0.0001) and other fit indices indicating marginal (CFI = 0.924) or inadequate fie (TLI = 0.881, RMSEA = 0.154).

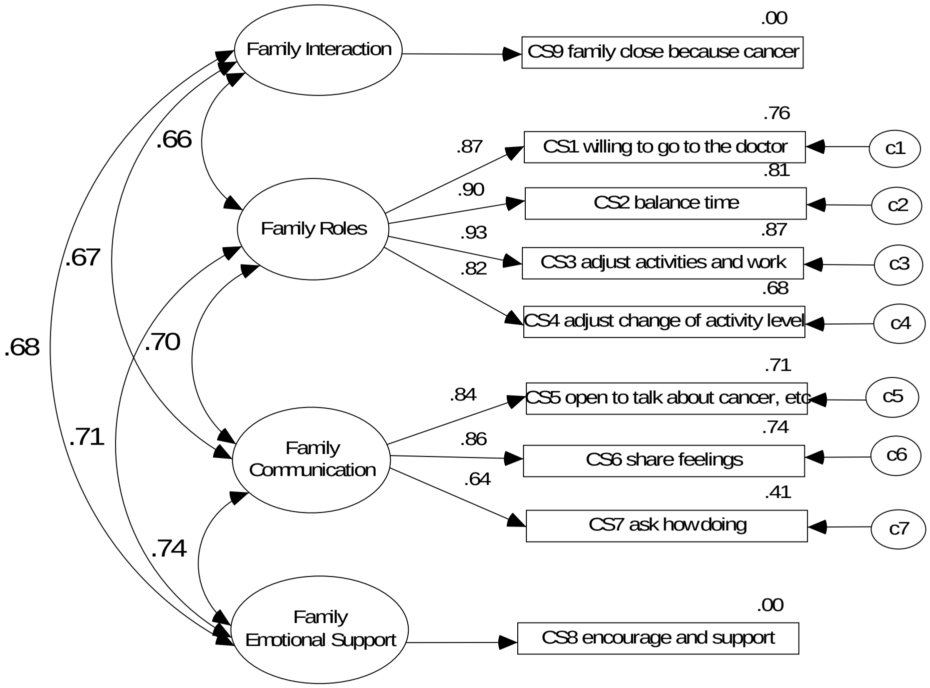

Figure 8. Model with Four Domains for Cancer Specific FQOL Questions for Cancer Patients

Model with a General Factor for the Cancer FQOL Specific Questions for the Cancer Patients. A unidimensional model for the cancer specific FQOL questions was analyzed (see Figure 9). Standardized regression weights between FQOL and each item ranged from 0.55 to 0.91 and R^2 for each item ranged from 0.30 to 0.84. The goodness of fit statistics indicated an inadequate fit, worse than for the four factor model, with a significant chi square (χ^2, 219.563, df = 27, p < 0.0001) and other goodness of fit very poor (CFI = 0.819, TLI = 0.759, RMSEA = 0.220).

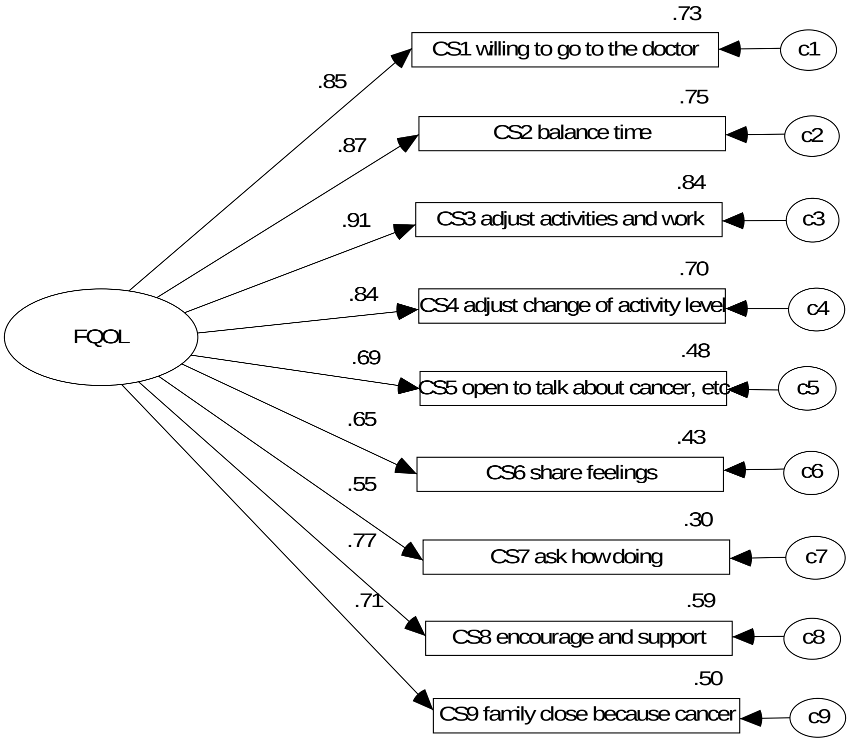

Figure 9. Single Factor Model for Cancer Specific FQOL Questions for Cancer Patients

Comparison for the Two Cancer Specific FQOL Questions Models. The chi square difference was used to examine the four domain and unidimensional models for the cancer specific FQOL questions. This difference was significant (χ^2=115.438, df = 4, p < 0.0001) (see Table 15). Thus, although neither model described the structure for the cancer specific FQOL questions well, the four domain model provided a better fit than the unidimensional model.

Table 15

Comparison of the Chi Square Goodness of Fit Statistics for the Four Domain versus Unidimensional Models for the Cancer Specific FQOL Questions for the Cancer Patients

Models	n	χ^2	χ^2 of test difference
Four domain model	149	104.125 (df = 23, p = 0.000)	115.438 (df = 4, p < 0.0001)
Unidimensional model	149	219.563 (df = 27, p = 0.000)	

Results for the Confirmatory Factor Analysis of General FQOL Questions with the Family Members

Of 151 family members, two had missing data on the general FQOL questions, so the final sample included 149 family members.

Model with Four Domains for the General FQOL Questions. As shown in Figure 10, the four domains were highly correlated with each other (r ranged from 0.81 to 0.91). For the Family Interaction factor, standardized regression weights ranged from 0.74 to 0.89 and R^2 for each item ranged from 0.55 to 0.79. For the Family Roles factor, standardized regression weights ranged from 0.46 to 0.86 and R^2 for each item ranged from 0.21 to 0.75. For the Family Communication factor, standardized regression weights ranged from 0.77 to 0.86 and R^2 for each item ranged from 0.59 to 0.73. For the Family Emotional Support factor, standardized regression weights ranged from 0.76 to 0.92 and R^2 for each item ranged from 0.58 to 0.85. The goodness of fit statistics indicated inadequate fit, with the chi square goodness of fit highly significant (χ^2=302.764, df = 113, p < 0.0001) and other goodness of fit marginal (CFI = 0.911, TLI = 0.893) or poor (RMSEA = 0.107).

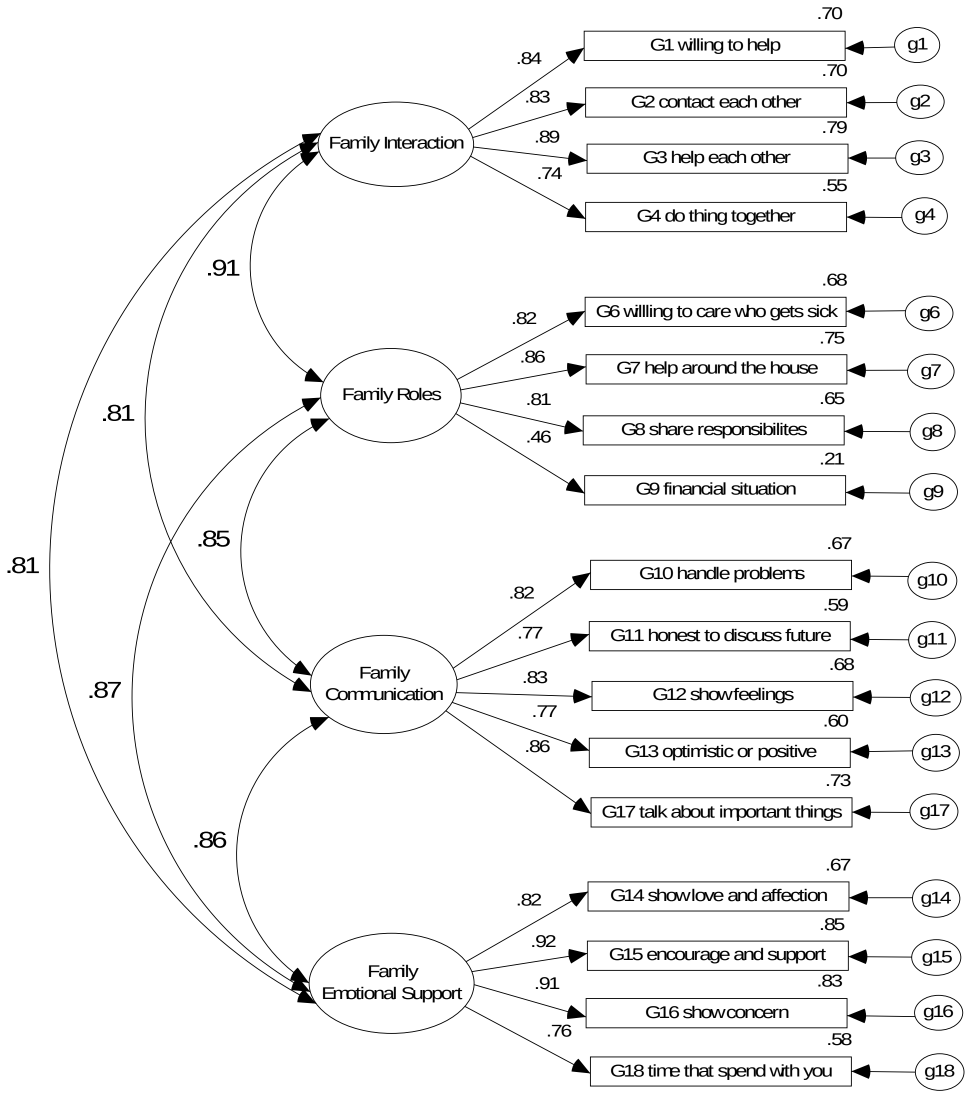

Figure 10. Model with Four Domains for the General FQOL Questions for Family Members

Model with a General Factor for the General FQOL Questions for Family Members. A unidimensional model for the general FQOL questions was analyzed (see Figure 11). Standardized regression weights between FQOL and each item ranged from 0.50 to 0.85 and R^2 for each item ranged from 0.25 to 0.73. The goodness of fit statistics indicated a poorer fit as compared to the four domain model. The chi square goodness of fit was highly significant (χ^2=460.251, df = 119, p < 0.0001) and other goodness of fit statistics were poor (CFI = 0.840, TLI = 0.817, RMSEA = 0.139).

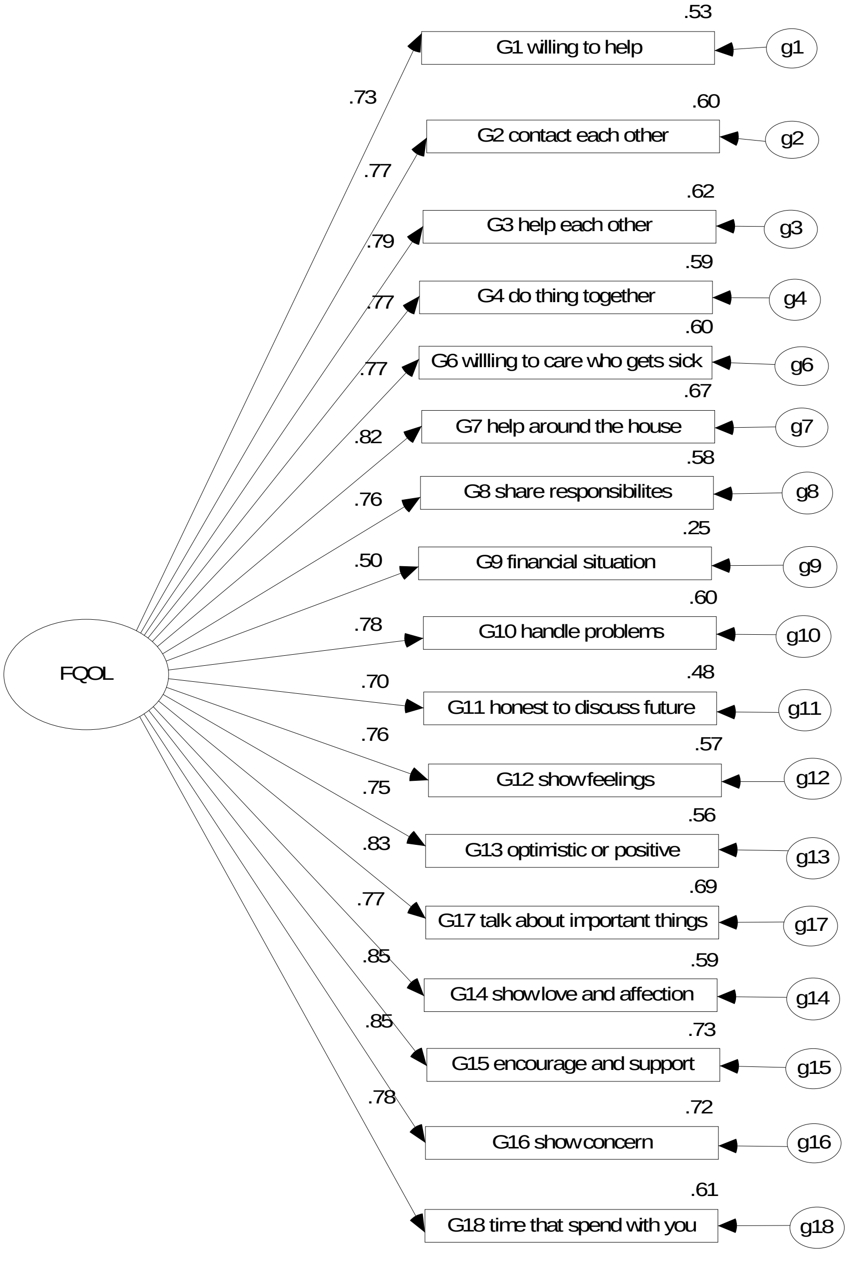

Figure 11. Single Factor Model for General FQOL Questions for Family Members

Comparison for the Two General FQOL Questions Models. The chi square difference was used to examine the difference between the four domain and unidimensional model for the family members data. This difference was significant (χ^2=157.487, df = 6, p < 0.0001) (see Table 16). Thus, although neither model described the structure for the general FQOL questions well, the four domain model provided a better fit than the unidimensional model.

Table 16

Comparison of the Chi Square Goodness of Fit Statistics for the Four Domain versus Unidimensional Models for the General FQOL Questions for the Family Members

Models	n	χ^2	χ^2 of test difference
Four domain model	149	302.764 (df = 113, p = 0.000)	157.487 (df = 6, p < 0.0001)
Unidimensional model	149	460.251 (df = 119, p = 0.000)	

Results for the Confirmatory Factor Analysis of Cancer Specific FQOL Questions with Family Members

Of 151 family members, three had missing data in cancer specific FQOL questions, so only 148 patients were analyzed.

Model with Four Domains for the Cancer Specific FQOL Questions. A model of four domains of cancer specific questions of family members was analyzed, as shown in Figure 12. The four domains were moderately to highly correlated with each other (r ranged from 0.67 to 0.82). For the Family Interaction and Family Emotional Support factor, standardized regression weights and R^2 were not computed because both of these factors had only a single item. For the Family Roles factor, standardized regression weights ranged from 0.83 to 0.92 and R^2 for each item ranged from 0.68 to 0.85. For the

Family Communication factor, standardized regression weights ranged from 0.73 to 0.97 and R^2 for each item ranged from 0.54 to 0.93. The goodness of fit statistics indicated an inadequate fit, with a significant chi square (χ^2=124.522, df = 23, p < 0.0001) and other goodness of fit marginal (CFI = 0.922) or poor (TLI = 0.878, RMSEA = 0.173).

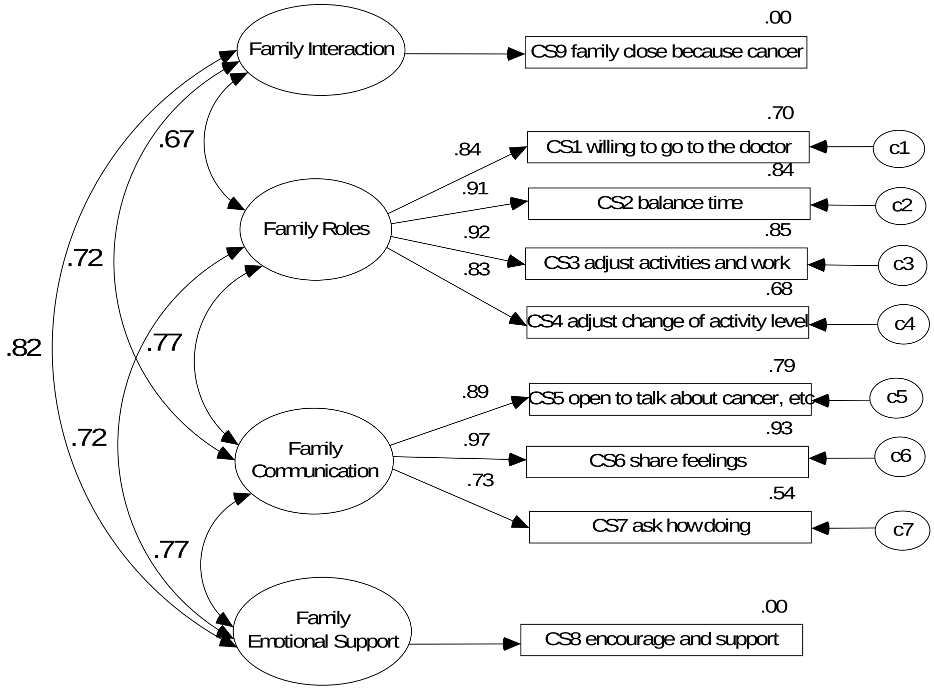

Figure 12. Model with Four Domains of Cancer Specific FQOL Questions for Family Members

Model with a General Factor for the Cancer FQOL Specific Questions for the Family Members. A unidimensional model for the cancer specific FQOL questions was analyzed (see Figure 13). Standardized regression weights between FQOL and each item ranged from 0.79 to 0.86 and R^2 for each item ranged from 0.62 to 0.73. The goodness of fit statistics indicated an inadequate fit, worse than for the four factor model, with a significant chi square (χ^2=291.713, df = 27, p < 0.0001) and other goodness of fit statistics poor (CFI = 0.796, TLI = 0.729, RMSEA = 0.258).

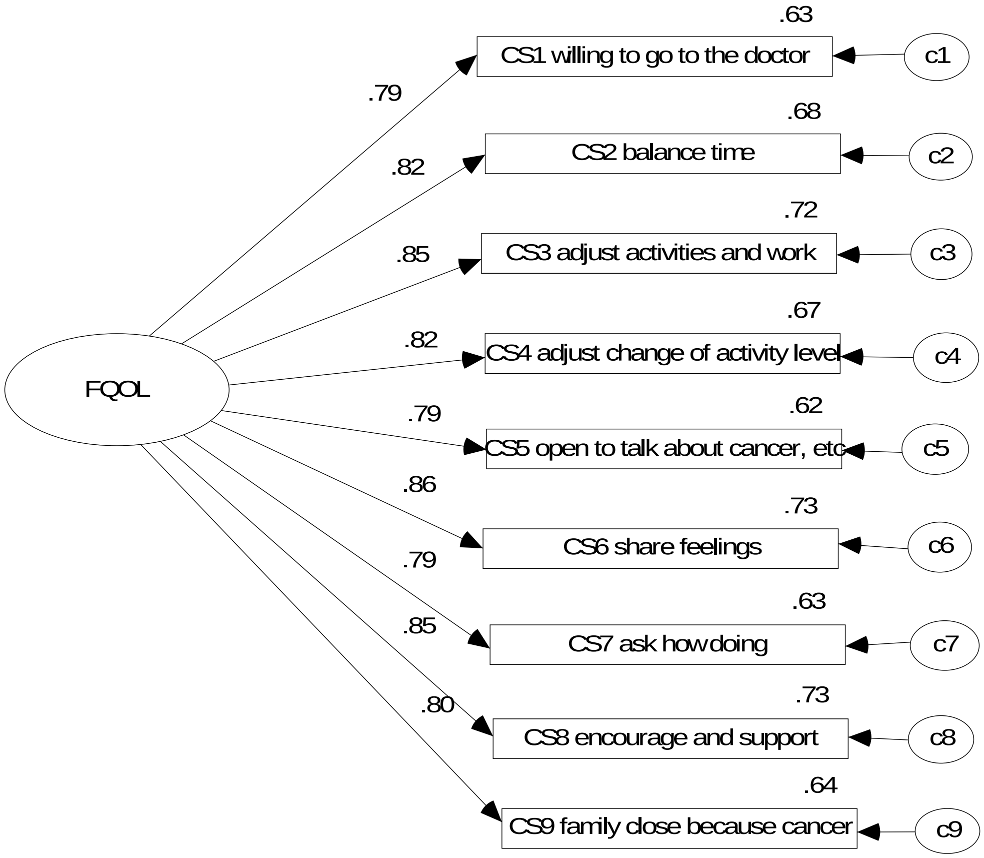

Figure 13. Single Factor Model for Cancer Specific FQOL Questions
for Family Members

Comparison for the Two Cancer Specific FQOL Questions Models. The chi square difference was used to examine the four domain and unidimensional models for the cancer specific questions. This difference was significant (χ^2=167.191, df = 4, p < 0.0001) (see Table 17). Thus, although neither model described the structure for the cancer specific FQOL questions for the family members well, the four domain model provided a better fit than the unidimensional model.

Table 17

Comparison of the Chi Square Goodness of Fit Statistics for the Four Domain versus Unidimensional Models for the Cancer Specific FQOL Questions for the Family Members

Models	n	χ^2	χ^2 of test difference
Four domain model	148	124.522 (df = 23, p = 0.000)	167.191 (df = 4, $p < 0.0001$)
Unidimensional model	148	291.713 (df = 27, p = 0.000)	

Psychometric Evaluation

Based on the findings of confirmatory factor analyses above the four domain model for the FQOL questionnaires provided a better fit than a unidimensional model (although the four domain model did not provide adequate, and needs to be refined), the reliability and validity for the four domains and the total FQOL scores for the cancer patients and family members were examined separately.

Internal Consistency Reliability

Cronbach's alphas were computed to examine the internal consistency reliability for the four subscales (Family Interaction, Family Roles, Family Communication, and Family Emotional Support) across the general and cancer specific items for the family members and cancer patients as well as for the total scores for the general and cancer specific questions and overall total score. Consistent with the factor analysis, item # 5 (which asks about satisfaction with sex life) was excluded from the analysis. Both the Family Interaction and Family Emotional Support subscales of cancer specific questions each contain only a single item, so internal consistency cannot be examined. Participants with missing data for each subscale and total scores were deleted from analyses. Internal consistency reliability was expected to be high.

For cancer patients, Cronbach's alpha for the total scores and all subscales were moderate to high ($\alpha \geq 0.76$), and for the family members, Cronbach's alpha for the total scores and all subscale were high ($\alpha \geq 0.81$; see Table 18).

Table 18

Cronbach's Alpha Coefficients for the FQOL scales for Cancer Patients and Family Members

Subscales / Total scales	Cancer Patients		Family Members	
	N	α	N	α
General Questions	148	0.95	149	0.96
Family Interaction	150	0.87	151	0.89
Family Roles	148	0.76	149	0.81
Family Communication	150	0.89	149	0.90
Family Emotional Support	151	0.90	149	0.91
Cancer Specific Questions	149	0.93	148	0.95
Family Interaction	-	-	-	-
Family Roles	150	0.93	149	0.93
Family Communication	149	0.81	148	0.88
Family Emotional Support	-	-	-	-
Total scales	147	0.96	147	0.97

Test - Retest Reliability

Pearson's correlations were used to examine test-retest reliability across 2 to 4 weeks for the FQOL subscales. Data for 41 cancer patients and 40 family members were analyzed.

For cancer patients, test - retest correlations for total score and all subscales for the general FQOL questions were high and significant (see Table 19). For the general FQOL questions, the correlation for total score between Time 1 and Time 2 was 0.76 ($p < 0.01$) and for the subscales test-retest correlations ranged from 0.63 to 0.72 ($p < 0.01$). The test-retest correlation for Item # 5 for the general questions (that asked about satisfaction for the participant's sex life) was also high and significantly correlated ($r = 0.78$, $p < 0.01$). For the cancer specific FQOL questions for the cancer patients, test - retest correlations for the total score and all subscales were moderate and significant, except for the Family Emotional Support subscale. The correlation for total score for the cancer specific FQOL questions between Time 1 and Time 2 was 0.68 ($p < 0.01$) and all subscales were significantly correlated, ranging from 0.46 to 0.67 ($p < 0.01$) except the Family Emotional Support subscale, which was not significantly correlated between Times 1 and 2. For the overall sub-domain ratings, test - retest coefficient reliability of each subscale of overall sub-domains were low to moderate but significant, with correlations for the sub-domain ratings ranging from 0.43 to 0.63 ($p < 0.01$). The correlation between Time 1 and Time 2 for the single item rating FQOL was low but significantly correlated ($r = 0.42$, $p < 0.01$). It is not surprising that the single item ratings had lower test-retest correlations, since it is well known that the reliability of scales increases up to an asymptote with increasing number of items. The total FQOL score between Time 1 and Time 2 was highly correlated ($r = 0.79$, $p < 0.01$).

For family members, test - retest correlates for total score and all subscales for the general FQOL questions were moderate and significant (see Table 19). For the general FQOL questions, the correlation for total score between Time 1 and Time 2 was 0.62 (p

<0.01) and the subscales correlations ranged from 0.51 to 0.61 ($p < 0.01$). The test-retest correlation for Item #5 (that asked about satisfaction for the participant's sex life) was in the moderate to high range and significantly correlated ($r = 0.65$, $p < 0.01$). For the cancer specific FQOL questions for the family members, test - retest correlations for the total score and all subscales were moderate to high and significant. The correlation for total score for the cancer specific FQOL questions between Time 1 and Time 2 was $r = 0.74$ ($p < 0.01$) and all subscale were significantly correlated, with correlations ranging from 0.55 to 0.72 ($p < 0.01$). For the overall sub-domain ratings, test - retest coefficient reliability of each subscale of overall sub-domains were low to moderate but significant, with correlations for the sub-domain ratings ranging from 0.42 to 0.65 ($p < 0.01$). The correlation between Time 1 and Time 2 for the single item rating overall FQOL was moderate and significantly correlated ($r = 0.67$, $p < 0.01$). The total FQOL score between Time 1 and Time 2 was highly correlated ($r = 0.70$, $p < 0.01$).

The majority of coefficients testing stability of the FQOL fell between the desired range of 0.50 to 0.80. The most notable exception was the single item cancer specific Family Emotional Support for cancer patients.

Table 19

Test-retest Correlations between Time 1 and Time 2 for the Subscales and Total Scores for the General and Cancer Specific FQOL Questions for Cancer Patients and Family Members

Subscales / Total scales	Cancer Patients (N = 41)	Family Member (N = 40)
General Questions	0.76**	0.62**
Family Interaction	0.63**	0.59**
G5: Satisfaction in sex life with their partner[a]	0.78**	0.65**
Family Roles	0.72**	0.60**
Family Communication	0.68**	0.61**
Family Emotional Support	0.67**	0.51**
Cancer Specific Questions	0.68**	0.74**
Family Interaction	0.46**	0.55**
Family Roles	0.67**	0.70**
Family Communication	0.64**	0.72**
Family Emotional Support	0.14	0.58**
Overall Sub-domains (Single Items)		
Family Interaction	0.43**	0.42**
Family Roles	0.56**	0.49**
Family Communication	0.63**	0.64**
Family Emotional Support	0.51**	0.65**
Overall FQOL (Single Item)	0.42**	0.67**
Total Scores	0.79**	0.70**

** $p < 0.01$

[a] N of cancer patients = 22, N of family member = 24

Descriptive Data for the FQOL Questionnaire and Other Questionnaires for the Cancer Patients and Family Members

In this section, descriptive statistics including the range, mean, and standard deviation for the FQOL scales and other questionnaires used for examining validity are reported in

Table 20. Cases with more than 20% of missing data for a particular measure were dropped from each analysis.

For cancer patients, the mean scores for each subscale, total scale, and single item rating overall FQOL were high, indicating in general that the patients were satisfied with their FQOL. For the general FQOL questions, the mean total score was 4.24 (SD = 0.67, range = 1.24 - 5); means for the subscales ranged from 4.14 (SD = 0.80) for Family Communication to 4.36 (SD = 0.74) for Family Emotional Support. For the cancer specific FQOL questions, the mean total score was 4.46 (SD = 0.65, range = 1.89 - 5), the mean for the subscales ranged from 4.36 (SD = 0.74) for Family Communication to 4.65 (SD = 0.67) for Family Emotional Support. The mean total score combining the general and cancer specific FQOL questions was 4.32 (SD = 0.64, range = 1.46 - 5) and the mean for the single item rating overall FQOL was 4.52 (SD = 0.71, range 1 – 5).

For family members, the mean scores for the subscales, total scale, and overall FQOL were high, indicating that in general family members were satisfied with their FQOL. For the general questions, the mean total score was 3.98 (SD = 0.81, range = 1.18 - 5), the mean for the subscales ranged from 3.85 (SD = 0.91) for Family Roles to 4.18 (SD = 0.86) for Family Emotional Support. For the cancer specific FQOL questions, the mean for the total score was 4.08 (SD = 0.91, range = 1 - 5), the mean for the subscales ranged from 4.01 (SD = 1.01) for Family Communication to 4.13 (SD = 0.94) for Family Roles. The mean total score combining general and cancer specific FQOL questions was 4.02 (SD = 0.80, range = 1.12 - 5) and the mean for the single item rating overall FQOL was 4.17 (SD = 0.99, range 1 – 5).

For the SF 36 of cancer patients, the mean of the physical component summary (PCS) was low (M = 36.73, SD = 12.17, range = 9.42 – 58.70) and the means of each scale of the PCS ranged from low for Role-Physical (M = 32.78, SD = 41.95) to high for Bodily Pain (M = 60.60, SD = 30.04). The mean of the mental component summary (MCS) was moderate (M = 49.01, SD = 10.67, range = 18.91 – 69.94) and the means of each scale of the MCS ranged from moderate for Vitality (M = 48.15, SD = 23.08) to high for Mental Health (M = 74.30, SD = 18.56). For the SF 36 of family members, the mean of the PCS was moderate (M = 48.76, SD = 10.49, range = 17.24 – 68.83) and the means of each scale of the PCS were high and ranged from 69.48 (SD = 19.38) for General Health to 80.73 (SD = 24.13) for Physical Functioning. The mean of the MCS was moderate (M = 46.12, SD = 12.36, range = 14.03 – 66.46) and the means of each scale of the MCS were high and ranged from 55.31 (SD = 20.59) for Vitality to 69.77 (SD = 20.07) for Mental Health.

For the FACT-G of cancer patients, the mean scores of each subscale and total scale were high. The means of each subscale ranged from 16.24 (SD = 4.07) for Emotional Well-Being to 23.60 (SD = 4.08) for Social / Family Well-Being. The mean of total scale was 79.64 (SD = 17.18, range = 24 – 106). For family members, the mean scores of each subscale and total scale of the FACT-G were high. The means of each subscale ranged from 14.57 (SD = 4.53) for Emotional Well-Being to 23.88 (SD = 4.29) for Physical Well-Being. The mean of total scale was 80.00 (SD = 15.43, range = 29 – 108).

For the Beach Center Family Quality of Life Scale, the mean scores of Family Interaction and Emotional Well-Being subscales were high for cancer patients (M = 4.34 and 4.21, SD = 0.61 and 0.70, respectively) and family members (M = 4.21 and 4.03, SD

= 0.75 and 0.83, respectively). The means of the Balanced Cohesion scale of the FACES IV of cancer patients and family members were high (M = 29.34 and 28.56, SD = 4.98 and 6.20, range = 12 – 35 and 7 – 35, respectively). The means of the total scale of the Family Communication Scale for cancer patients and family members were high (M = 40.26 and 39.09, SD = 7.33 and 8.35, range = 12 – 50 and 10 – 50, respectively). Based on Olson and Barnes (2004) norms, the cancer patients had very good family communication (scores of 40 – 50), and family members had good family communication (scores of 35 – 39). The means of the Family Satisfaction Scale total scores for cancer patients and family members were high (M = 39.76 and 37.97, SD = 7.72 and 9.06, range = 17 – 50 and 12 – 50, respectively). Based on Olson (2004), that cancer patients were very happy about their family (scores of 40 – 50), and family members were generally happy about their family (scores of 35 – 39).

Table 20

Range, Means, and Standard Deviations for Study Questionnaires for Cancer Patients and Family Members

Questionnaires	Cancer Patients (N = 150 – 151)			Family Members (N = 149 – 151)		
	Range	M	SD	Range	M	SD
FQOL subscale						
General Questions	1.24 - 5	4.24	0.67	1.18 - 5	3.98	0.81
Family Interaction	1 - 5	4.32	0.72	1 - 5	4.06	0.87
Family Roles	1 - 5	4.17	0.77	1.50 - 5	3.85	0.91
Family Communication	1.20 - 5	4.14	0.80	1.20 - 5	3.89	0.91
Family Emotional Support	1.75 - 5	4.36	0.74	1 - 5	4.18	0.86

Table 20, continued

Questionnaires	Cancer Patients (N = 150 – 151)			Family Members (N = 149 – 151)		
	Range	M	SD	Range	M	SD
Cancer Specific Questions	1.89 - 5	4.46	0.65	1 - 5	4.08	0.91
Family Interaction	1 - 5	4.45	0.79	1 - 5	4.11	1.13
Family Roles	1 - 5	4.49	0.75	1 - 5	4.13	0.94
Family Communication	2 - 5	4.36	0.74	1 - 5	4.01	1.01
Family Emotional Support	2 - 5	4.65	0.67	1 - 5	4.06	1.07
Total Scale	1.46 - 5	4.32	0.64	1.12 - 5	4.02	0.80
Overall FQOL	1 - 5	4.52	0.71	1 - 5	4.17	0.99
SF 36						
Physical Component Summary	9.42 - 58.70	36.73	12.17	17.24 - 68.83	48.76	10.49
Physical Functioning	0 - 100	57.81	28.47	0 - 100	80.73	24.13
Role-Physical	0 - 100	32.78	41.95	0 - 100	70.03	36.29
Bodily Pain	0 - 100	60.60	30.04	0 - 100	73.07	23.78
General Health	0 - 100	54.41	24.91	25 - 100	69.48	19.38
Mental Component Summary	18.91 - 69.94	49.01	10.67	14.03 - 66.46	46.12	12.36
Vitality	0 - 100	48.15	23.08	0 - 95	55.31	20.59
Social Functioning	0 - 100	63.58	27.87	0 - 100	73.84	24.97
Role-Emotional	0 - 100	64.68	40.96	0 - 100	69.09	40.37
Mental Health	8 - 100	74.30	18.56	4 - 100	69.77	20.07
FACT-G						
Physical Well-Being	0 - 28	19.13	6.75	5 - 28	23.88	4.29
Social / Family Well-Being	8 - 28	23.60	4.08	7 - 28	21.98	5.03
Emotional Well-Being	2 - 24	16.24	4.07	1 - 24	14.57	4.53
Functional Well-Being	1 - 28	18.19	6.68	4 - 28	19.91	5.97
Total score of FACT-G	24 -106	76.94	17.18	29 - 108	80.00	15.43
Beach Center Family Quality of Life Scale						
Family Interaction	1.83 - 5	4.34	0.61	1.33 - 5	4.21	0.75
Emotional Well-Being	1.25 - 5	4.21	0.70	1 - 5	4.03	0.83

Table 20, continued

Questionnaires	Cancer Patients (N = 150 – 151)			Family Members (N = 149 – 151)		
	Range	M	SD	Range	M	SD
FACE - IV						
Balanced Cohesion	12 - 35	29.34	4.98	7 - 35	28.56	6.20
Family Communication Scale						
Total scale of Family Communication Scale	12 - 50	40.26	7.33	10 - 50	39.09	8.35
Family Satisfaction Scale						
Total scale of Family Satisfaction Scale	17 - 50	39.76	7.72	12 - 50	37.97	9.06

Convergent Validity

Pearson correlation coefficients were used to examine the relationships between the FQOL scales and the other questionnaires, as hypothesized. Three scores tested for each subscale of the FQOL are reported; (a) the subscale score for the general questions, (b) the subscale score for the cancer specific questions, and (c) a total score with the general and cancer specific subscales combined. Cases with more than 20% of missing data for a particular measure were dropped from each analysis, with pairwise deletion.

Family Interaction. The Family Interaction subscales for the general, cancer specific and the total scores for Family Interaction subscales were significantly positively correlated with the Family Interaction subscale the Beach Center Family Quality of Life Scale and the Balanced Cohesion subscale of the FACES IV for both cancer patients and family members, as hypothesized. The correlations between the Family Interaction scores from the FQOL and the validation instruments ranged from 0.60 to 0.74 for cancer patients and 0.73 to 0.79 for family members (see Table 21). These correlations supported the construct validity of the Family Interaction subscales for both general and cancer specific FQOL questionnaires.

Table 21

Pearson Correlation Coefficients between the FQOL Family Interaction Subscale and the Validation Questionnaires for Cancer Patients and Family Members

Family Interaction	Cancer Patients (N = 151)			Family Members (N = 149 – 151)		
	General Questions	Cancer Specific Questions	Total Score[a]	General Questions	Cancer Specific Questions	Total Score[a]
Beach Center Family Quality of Life Scale						
Family Interaction	0.69**	0.70**	0.74**	0.73**	0.77**	0.79**
FACE - IV						
Balanced Cohesion	0.66**	0.60**	0.70**	0.73**	0.74**	0.78**

** $p < 0.01$

[a] Combined scores for the Family Interaction subscale for the General and Cancer Specific FQOL questions

Family Roles. For cancer patients, the Family Roles subscale for the general FQOL questions and for the total Family Roles subscale was significantly positively correlated with the Role-Emotional subscale from the SF-36 as hypothesized, but not for Role-Physical subscale from the SF 36. Although these general subscale and total score were positively associated with the Role-Emotional subscale, the correlation was weak ($r \leq 0.21$). The Family Roles subscale for the cancer specific FQOL questions was not correlated with Role-Physical or Role-Emotional subscales (see Table 22). For the family members, the Family Roles subscales for the general and cancer specific FQOL questions, and the total Family Roles subscale were significantly positively correlated with Role-Physical and Role-Emotional subscales as hypothesized. These correlations ranged from 0.20 to 0.25 for family members. Thus, the construct validity of the family Roles subscales was partially supported for cancer patients, with slightly stronger support for family members.

Table 22

Pearson Correlations between the FQOL Family Roles Subscale and the SF 36 Subscales for the Cancer Patients and Family Members

Family Roles	Cancer Patients (N = 150 – 151)			Family Members (N = 149 – 151)		
	General Questions	Cancer Specific Questions	Total Score[a]	General Questions	Cancer Specific Questions	Total Score[a]
SF 36						
Role-Physical	0.13	0.08	0.12	0.23**	0.22**	0.25**
Role-Emotional	0.21*	0.09	0.16*	0.24**	0.20*	0.24**

* $p < 0.05$, ** $p < 0.01$

[a] Combined scores for the Family Roles for the General and Cancer Specific FQOL questions

Family Communication. The Family Communication subscale for the general and cancer specific FQOL questions, and the total Family Communication subscale for the cancer patients and family members were significantly positively correlated with the Family Communication Scale as hypothesized. The correlations between scales were moderate to strong for cancer patients (r = 0.59 – 0.70) and family members (r = 0.70 –

0.78), supporting the construct validity of the Family Communication subscales (see Table 23).

Table 23

Pearson Correlation Coefficients between the FQOL Family Communication Subscales and the FACES IV Family Communication Scale for Cancer Patients and Family Members

Family Communication	Cancer Patients (N = 150 – 151)			Family Members (N = 150 - 151)		
	General Questions	Cancer Specific Questions	Total Score[a]	General Questions	Cancer Specific Questions	Total Score[a]
FACES IV Family Communication Scale	0.68**	0.59**	0.70**	0.75**	0.70**	0.78**

** $p < 0.01$

[a] Combined scores for the Family Communication for the General and Cancer Specific FQOL questions

Family Emotional Support. For the cancer patients, the FQOL Family Emotional Support subscales for the general, cancer specific and the combined Family Emotional Support score were significantly positively correlated with Emotional Well-Being subscale from the Beach Center Family Quality Life Scale (r = 0.60 - 0.67) as hypothesized. However, the FQOL subscales were not correlated with the Emotional Well-Being subscale from the FACT-G (See Table 24). For the family members, the FQOL Family Emotional Support subscales (general, cancer specific, and total) were significantly positively correlated with Emotional Well-Being subscale from the Beach Center Family Quality Life Scale (r = 0.70 - 0.74) and with the Emotional Well-Being subscale from the FACT-G (r = 0.17 - 0.19) as hypothesized (see Table 24). For both cancer patients and family members, the association with the Beach Center Family Quality Life Scale was stronger than with the subscale form the FACT-G. Construct validity for the Family Emotional Support subscales was partially supported in these samples.

Table 24

Pearson Correlation Coefficients between the FQOL Family Emotional Support Subscale and the Beach Center Family Quality of Life Scale and FACT-G Questionnaires for Cancer Patients and Family Members

Family Emotional Support	Cancer Patients (N = 150 – 151)			Family Members (N = 149 – 150)		
	General Questions	Cancer Specific Questions	Total Score[a]	General Questions	Cancer Specific Questions	Total Score[a]
Beach Center Family Quality for the Life Scale						
Emotional Well-Being	0.64**	0.60**	0.67**	0.70**	0.74**	0.74**
FACT-G						
Emotional Well-Being	0.14	0.07	0.14	0.17*	0.19*	0.18*

* $p < 0.05$, ** $p < 0.01$

[a] Combined scores for the Family Emotional Support subscale, for the General and Cancer Specific FQOL questions

Total Scores. Total FQOL scores (mean score summed across all general questions and cancer specific questions) for the cancer patients and family members were significantly positively correlated with the total scores for the FACT-G and the Family

Satisfaction Scale, as hypothesized. Correlations for the total FQOL score with the FACT-G and the Family Satisfaction Scale were moderate to strong (r = 0.28 – 0.70) for cancer patients and strong (r = 0.53 – 0.76) for family members (see Table 25). Thus, the total FQOL scores are associated with more general measures of quality of life.

Table 25

Pearson Correlation Coefficients between the FQOL Subscales and FACT-G and Satisfaction Scale for Cancer Patients and Family Members

Total Scores	Cancer Patients (N = 150 – 151)			Family Members (N = 150 – 151)		
	General Questions	Cancer Specific Questions	FQOL's Total Scale	General Questions	Cancer Specific Questions	FQOL's Total Scale
FACT-G	0.33**	0.28**	0.32**	0.61**	0.53**	0.62**
Family Satisfaction Scale	0.69**	0.61**	0.70**	0.73**	0.72**	0.76**

** $p < 0.01$

Discriminant Validity

Pearson correlation coefficients and tests of the difference between two dependent correlations (Steiger, 1980) were used to evaluate discriminant validity. The correlations between the general, cancer specific and total FQOL scores were stronger with the Mental Component Summary (MCS) than the Physical Component Summary (PCS) scores of the SF-36. For the cancer patients, the correlations between scores for the FQOL scales and the MCS and PCS did not differ significantly (see Table 26). For the family members, the correlations between scores for the general FQOL scale and the total

FQOL score were more highly positively correlated with the MCS than with the PCS, as hypothesized. However, the correlation between scores for the cancer specific FQOL scale and the SF-36 component summary scores did not differ significantly. Thus, discriminant validity using the SF-36 component scales was only partially supported for the family member data and not supported for the cancer patient data.

Scores for the general FQOL scale, the cancer specific FQOL scale, and the total FQOL score for both the cancer patients and family members were more highly positively correlated with the FACT-G Social/Family Well-Being subscale (SWB) than the FACT-G Physical Well-Being subscale (PWB), as hypothesized.

For the cancer patients and family members, correlations for the general, cancer specific FQOL and total FQOL scores were not more highly correlated with the FACT-G Emotional Well-Being subscale (EWB) than the FACT-G Physical Well-Being (PWB) subscale (see Table 26).

Correlations between the general, cancer specific, and total FQOL scores for the cancer patients and family members were more highly positively correlated with the FACT-G Functional Well-Being subscale (FWB) than the PWB, as hypothesized. Thus, the discriminant validity was supported for the SWB and FWB subscales of the FACT-G but not the EWB subscale.

Table 26

Pearson Correlation Coefficients and T-Test Differences of Dependent Correlations for the FQOL scales and the SF36 and the FACT-G, for the Cancer Patients and Family members

Questionnaire	Cancer Patients (N = 150 -151)		Family Members (N = 150 - 151)	
	r	t	r	t
FQOL: General – SF36: MCS	0.22**	0.92	0.39**	2.22*
FQOL: General – SF36: PCS	0.12		0.14	
FQOL: Cancer Specific – SF36: MCS	0.13	0.30	0.32**	1.61
FQOL: Cancer Specific – SF36: PCS	0.10		0.13	
FQOL: Total Score - SF36: MCS	0.20*	0.72	0.38**	2.05*
FQOL: Total Score - SF36: PCS	0.12		0.14	
FQOL: General – FACT-G: SWB	0.67**	7.40***	0.73**	6.57***
FQOL: General – FACT-G: PWB	0.08		0.32**	
FQOL: Cancer Specific – FACT-G: SWB	0.56**	5.55***	0.69**	6.64***
FQOL: Cancer Specific – FACT-G: PWB	0.06		0.25**	
FQOL: Total Score – FACT-G: SWB	0.66**	7.21***	0.76**	7.30***
FQOL: Total Score – FACT-G: PWB	0.08		0.31**	
FQOL: General – FACT-G: EWB	017*	1.28	0.28**	-0.42
FQOL: General – FACT-G: PWB	0.08		0.32**	
FQOL: Cancer Specific – FACT-G: EWB	0.14	1.08	0.22**	-0.31
FQOL: Cancer Specific – FACT-G: PWB	0.06		0.25**	
FQOL: Total Score – FACT-G: EWB	0.17*	1.25	0.28**	-0.37
FQOL: Total Score – FACT-G: PWB	0.08		0.31**	
FQOL: General – FACT-G: FWB	0.25**	3.06***	0.53**	3.29***
FQOL: General – FACT-G: PWB	0.08		0.32**	
FQOL: Cancer Specific – FACT-G: FWB	0.22**	2.80**	0.45**	2.95***
FQOL: Cancer Specific – FACT-G: PWB	0.06		0.25**	
FQOL: Total Score – FACT-G: FWB	0.25**	3.10***	0.53**	3.36***
FQOL: Total Score – FACT-G: PWB	0.08		0.31**	

* p < 0.05, ** p < 0.01, *** p < 0.001

Summary

A four factor structure, as hypothesized, was found to provide a better fit than a general one factor structure for the 17-item general FQOL scale and the 9-item cancer specific FQOL scale. The internal consistency reliability of all subscales was adequate for a newly developed instrument. Tests of convergent validity (see Table 27 for summary of convergent validity analyses) for the four subscales of the general and cancer specific and the total scores of the FQOL supported the Family Interaction and Family Communication subscales for all participants. The Family Role and Family Emotional Support subscales, however, had inconsistent findings but this may have been due to selection of inappropriate convergent validity measures. Discriminant validity (see Table 28 for summary of discriminant validity), which tested for differences in correlations, was only partially supported in this study but this also may have been due to selection of inappropriate measures to assess discriminant validity.

Table 27

Convergent Validity for Cancer Patients and Family Members: Pearson Correlation Coefficients between the FQOL Subscales and FQOL Total Score, and the Validation Questionnaires

Questionnaires	Cancer Patients (N = 150 – 151)			Family Members (N = 149 – 151)		
	FQOL General Questions	FQOL Cancer Specific Questions	FQOL Total Score[a]	FQOL General Questions	FQOL Cancer Specific Questions	FQOL Total Score[a]
Family Interaction						
Beach Center Family Quality of Life Scale: Family Interaction	0.69**	0.70**	0.74**	0.73**	0.77**	0.79**
FACE - IV: Balanced Cohesion	0.66**	0.60**	0.70**	0.73**	0.74**	0.78**
Family Roles						
SF 36: Role-Physical	0.13	0.08	0.12	0.23**	0.22**	0.25**
SF 36: Role-Emotional	0.21*	0.09	0.16*	0.24**	0.20*	0.24**
Family Communication						
FACES IV: Family Communication Scale	0.68**	0.59**	0.70**	0.75**	0.70**	0.78**

Table 27, continued

Questionnaires	Cancer Patients (N = 150 – 151)			Family Members (N = 149 – 151)		
	FQOL General Questions	FQOL Cancer Specific Questions	FQOL Total Score[a]	FQOL General Questions	FQOL Cancer Specific Questions	FQOL Total Score[a]
Family Emotional Support						
Beach Center Family Quality for Life Scale: Emotional Well-Being	0.64**	0.60**	0.67**	0.70**	0.74**	0.74**
FACT-G: Emotional Well-*Being*	0.14	0.07	0.14	0.17*	0.19*	0.18*
Total Score						
FACT-G	0.33**	0.28**	0.32**	0.61**	0.53**	0.62**
Family Satisfaction Scale	0.69**	0.61**	0.70**	0.73**	0.72**	0.76**

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* $p < 0.05$, ** $p < 0.01$.

[a] The Total Score is the total score across the General and Cancer Specific FQOL questions.

Table 28

Discriminant Validity for Cancer Patients and Family Members: Pearson Correlation Coefficients and T-Test Differences of Dependent Correlations between the FQOL and Validation Questionnaires

Questionnaires	Cancer Patients (N = 150 – 151)			Family Members (N = 150 – 151)		
	FQOL General Questions	FQOL Cancer Specific Questions	FQOL Total Score[a]	FQOL General Questions	FQOL Cancer Specific Questions	FQOL Total Score[a]
SF-36						
Physical Health Component Summary	0.12	0.10	0.12	0.14	0.13	0.14
Mental Health Component Summary	0.22**	0.13	0.20*	0.39**[b]	0.32**	0.38**[b]
FACT-G						
Physical Well-Being	0.08	0.06	0.08	0.32**	0.25**	0.31**
Social/Family Well-Being	0.67**[c]	0.56**[c]	0.66**[c]	0.73**[c]	0.69**[c]	0.76**[c]
Emotional Well-Being	0.17*	0.14	0.17*	0.28**	0.22**	0.28**
Functional Well-Being	0.25**[d]	0.22**[d]	0.24**[d]	0.53**[d]	0.45**[d]	0.53**[d]

Significance of individual correlations: * $p < 0.05$, ** $p < 0.01$.

[a] The Total Score is the total score across the General and Cancer Specific FQOL questions.

[b] significant t-test for the difference between correlations for the FQOL scales, and the SF-36 MCS vs. SF-36 PCS subscales.

[c] significant t-test for the difference between correlations for the FQOL scales, and the FACT-G Social / Family Well-Being vs. FACT-G Physical subscales.

[d] significant t-test for the difference between correlations for the FQOL scales and the FACT-G Functional Well-Being vs. FACT-G Physical subscales.

CHAPTER IX

DISCUSSION

Overview. The purpose of this study was to develop a Family Quality of Life Questionnaire for use with families with an adult cancer patient. The conceptual model for the development of the questionnaire was based on Family Systems Theory, previous FQOL studies in sociology, special education, and health care arena, and previous cancer studies on the impact of cancer and its treatment on families. Based on these frameworks, FQOL is subjective and multidimensional. Thus, in this study (a) FQOL was hypothesized to be multidimensional; (b) Family Interaction, Family Roles, Family Communication, and Family Emotional Support were hypothesized to be important aspects of FQOL, and (c) the reliability and validity of the FQOL questionnaire were evaluated. In this Chapter, the main results are summarized and interpreted, and the significance of the study, its strengths, limitations, and implications, and recommendations for future research are discussed.

Summary of Main Results

The FQOL questionnaire was developed based on a literature review and qualitative interviews in Phase 1. Its content validity was assessed in Phase 2 by ten cancer experts. Results of Phase 1 and Phase 2 were supportive of the position that four core domains of FQOL are: (a) Family Interaction, (b) Family Roles, (c) Family Communication, and (d) Family Emotional Support. Based on the Phase 2 results, the FQOL questionnaire was developed to contain four parts: (a) general questions regarding FQOL (18 items); (b) questions regarding FQOL specific to families with a member with cancer (9 items); (c) four items assessing overall satisfaction with the four sub-domains; and (d) one item assessing overall FQOL; the general and cancer specific questions each assessed the four domains. Finally, the FQOL questionnaire has two versions, one for the cancer patient, and one for the family members. The two versions of the questionnaire are essentially the same but minor wording modifications to reflect the patients' or family members' perspective. Wording of the FQOL items were adjusted so as to be at the 6th grade level by a Vanderbilt Medical Center Editor.

In Phase 3, the reliability and validity of the FQOL questionnaire was assessed with a sample of 151 cancer families. A confirmatory factor analysis found that the four domain models provided a better fit than the unidimensional models for both the general and cancer specific questions. The four domain models, however, did not provide a fully adequate fit to the data for either the cancer patients or family members.

The reliability of the FQOL questionnaire was adequate in this sample. The internal consistency reliability of the subscales was moderate to high. The test - retest reliability across two to four weeks for the various subscales and ratings were moderate to high, with four exceptions. The single item Family Interaction rating for the cancer patients and family members and the single item overall FQOL item for cancer patients were significantly correlated but somewhat lower than expected, suggesting instability in responses over two to four weeks. The test - retest reliability for the Family Emotional Support for the cancer specific questions for cancer patients was not significantly correlated, suggesting a high degree of instability.

The construct validity of the FQOL questionnaire was assessed through evaluation of hypotheses about the relation between the FQOL and measures selected to have conceptually similar content (See Chapters 1 and 7). The main results for the tests of convergent validity were:

Family Interaction subscale. The FQOL *Family Interaction* subscales were consistently related to other measures of family interaction. These results were found for both cancer patients and family members, providing support for the construct validity of this subscale.

Family Roles subscale. Results for the FQOL *Family Roles* subscales provided mixed support for the construct validity of this subscale. For cancer patients, the Family Roles subscale was not related to the SF-36 Role-Physical subscale and had mixed results for the SF-36 Role-Emotional subscale. In contrast, for family members, correlations between FQOL subscales and total scores were significantly correlated with the SF-36 Role-Physical and Role-Emotional subscales, but the correlations were low.

Family Communication subscale. The FQOL *Family Communication* subscales were consistently related to Olson and Barnes' *Family Communication Scale*. These results were found for both cancer patients and family members, providing support for the construct validity of this subscale.

Family Emotional Support subscale. Results for the FQOL *Family Emotional Support* subscales provided partial support for the construct validity of this subscale. The FQOL Family Emotional Support subscales were consistently related to the Beach Center Family Quality of Life Scale *Emotional Well-Being* subscale for both cancer patients and family members, providing support for the convergent validity of this subscale. In contrast, the correlations between the FQOL *Family Emotional Support* subscale and the FACT-G *Emotional Well-Being* subscale were low for family members and for cancer patients, the correlations were non-significant. Thus, only partial support for the convergent validity of this subscale was found.

Total FQOL scores. The FQOL *Total Scores* were consistently related to total scores of convergent validity measures. These results were found for both cancer patients and family members, providing support for the construct validity of the Total Scores, although the correlations between the FQOL total scores and the FACT-G total scores for cancer patients were low to moderate.

The main results for the tests of discriminant validity were:

FQOL Total Scores and the SF-36 MCS and PCS. The results of these tests partially supported the discriminant validity in this sample. For the family member, the correlations between the FQOL total scores for the general and the total (combined) FQOL questions were significantly higher with the SF-36 MCS than with the SF-36 PCS, providing support for discriminant validity of the FQOL total score. However, the correlations between the total scores for the cancer specific FQOL questions and the SF-36 MCS did not differ significantly from the correlations with the SF-36 PCS. For cancer patients, there was no support for discriminant validity.

FQOL Total Scores and FACT-G Subscales. Discriminant validity was partially supported in this sample by these analyses. The correlations between the FQOL total scores for the general, cancer specific, and the total (combined) FQOL questions for cancer patients and family members were higher with the FACT-G Social / Family Well-Being and Functional Well-Being subscales than with the FACT-G Physical Well-Being subscale, demonstrating discriminant validity. However, for both the cancer patients and family members the correlations between the FQOL total scores for the general, cancer specific, and the total (combined) FQOL questions and the FACT-G Emotional Well-Being did not differ significant from the correlations with the FACT-G Physical Well-Being subscale.

Discussion of Results

The following discussion suggests why some results were as hypothesized whereas other results were not, and what the implications of these discrepancies are in regards to FQOL among cancer patients as a construct as well as in regards to this specific FQOL questionnaire.

Research Question #1: Are (a) Family Interaction, (b) Family Roles, (c) Family Communication, and (d) Family Emotional Support central aspects of FQOL for cancer patients and their families?

Results of Phase 1, which involved interviewing 12 cancer families, strongly supported the perspective that Family Interaction, Family Roles, Family Communication, and Family Emotional Support were important aspects of FQOL among cancer patients. In addition, the results of the Phase 2 assessment of content validity via cancer experts' evaluation of the questionnaire also supported the perspective that these four domains were relevant as well as sufficient for describing FQOL among cancer patients. The item analyses of each domain sub-scale in Phase 3 found that good internal consistency which suggests that the items in each domain sub-scale were measuring essentially the same concept (Garson, 2009).

In contrast, the results of the confirmatory factor analysis in Phase 3 found that the four domain model provided an inadequate fit to the data although the four domain model did provide a better fit than a unidimensional model. There are a number of issues that can be considered in interpreting these results. First, it is important to understand exactly what the results of the confirmatory factor analysis mean. What this analysis suggests is that these four domains may not be distinct or separate (i.e., that when participants rate Family Interaction FQOL high, or low, they also rate Family Roles FQOL high, or low), which does not mean that these are not important domains but rather that the domains may covary relatively highly. In fact, although the four domains were highly correlated with each other, some domains were more highly correlated with each other than with other sub-domains. For example, for the general FQOL questions for the cancer patients and family members, the Family Communication and Family Emotional Support domains were very highly correlated ($r = 0.92$ and $r = 0.86$, respectively) and Family Interaction and Family Roles domains were very highly correlated ($r = 0.84$ and $r = 0.91$, respectively), whereas the correlations across these two pairs of domains were lower. This suggests that each of these sets of domains may actually be a single domain. Further supporting this perspective, the results from qualitative interviews in Phase 1 found that subthemes of the four domains overlapped, although all of the domains were seen as important. For example, the “Helping and Supporting Each Other” subtheme from the Family Interaction domain overlapped with the Family Roles and Family Emotional Support domains, since helping family members in household chores, taking care of the patient or children, etc. also can be experienced as a form of emotional support within the family.

Themes within the Family Communication and Family Emotional Support domains also overlapped. For instance, when family members talked about how they were doing and what was happening, this involved sharing their feelings with each other, or talking about positive things, which can serve to provide emotional support and share feelings among patients and family members. Thus, the results of Phase 1 and Phase 2 suggest that Family Interaction, Family Roles, Family Communication, and Family Emotional Support are central aspects of FQOL among cancer patients, but the confirmatory factor analysis suggests that these domains may not all be entirely distinct from each other.

Second, the results of the confirmatory factor analysis indicated that for some of the domains some of the items were not highly correlated with the latent factor, which suggests that those items may not be part of the same domain (Albright & Park, 2008). That is, the a priori assignment of the items to the subscales may not have been entirely correct, which also could have resulted in the less than fully adequate fit of the model. Inappropriate item assignment would not necessarily imply that the four domain model was inappropriate.

This variability in the relation between items and the latent factor was seen in several places. For instance, the R^2 for two items on Family Interaction and Family Roles domains were lower than R^2 for other items in the same domains. For example, for the Family Interaction subscale for the general FQOL questions, the R^2 for Item #4 (doing things together in the family) for the cancer patients was 0.46 and for the family members it was 0.55 whereas R^2 for the other items on the Family Interaction subscale of cancer patients ranged from 0.64 to 0.82 for the cancer patients and 0.70 to 0.79 for the family members. Thus, the less than fully adequate fit for the confirmatory factor analysis could be due to inappropriate assignment or inadequate items rather than the four domain model being invalid.

Clark and Watson (1995) have suggested that if an item that reflects the theoretical core of the construct does not empirically correlate strongly with the factor, it is not necessarily wise simply to eliminate the item without consideration as to why it did not correlate as expected. For example, item #4, which asked participants' satisfaction with how often family members did things together, might have been influenced by the distance that family members and the cancer patients lived from each other, whereas other items on this subscale might have been less influenced by this factor. This would reduce the correlation between this item and the other items on the subscale. Consequently, Clark and Watson (1995) have suggested that theoretical as well as empirical considerations with data from diverse samples should be considered when making a decision regarding whether subscales are warranted. Thus, it would be premature to firmly conclude that the FQOL questionnaire should not contain the four hypothesized domains or that specific items should be dropped.

Research Question #2: Is FQOL unidimensional or multidimensional?

Results of the confirmatory factor analysis for the cancer patients and family members found that although neither the four domain models nor the unidimensional models for the cancer patients and family members provided a fully adequate fit for the general and cancer specific FQOL data, the four domain models provided a significantly better fit than the unidimensional models. Thus, it does appear that FQOL as assessed by this questionnaire is multidimensional, as suggested by this study's conceptual framework. However, the exact number of domains and the content of domains for the FQOL questionnaire need to be further investigated.

Research Question #3: What are the reliability and validity of the FQOL questionnaire?

Internal Consistency Reliability. The internal consistency reliability of the FQOL questionnaire was examined for the cancer patients and for the family members using Cronbach's Alpha Coefficient. For all of the subscales, total scores for the general and cancer specific FQOL questions, and the total FQOL score, Cronbach's Alpha Coefficient were above 0.70, which indicates that the internal reliability of the FQOL questionnaire was in the acceptable range (Nunnally, 1978). This result might seem contradictory with the results of the confirmatory factor analysis, which found that some items did not load as highly on their factor as other items (i.e., the items were not internally consistent). However, Cronbach's alpha assesses the overall internal consistency whereas the confirmatory factor analysis assesses the individual contribution of each item to the internal consistency. Thus, these results suggest that the overall internal consistency is adequate but that a small number of items are not consistent but not to a sufficient degree to significantly decrease the overall internal consistency.

Test - Retest Reliability. The test-retest reliability of the FQOL questionnaire was examined across a two to four week time period, with the expectation that the correlations would be moderate to high (r = 0.5 to 0.8). For the cancer patients, the test-retest correlations for most of the subscales for general and cancer specific FQOL questions as well as the total (combined) scores for the general and cancer specific FQOL questions, and total scores of the FQOL questionnaire were moderate to high. The test-retest correlation for the overall domain rating for Family Interaction, and for the single item overall rating of FQOL were significantly correlated ($r = 0.43$, $p < 0.01$ and $r = 0.42$, $p < 0.01$, respectively) but slightly lower than expected. In addition, the test-retest correlation for the Family Emotional Support subscale for the cancer specific FQOL questions was not significantly correlated. Thus, there were three test-retest correlations that were lower than hypothesized. It should be noted all three of these tests involved single items, the first two are single item ratings, and the Family Emotional Support subscale for the cancer specific FQOL questions contains only one item. It is well known that the reliability of scales with a small number of items tends to be low, because having multiple items on a questionnaire allows for random error canceling out across items, which is not possible with single item ratings. For the family members, the test-retest correlations for all of the subscales and ratings were moderate to high, as expected, with one exception. The test-retest correlation for the overall single item rating of Family Interaction was significantly correlated ($r = 0.43$, $p < 0.01$) but slightly lower than expected. Again, it should be noted that this was a single item. Thus, overall, the FQOL subscales and ratings showed good test-retest reliability.

Convergent Validity. The convergent validity for the four FQOL subscales was examined by correlating the subscales with other conceptually related measures. The convergent validity of the FQOL *Family Interaction* subscales was assessed by correlating the various Family Interaction scores with the Beach Center Family Quality of Life Scale Family Interaction subscale, and the FACES IV Balanced Cohesion subscale. All of the correlations were high, indicating that the FQOL Family Interaction subscales assess constructs similar to those assessed by these other two scales.

The convergent validity of the FQOL *Family Roles* subscales was assessed by correlating the various Family Roles scores with the SF-36 Role Physical and the SF-36 Role Emotional subscales. Across the 12 correlations (family members vs. cancer patients, general vs. cancer specific FQOL questions, etc.), eight were significantly positively correlated with the SF-36 scales but all correlations were low (all $r \leq 0.25$). Thus, convergent validity between the FQOL Family Roles subscale and the SF-36 Role Physical and Role Emotional subscales was not supported. Review of the items contained on the SF-36 indicates that although these subscales are labeled “Role” they assess a different construct from the FQOL Family Roles subscale. The items of the FQOL Family Roles subscale assess satisfaction with concrete tasks and responsibilities within the family (e.g., helping care for the patient; household chores; being the breadwinner) whereas the SF-36 Role Physical and Role Emotional subscales focus on the extent to which ones ability to perform basic daily activities or work has been impaired as a result of physical or emotional problems (e.g., cutting down the amount of time spent on work or activities as a function of one physical health; accomplishing less than one desired because of emotional health problems; Ware, et al., 1994). Thus, although the names of the FQOL Family Roles subscale and the SF-36 Role Physical and Role Emotional subscales suggest a similarity, in reality the subscales measure different constructs. Thus, it is not surprising that the FQOL Family Roles subscales did not show convergent validity with the SF-36 Role Physical and Role Emotional subscales. Further testing with more conceptually equivalent instruments is warranted.

The convergent validity of the FQOL *Family Communication* subscales was assessed by correlating the various Family Communication scores with the FACES IV Family Communication subscale. All of the correlations were high, showing good convergent validity and indicating that the FQOL Family Communication subscales assess constructs similar to those assessed by this FACES IV subscale.

The convergent validity of the FQOL *Family Emotional Supports* subscales was assessed by correlating the various Family Emotional Support scores with the Beach Center Family Quality of Life Scale Emotional Well-Being subscale and the FACT-G Emotional Well-Being subscale. All of the correlations between the FQOL Family Emotional Support subscales and the Beach Center Family Quality of Life Scale Emotional Well Being subscale were moderate to high ($r \geq 0.60$), showing good convergent validity and indicating that the FQOL Family Emotional Support subscales assess constructs similar to those assessed by the Beach Center Family Quality of Life Scale Emotional Well Being subscale.

In contrast, across the six correlations (family members vs. cancer patients, general vs. cancer specific FQOL questions, etc.) between the FQOL Family Emotional Support subscales and the FACT-G Emotional Well-Being, three were significantly positively correlated but all correlations were low (all $r \leq 0.19$). Thus, convergent validity between the FQOL Family Emotional Support subscales and the FACT-G Emotional Well-Being subscale was not supported. Review of the items contained on the FQOL Family Emotional Support subscales and the FACT-G Emotional Well-Being subscale indicates that although both of these subscales involve “emotion” they assess different constructs. The FQOL Family Emotional Support subscale assesses satisfaction with how the family provides emotional support for each other (e.g., providing encouragement; expressing love) whereas the FACT-G Emotional Well-Being subscale focuses on participants' current emotions, such as the extent to which they are feeling sad, nervous, or worried. Thus, it is not surprising that the FQOL Family Emotional Support subscale and the FACT-G Emotional Well-Being did not show convergent validity.

The convergent validity for the FQOL *Total Scores* for the general, cancer specific, and the total (combined) FQOL questions was assessed by correlating these FQOL scores with the FACT-G and the Family Satisfaction Scale Total Scores. All of the correlations between the FQOL scores and the Family Satisfaction Scale Total Scores were moderate to high ($r \geq 0.61$), indicating that these FQOL Total Scores assess constructs similar to that assessed by the Family Satisfaction Scale Total Score.

For the family members, all of the correlations between the FQOL Total Scores and the FACT-G Total Score were moderate to high ($r \geq 0.53$), indicating convergent validity for these two scales. However, for the cancer patients, the correlations between the FQOL Total Scores and the FACT-G Total Score were low ($r = 0.28$ to 0.33) although significant. This suggests that for cancer patients' individual quality of life (as assessed by the FACT-G) is less related to FQOL (as assessed by the FQOL) than for family members. This in turn suggests that for cancer patients, the determinants of FQOL are more independent from individual quality of life than is true for non-cancer family members. This may reflect the reality of living with a chronic, life-threatening disease such as cancer, and the sense of burden on ones family that may develop (Simmons, 2007).

Overall, although some of the convergent validity tests were not confirmed, these results do provide moderate to strong support for the convergent validity of the FQOL questionnaire. In 61% of the tests, strong convergent validity was found with a mean correlation between measures of 0.68. In most instances where convergent validity was not found, close review of the measures made it apparent that the FQOL subscale and measure selected to assess convergent validity were in fact not measuring the same or even similar constructs. Thus, the lack of "convergent validity" probably reflects not a true problem in convergent validity for the FQOL measure but rather a problem in the selection of the convergent validity measures. For instance, the FACT-G Emotional Well-Being subscale failed to show convergent validity with the FQOL Family Emotional Support subscales because they measured different constructs.

Discriminant Validity. The discriminant validity of the total scores for the general, cancer specific, and total (combined) FQOL questions was examined by correlating these scores with subscales from the SF-36 and the FACT-G, with the hypothesis that the FQOL questionnaire would be more highly related to social, mental, and functional well being than physical well being. Thus, it was hypothesized that the FQOL scores would be more highly correlated (a) with the SF-36 Mental Component Summary (MCS) than with the SF-36 Physical Component Summary (PCS), and (b) with the FACT-G Social/Family Well-Being, Emotional Well-Being, and Functional Well-Being subscales than with the FACT-G Physical Well-Being subscale.

In regards to the SF–36, two of the six correlations were significantly different (see Table 28). In reviewing the correlations involving the SF-36 that did not show discriminant validity, it is apparent that the lack of discriminant validity primarily resulted from the fact that these FQOL scores were not highly, or even moderately, correlated with the SF-36 MCS ($r = 0.13$ to 0.32; see Table 28). This again appears to be a result of the fact that two subscales (the FQOL and the SF-36 Mental Component Summary) do not measure similar or even related constructs, as is necessary to demonstrate discriminant validity. The FQOL measures satisfaction with family relationships whereas the SF-36 MCS measures how one is feeling emotionally. It appears that how one is feeling emotionally is not strongly related to satisfaction with ones family. In order to demonstrate discriminant validity, it is necessary to compare the relations of a measure to a similar and to a dissimilar measure but in the present case, it appears that the comparison was between two fairly dissimilar measures.

All FQOL correlations were significantly higher with the FACT-G Social/Family Well-Being subscale and the Functional Well-Being subscales than with the Physical Well-Being subscale, demonstrating discriminant validity as hypothesized. However, FQOL correlations with the FACT-G Emotional Well-Being vs. the Physical Well-Being subscales did not differ significantly, for either the cancer patients or the family members. Again, this appears to have been in large part a result of the fact that the FQOL scores were not highly, or even moderately, correlated with the component of the discriminant validity comparison with which they were supposed to be related (the FACT-G Emotional Well-Being subscale; $r = 0.14$ to 0.28).

In sum, 58% of the hypothesized differences were found to demonstrate significant discriminant validity, which provides moderate support for the discriminant validity of the FQOL measure, especially when considering the fact that the instances where discriminant validity was not found appear to at least be in part due to selection of dissimilar measures. Thus, the instances that found a lack of “discriminant validity” may reflect not a true problem in discriminant validity for the FQOL measure but rather a problem in the selection of the discriminant validity measures.

Based on these results, it is clear that the FQOL questionnaire focuses more highly on functional, social, and family function than on the physical function of cancer families, as would be hypothesized based on our conceptual model. The extent to which the FQOL measure more heavily focuses on the emotional life of cancer families than their physical function is not yet clear. This ambiguity may reflect problems in measurement selection rather than with the measure.

Strengths of the Study

The study had a number of strengths. First, questionnaire development was based on a systematic plan, with three phases, based both on measurement development techniques as well as Family Systems Theory as a theoretical basis. Second, the study recruited participants from a relatively wide range of sites using a number of different methods to identify participants, which should increase the generalizability of the results. These sites included urban and rural medical centers and community hospitals, a hotel accommodation for cancer patients receiving treatment (Hope Lodge), a mass email communication to Vanderbilt Medical Center, and advertisements via a cancer website, and flyer. Most participants lived in Tennessee but the sample did include participants from other states such as Alabama, Kentucky, Georgia, and Virginia, as well as Missouri, New Jersey, New York, and Texas. Third, the study recruited patients with a variety of types of cancer, treatments, and treatment phases, also increasing generalizability. Finally, the study recruited both cancer patients and their family members, and analyzed their data separately, allowing for development of questionnaires that reflect their specific perspectives on FQOL.

Limitations of the Study

There also were several limitations to this study, including use of a convenience sample, a somewhat limited sample size, a cross-sectional design, and in a minority of cases, inappropriate measures selected to assess convergent and discriminant validity. This study used a convenience sample rather than a sample that was designed to be representative of the population of cancer patients and their families. One particular issue is that only patients with a family member willing to participate were recruited, which might have biased results since results from patients who did not have a family member highly involved in the treatment might have been different. In addition, most participants in the study were Caucasian, and had relatively high levels of education and income, which could have influenced the results. Sidani (2003) has noted that a drawback of convenience sampling is that it yields samples that may not be representative of the target population, which would limit the generalizability of the results. Consequently, future studies should consider using other sampling approaches, such as stratified random sampling.

In the field, there is not agreement as to what an optimal sample size for a questionnaire development study should be. A ratio of at least 10 subjects for each variable or item has been proposed by Dixon (2001). Aroian and Noris (2001) have proposed that 100 to 200 subjects is an acceptable sample size for factor analysis. Although sample size for Phase 3 of 151 families fits within these criteria, a larger sample size might have produced clearer results from the confirmatory factor analysis.

Decoster (1998) has suggested that because confirmatory factor analysis involves inferential statistics it needs a larger sample size than exploratory factor analysis; he has suggested the minimum sample size should be approximately 200 subjects for a standard model.

This study collected data from cancer families at one point in time. Thus, it was not possible to determine how FQOL changes across time as treatment and the disease progress, nor was it possible to identify predictors of changes in FQOL. The test-retest data collection had the purpose of assessing the stability of the questionnaire, not predictive relations. Longitudinal studies might help to better understand FQOL for cancer families.

Finally, in several instances it appears that inappropriate measures were selected to assess convergent and discriminant validity. In order for a correlation between two variables to represent convergent validity, the two variables must assess the same or similar constructs. In a few instances, careful review of the item content for some of the convergent validity measures suggested that this was not the case. Similarly, in order for the difference between two correlations to represent discriminant validity, one variable must be correlated with a second variable representing a similar construct and a third variable representing a dissimilar construct. But in a few cases it appears that the FQOL variable of interest was being correlated with two dissimilar measures.

Implications of Results

Implications for Research

The FQOL questionnaire is a new tool for researchers interested in the functioning of cancer families, in particular in regards to FQOL. In general, the questionnaire has high internal consistency reliability and adequate test-retest reliability. Tests of convergent validity showed that the FQOL questionnaire is highly correlated with other non-cancer QOL questionnaires. The tests of discriminant validity suggest that the FQOL questionnaire is focused on social, family, and functional aspects of family life rather than physical health. However, the precise domains underlying the FQOL questionnaire are not yet clear and need further investigation. If the purpose of a study is to assess overall FQOL among cancer families, then the study can focus on the total score of the FQOL questionnaire, treating it as a unidimensional scale. For researchers interested in a more detailed assessment of FQOL among cancer families, they can examine the domains within their own samples.

Implications for Practice

Based on the results of the three phases of this study, this questionnaire appears to be sufficiently valid for nurses to use for an FQOL assessment with their patients. In addition to more generally using patients' and family members' responses, it may be useful for nurses to compare patients' and family members' responses on items to see where they disagree, which could guide interventions to help families cope with cancer and its treatment. Overall, study results suggest that this measure may be useful to help nurses promote and maintain FQOL, family function, and relationships among cancer families.

Recommendations for Future Research

Based on the results and limitations of this study, the following recommendations for future research are made:

First, the FQOL questionnaire should be further developed. The number of domains and their precise nature needs to be further investigated. Based on the results of Phase 1 versus the confirmatory factor analysis in Phase 3, the four FQOL domains in this questionnaire may be overlapping. Thus, an exploratory factor analysis would be useful to clarify the number and nature of the domains underlying the FQOL questionnaire. After the domains are identified, then it would be useful to conduct a confirmatory factor analysis with another sample to evaluate the model fit, with a sample size of at least 200 families.

More generally, the fact that the confirmatory factor analysis did not confirm the four a priori dimensions suggests that it might be useful in future research to consider whether the theoretical framework for this study, which generated the four dimensions, should be revised. However, the theoretical framework was used to identify dimensions that were important for FQOL for cancer patients, and the results of Phase 1 and Phase 2 suggest it was successful in this regard. The results of the confirmatory factor analysis suggest that some of the four domains may not be distinct but it does not address whether cancer patients and family members view these domains as important. It seems unlikely that a conceptual framework could determine the extent to which certain dimensions were distinct or overlapping, exploratory factor analyses would be more useful for this purpose.

Second, it would be useful for future studies to collect data from more than one time point, using a longitudinal design. This type of design would provide data on how changes in FQOL over time relate to the progression and treatment of cancer. Such a design would allow for examination of whether changes in FQOL are associated with changes in individual QOL as well as other factors that might be related to the development or impairment in FQOL.

Third, it also would be interesting to determine the effects of differences between family members in their perceptions of FQOL. Although the patients' and family members' scores were moderately to highly correlated, there were still many differences between these two perspectives. It would be important to determine if a lack of agreement would predict future dysfunction, poorer mental health outcomes, or perhaps poorer health outcomes. If the family is functioning as a unit to cope with cancer, then a lack of coordination in members' perceptions regarding the functioning of the unit could result in problems in a variety of areas.

Fourth, given that the United States only represents a small portion of the human population, it would be important to examine FQOL in other countries to determine the influences of culture on FQOL. Along these same lines, it would be useful to obtain more ethnically diverse U.S. samples to determine if FQOL differs across different sub-populations in the U.S.

Finally, it would be interesting to assess FQOL in other chronic diseases such as diabetes, hypertension and heart disease to determine the extent to which cancer's effects on FQOL are related to the chronic nature of cancer. In addition, a modified version of this questionnaire might prove useful clinically for families coping with other chronic diseases.

Conclusion

This study focused on development of a FQOL questionnaire for cancer families. It represents the first stage in the development of the questionnaire. At present, the FQOL construct is not entirely clear and needs further investigation. Nonetheless, the results from this study suggest that this questionnaire represents a good starting place both from a research and clinical practice standpoint in regards assessment of FQOL among families with a cancer patient.

Appendix A

Interview Guide --- Patient Version

Interview Guide ---Patient Version

Before we begin, I wanted to mention to you that because this is a research interview, it will need to be somewhat formal. I'll be reading the questions to you so that everyone receives the questions the same way, and I won't react to anything you say. But when we're done with the formal research interview, we can talk in a more natural way.

START THE RECORDER

At beginning of tape, record subject ID, Date and Time of the interview

1. We know that everyone's experience with cancer is different. To begin our discussion, can you please tell me what it has been like for you to live with cancer?
2. What worries you most about having cancer?
3. Some patients have told us that their family life has changed a lot after a cancer diagnosis, and other patients have said that there really haven't been a lot of changes. How has your family life changed since your cancer diagnosis?
4. Sometimes the changes in families don't really show up until after the person begins treatment. How has your family life changed since your treatment began?
5. In previous studies some people have talked about changes in their family interactions, how their families treat and behave with each other. Other people have said that they haven't really noticed many changes in their family. I'd like you to take a minute and think back over the time since you were diagnosed with cancer. In what ways, if any, have your interactions with your family members changed? **[WAIT FOR ANSWER] [IF THEY SAY NO CHANGES: So there**

really haven’t been any changes that you have noticed] How do you feel about these changes? How would you like these interactions to be?

6. We all have different roles in our families. Some people have the “breadwinner” role in the family and are the main source of money for the family. Some people are responsible for taking care of the house, or for taking care of the children, or taking care of someone when they’re sick. Other people have the role of being the “man of the house” or the “woman of the house.” Now I’d like to talk about your roles in your family. Have any of your roles in the family changed since you were diagnosed with cancer? **[WAIT FOR AN ANSWER]** How have your roles changed? How do you feel about these changes?
7. How have the roles of the other members of your family changed? How have your family members dealt with or coped with these changes?
8. Some patients have talked about the difficulties that cancer has caused them with communication in their family. What kind of communication problems have you and your family faced? How do you feel about these problems? How have you and your family tried to solve these problems?
9. Many cancer patients have talked about how important emotional and other kinds of support are for them, especially from their families. They’ve said that sometimes the support is helpful but other times their family’s attempts at support aren’t so helpful. What kinds of support have you received from your family? Do you feel like you have received the support you need from your family? Has this support been helpful? What other kinds of family support would be helpful for you?

10. We know that when someone has cancer, other members of the family often have their own concerns or worries related to the cancer. In your family, what worries have other family members had?
11. We're interested in understanding what FQOL means to people, and the types of things that affect their FQOL. What I mean by FQOL is how satisfied someone is with their life in their family, how good someone feels about being in their family. There are lots of different parts to FQOL, the different parts of our family life about which we're satisfied, and the parts of our family life about which we're not so happy.
    a. When you think about your family life, what parts are you most satisfied with?
    b. What parts are you not so happy about, and wish could be different?
12. In your opinion, what factors have helped to maintain or improve your family quality of life?
13. And what kinds of things have reduced your family quality of life?
14. What have you and your family done that's helped to hold you together?
15. If a friend of yours was diagnosed with cancer and asked you, what advice would you give them and their family members about how to best cope with cancer?
16. Is there anything else that would be helpful for me to understand about your experience?

Okay, now we're done with the formal interview. I really appreciate your taking the time to talk with me. This information should be helpful in helping us understand how to help families coping with cancer improve their family quality of life.

Appendix B

Interview Guide --- Family Member Version

Interview Guide ---Family Member Version

Before we begin, I wanted to mention to you that because this is a research interview, it will need to be somewhat formal. I'll be reading the questions to you so that everyone receives the questions the same way, and I won't react to anything you say. But when we're done with the formal research interview, we can talk in a more natural way.

START THE RECORDER

At beginning of tape, record subject ID, Date and Time of the interview

1. We know that everyone's experience with cancer is different. To begin our discussion, can you please tell me what it has been like for you to live with a family member who had cancer?
2. What worries you most about [patient's name] having cancer?
3. Some family members have told us that their family life has changed a lot after their family members were diagnosed cancer, and other family members have said that, there really haven't been a lot of changes. How has your family life changed since [patient's name]'s cancer diagnosis?
4. Sometimes the changes in families don't really show up until after the person begins treatment. How has your family life changed since [patient's name]'s treatment began?

5. In previous studies some people have talked about changes in their family interactions, how their families treat and behave with each other. Other people have said that they haven't really noticed many changes in their family. I'd like you to take a minute and think back over the time since [patient's name] was diagnosed with cancer. In what ways, if any, have your interactions with your family members changed? **[WAIT FOR ANSWER] [IF THEY SAY NO CHANGES: So there really haven't been any changes that you have noticed]** How do you feel about these changes? How would you like these interactions to be?
6. We all have different roles in our families. Some people have the "breadwinner" role in the family and are the main source of money for the family. Some people are responsible for taking care of the house, or for taking care of the children, or taking care of someone when they're sick. Other people have the role of being the "man of the house" or the "woman of the house." Now I'd like to talk about your roles in your family. Have any of your roles in the family changed since [patient's name] was diagnosed with cancer? **[WAIT FOR AN ANSWER]** How have your roles changed? How do you feel about these changes?
7. How have the roles of the other members of your family changed? How have your family members dealt with or coped with these changes?
8. Some patients and family members have talked about the difficulties that cancer has caused them with communication in their family. What kinds of communication problems have you and your family faced? How do you feel

about these problems? How have you and your family tried to solve these problems?

9. Many family members have talked about how important emotional and other kinds of support are for them, especially from their families. They've said that sometimes the support is helpful but other times their family's attempts at support aren't so helpful. What kinds of support have you received from your family? Do you feel like you have received the support you need from your family? Has this support been helpful? What other kinds of family support would be helpful for you?
10. We know that when someone has cancer, other members of the family often have their own concerns or worries related to the cancer. In your family, what worries have family members had?
11. We're interested in understanding what family quality of life means to people, and the types of things that affect their family quality of life. What I mean by family quality of life is how satisfied someone is with their life in their family, how good someone feels about being in their family. There are lots of different parts to family quality of life, the different parts of our family life about which we're satisfied, and the different parts of our family life about which we're not so happy.
    a. When you think about your family life, what parts are you most satisfied with?
    b. What parts are you not so happy about, and wish could be different?

12. In your opinion, what factors have helped to maintain or improve your family quality of life?
13. And what kinds of things have reduced your family quality of life?
14. What have you and your family done that's helped to hold your family together?
15. If a friend of yours was diagnosed with cancer and asked you, what advice would you give them and their family members about how to best cope with cancer?
16. Is there anything else that would be helpful for me to understand about your experience?

Okay, now we're done with the formal interview. I really appreciate your taking the time to talk with me. This information should be helpful in helping us understand how to help families coping with cancer improve their family quality of life.

Appendix C

Cancer Expert Rating Form

Cancer Expert Rating Form

The Preliminary Family Quality of Life Questionnaire for Cancer Families to Examine Content Validity

Part I: General Questions

For each item below, please rate its relevance to the construct of Family Quality of Life (the definition for which has been provided to you in the Introductory Letter). By relevance, we mean how well the item assesses Family Quality of Life in general, or some aspect of Family Quality of Life. Then, please rate how clearly the item is worded. If you have any comments or suggestions how to improve the item, please put them in the space in the right hand column (e.g., that an item should be dropped from the questionnaire because it is not relevant; re-wording suggestions). After these ratings are completed, you will be asked to rate the sufficiency of the items (i.e., how well they cover the domain of Family Quality of Life).

Relevance:	0 - not relevant	1 - somewhat relevant
	2 - fairly relevant	3 - very relevant
Clarity:	0 - not clear	1 - somewhat clear
	2 - fairly clear	3 - very clear

How satisfied are you with…

Items	Relevance				Clarity				Suggestion or Comment
	0	1	2	3	0	1	2	3	
Family Interaction									
1. How available family members are when someone in the family needs something.									
2. The contact family members have with each other.									
3. The help my family members give each other.									
4. How involved family members are in activities together.									
5. My sex life with my partner. *If you prefer not to answer, please check this box* ☐									

Items	Relevance				Clarity				Suggestion or Comment
	0	1	2	3	0	1	2	3	
Family Roles and Responsibility									
6. How available family members are to care for someone who gets sick.									
7. The help family members give each other with household chores.									
8. The sharing of responsibility for taking care of the children or pets *If your family does not have children or pets, please check this box* ☐									
9. Our family's financial situation.									
Family Communication									
10. The discussions and solutions to our problems with which we come up as a family.									
11. How openly my family talks about important things.									
12. How openly family members express their feelings.									
13. How positively my family talks with each other.									
14. How openly my family discusses the future.									
Family Emotional Support									
15. How often family members are there for each other.									
16. How much my family cares for each other.									

Items	Relevance				Clarity				Suggestion or Comment
	0	1	2	3	0	1	2	3	
17. How often my family checks on each others' health and other needs.									
18. How concerned my family is for each other.									
19. How much my family encourages each other.									
20. How much my family supports each other.									
21. How family members show their love for each other.									

Part II: Questions Specific to Cancer Patient (or Family Caregiver)

Below are family quality of life items that refer to aspects of family quality of life specific to the cancer patient (or, in italics, to the family caregiver). Please make the same ratings for these items.

Items	Relevance				Clarity				Suggestion or Comment
	0	1	2	3	0	1	2	3	
Family Interaction									
1. How close my family is to each other because of my cancer. *For Family Member version*: How close my family is to each other because of the cancer.									
Family Roles and Responsibility									
2. How available family members are to go with me to the doctor. *For Family Member version:* How available family members are to go with the patient to the doctor.									

Items	Relevance				Clarity				Suggestion or Comment
	0	1	2	3	0	1	2	3	
3. How the members of my family balance their own responsibilities with their need to help take care of me. *For Family Member version:* How the members of my family balance their own responsibilities with their need to help take care of the patient.									
4. How well members of my family are able to change their roles to respond to my illness. *For Family Member version:* How well members of my family are able to change their roles to respond to the patient's illness.									
5. The ability of my family to adjust to my activity level because of my cancer. *For Family Member version:* The ability of my family to adjust to the patient's activity level because of his / her cancer.									
6. How well my family members are able to balance the time demands of their own schedules and the time required to help me.									

Items	Relevance				Clarity				Suggestion or Comment
	0	1	2	3	0	1	2	3	
For Family Member version: How well my family members are able to balance the time demands of their own schedules and the time required to help the patient.									
Family Communication									
7. The openness with which my family talks about cancer.									
8. Family discussions about cancer, medical treatments, and their side effects.									
9. The openness with which family members express their feelings about my situation. *For Family Member version:* The openness with which family members express their feelings about the patient's situation.									
10. The frequency with which family members ask me how I am doing.									
Family Emotional Support									
11. The amount of time that my family spends with me.									

Please consider the items that you just rated for relevance and clarity. Now, please rate how sufficiently these items as a whole cover the construct of Family Quality of Life, by circling the appropriate number below. That is, please rate the extent to which you think that these items cover the construct of Family Quality of Life, in particular among families with a cancer patient. If the items are less than "Very Sufficient," please comment on what is missing and suggest what needs to be added.

0	1	2	3
not sufficient	somewhat sufficient	fairly sufficient	very sufficient

Suggestion or Comments: ____

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____

We are considering asking patients and family members to rate each of the items for how important the area is to them, because a patient may not be satisfied with an area but the area may not be important to him / her. Patients will be asked: *Also, for each item, please rate how important this part of family life is to you.* Please rate the extent to which you think asking patients how important a domain is, then please make any comments or suggestions you have about asking patients about importance

0	1	2	3
not a good idea	somewhat of a good idea	a good idea	a very good idea

Suggestion or Comments: ____

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Part III: Overall Family Quality of Life

The items below assess overall dimensions of Family Quality of Life. For each item, please rate its relevance in relation to the construct of Family Quality of Life, and how clearly it is worded. If you have any comments or suggestions to improve the item, please put it in the space in the right hand column. After the ratings for the items are completed, you will be asked to rate the sufficiency of the items.

Relevance:	0 - not relevant	1 - somewhat relevant
	2 – fairly relevant	3 – very relevant
Clarity:	0 - not clear	1 - somewhat clear
	2 – fairly clear	3 – very clear

Items	Relevance				Clarity				Suggestion or Comment
	0	1	2	3	0	1	2	3	
1. Interactions in your family.									
2. Distribution of responsibilities in your family.									
3. Communication among members of your family.									
4. The emotional support that people in your family give each other.									
5. Overall, how satisfied are you with your family life?									

Please consider the items you just rated for relevance and clarity. Now, please rate how sufficiently these dimensions as a whole cover the construct of Family Quality of Life, by circling the appropriate number below. That is, do you think that the found dimensions represented by the first items cover the basic dimensions of Family Quality of Life. If the items are less than “Very Sufficient,” please suggest what dimensions you think are missing and what needs to be added to improve the sufficiency.

0	1	2	3
not sufficient	somewhat sufficient	fairly sufficient	very sufficient

Suggestion or Comments: ____
____
____
____
____
____

Finally, please consider the overall format of the actual questionnaire (which has been provided to you separately from this Cancer Expert Rating Form) in terms of ease of use, and please give any suggestions or comments you may have about the overall structure and response format of the questionnaire:

____
____
____
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Other Suggestions or Comments:_______________________________________
____
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Appendix D

Sequence of Item Modification during Phase 2

Sequence of Item Modification during Phase 2

General FQOL Questions

How satisfied are you with…

Original items from Phase 1 sent to cancer experts in Phase 2	Items after content validity assessment in Phase 2	Items after modifications suggested by Medial Center Editor	Items after pilot testing	Final items after committee suggestions, used to collect data in Phase 3
1. How available family members are when someone in the family needs something.	how available family members are when someone in the family is in need?	how willing family members are to help when someone in the family needs extra help?	how willing family members are to help when someone in the family needs extra help?	how willing family members are to help when someone in the family needs extra help?
2. The contact family members have with each other.	the contact that family members have with each other?	the contact that family members have with each other?	the contact that family members have with each other?	the contact that family members have with each other in person, or on the phone, etc.?
3. The help my family members give each other.	the help that family members give each other?	the help that family members give each other?	the help that family members give each other?	the help that family members give each other in their lives?
4. How involved family members are in activities together.	how often family members participate in activities together?	how often family members do things together, at home, or going out, etc.?	how often family members do things together either at home or going out?	how often family members do things together either at home or going out?

Original items from Phase 1 sent to cancer experts in Phase 2	Items after content validity assessment in Phase 2	Items after modifications suggested by Medial Center Editor	Items after pilot testing	Final items after committee suggestions, used to collect data in Phase 3
5. My sex life with my partner. *If you prefer not to answer, please check this box* ☐	your sex life with your partner? *If it is not applicable, please check this box* ☐	your sex life with your partner? *If it is not applicable, please check this box* ☐	your sex life with your partner? *If it is not applicable, please check this box* ☐	your sex life with your partner? *If this is not applicable or you prefer not to answer, please check this box* ☐
6. How available family members are to care for someone who gets sick.	how available family members are to care for someone who gets sick?	how willing family members are to care for someone who gets sick?	how willing family members are to care for someone who gets sick?	how willing family members are to care for someone who gets sick?
7. The help family members give each other with household chores.	the help family members give each other with household chores?	the help family members give each other around the house?	the help family members give each other around the house?	the help family members give each other around the house?
8. The sharing of responsebility for taking care of the children or pets. *If your family does not have children or pets, please check this box* ☐	how your family shares responsibilities (e.g., taking care of children or pets)?	how your family shares responsibilities, such as taking care of children or pets or shopping for food?	how your family shares responsibilities, such as taking care of children or pets or shopping for food?	how your family shares responsibilities, such as taking care of children or pets or shopping for food?

Original items from Phase 1 sent to cancer experts in Phase 2	Items after content validity assessment in Phase 2	Items after modifications suggested by Medial Center Editor	Items after pilot testing	Final items after committee suggestions, used to collect data in Phase 3
9. Our family's financial situation.	your family's financial situation?	your family's financial situation?	your family's financial situation?	your family's financial situation?
10. The discussions and solutions to our problems with which we come up as a family.	how your family handles the problems that come up?	how your family handles the problems that come up?	how your family handles the problems that come up?	how your family handles the problems that come up?
11. How openly my family talks about important things.	how your family members talk about important issues?	how family members talk about important things that come up?	how family members talk about important things that come up?	how family members talk about important things that come up?
12. How openly family members express their feelings.	how openly family members express their feelings?	how family members show feelings such as sadness, happiness, or disappointment?	how family members show feelings such as sadness, happiness, or disappointment?	how family members show feelings such as sadness, happiness, or disappointment?
13. How positively my family talks with each other.	how optimistic your family is?	how optimistic your family is?	how optimistic your family is?	how optimistic or positive your family is?
14. How openly my family discusses the future.	how openly your family discusses the future?	how honestly your family discusses the future?	how honestly your family discusses the future?	how honestly your family discusses the future?

Original items from Phase 1 sent to cancer experts in Phase 2	Items after content validity assessment in Phase 2	Items after modifications suggested by Medial Center Editor	Items after pilot testing	Final items after committee suggestions, used to collect data in Phase 3
15. How often family members are there for each other.	how available family members are for emotional support?	how much family members encourage and support each other?	how much family members encourage and support each other?	how much family members encourage and support each other?
16. How much my family cares for each other.	*Delete this item because it is not clear and redundant.*	*Delete this item.*	*Delete this item.*	*Delete this item.*
17. How often my family checks on each others' health and other needs.	*Delete because similar to #15, and the meaning could be confusing (could refer to intrusiveness).*	*Delete this item.*	*Delete this item.*	*Delete this item.*
18. How concerned my family is for each other.	how concerned family members are for each other?	how family members show concern for each other?	how family members show concern for each other?	how family members show concern for each other?
19. How much my family encourages each other.	*Delete this item because it is similar to No. 20 and experts were concerned about the meaning of encouragement.*	*Delete this item and add the word "encourage" in item No. 15.*	*Delete this item and add the word "encourage" in item No. 15.*	*Delete this item and add the word "encourage" in item No. 15.*

Original items from Phase 1 sent to cancer experts in Phase 2	Items after content validity assessment in Phase 2	Items after modifications suggested by Medial Center Editor	Items after pilot testing	Final items after committee suggestions, used to collect data in Phase 3
20. How much my family supports each other.	Move this item to cancer specific item and modify it to be “the emotional support that family members provide to you related to the cancer.”	Move this item to cancer specific question and modify it to be "the encouragement and support that family members give you to help you live with cancer?"	Move this item to cancer specific question and modify it to be "the encouragement and support that family members give you to help you live with cancer?"	Move this item to cancer specific question and modify it to be "the encouragement and support that family members give each other to cope with the situation"
21. How family members show their love for each other.	the love and affection family members show each other?	the love and affection family members show each other?	the love and affection family members show each other?	the love and affection family members show each other?

Cancer Specific Questions

How satisfied are you with…

Original items from Phase 1 that sent to experts in Phase 2	Items as a result of content validity in Phase 2	Items as a result of discussing with a Medial Center Editor	Items as a result of the pilot test	Items from the suggestion of the committees and final items to collect data in Phase 3
1. How close my family is to each other because of my cancer.	How close my family is to each other because of your cancer?	how close your family members have become because of your cancer?, and move this item to be the last question.	how close your family members have become because of your cancer?	how close your family members have become because of the cancer?

Original items from Phase 1 that sent to experts in Phase 2	Items as a result of content validity in Phase 2	Items as a result of discussing with a Medial Center Editor	Items as a result of the pilot test	Items from the suggestion of the committees and final items to collect data in Phase 3
2. How available family members are to go with me to the doctor. *For Family Member version:* How available family members are to go with the patient to the doctor.	how available family members are to go with you to the doctor or the hospital? *For family member version*: how available family members are to go with your family member with cancer to the doctor or hospital?	how willing family members are to go with you to the doctor or the hospital? *For family member version*: how willing family members are to go the doctor or the hospital with the person who has cancer?	how willing family members are to go with you to the doctor or the hospital? *For family member version*: how willing family members are to go the doctor or the hospital with the person who has cancer?	how willing family members are to go with you to the doctor or the hospital? *For family member version*: how willing family members are to go the doctor or the hospital with the person who has cancer?
3. How the members of my family balance their own responsibilities with their need to help take care of me. *For Family Member version:* How the members of my family balance their own responsibilities with their need	how well family members balance their own responsibilities with the need to help take care of you? *For family member version*: how well family members balance their own responsibilities with the need to help take care	how well family members find the time to take care of their own responsibilities as well as to help take care of you? *For family member version*: how well family members find the time to take care of their own responsibilities as well as to	how well family members find the time to take care of their own responsibilities as well as to help take care of you? *For family member version*: how well family members find the time to take care of their own responsibilities as well as to	how well family members find the time to take care of their own responsibilities as well as to help take care of you? *For family member version*: how well family members find the time to take care of their own responsibilities as well as to

Original items from Phase 1 that sent to experts in Phase 2	Items as a result of content validity in Phase 2	Items as a result of discussing with a Medial Center Editor	Items as a result of the pilot test	Items from the suggestion of the committees and final items to collect data in Phase 3
to help take care of the patient.	of your family member with cancer?	help take care of the family member with cancer?	help take care of the family member with cancer?	help take care of the family member with cancer?
4. How well members of my family are able to change their roles to respond to my illness. *For Family Member version:* How well members of my family are able to change their roles to respond to the patient's illness.	how well family members adapt their roles in response to your illness? *For family member version:* how well family members adapt their roles in response to your family member's cancer?	how well family members are able to adjust their own activities and work in response to your illness? *For family member version:* how well family members are able to adjust their own activities and work in response to your family member's illness?	how well family members are able to adjust their own activities and work in response to your illness? *For family member version:* how well family members are able to adjust their own activities and work in response to your family member's illness?	how well family members are able to adjust their own activities and work in response to your illness? *For family member version:* how well family members are able to adjust their own activities and work in response to your family member's illness?
5. The ability of my family to adjust to my activity level because of my cancer. *For Family Member version:* The ability	how well your family adjusts to changes in your activity level and function because of your cancer? *For family member version:* how well your	how well your family adjusts to changes in your activity level and abilities because of your cancer? *For family member version:* how well your	how well your family adjusts to changes in your activity level and abilities because of your cancer? *For family member version:* how well your	how well your family adjusts to changes in your activity level and abilities because of your cancer? *For family member version:* how well your

Original items from Phase 1 that sent to experts in Phase 2	Items as a result of content validity in Phase 2	Items as a result of discussing with a Medial Center Editor	Items as a result of the pilot test	Items from the suggestion of the committees and final items to collect data in Phase 3
of my family to adjust to the patient's activity level because of his / her cancer.	family adjusts to changes in the activity level and function of your family member who has cancer?	family adjusts to changes in the activity level and abilities of your family member who has cancer?	family adjusts to changes in the activity level and abilities of your family member who has cancer?	family adjusts to changes in the activity level and abilities of your family member who has cancer?
6. How well my family members are able to balance the time demands of their own schedules and the time required to help me. *For Family Member version:* How well my family members are able to balance the time demands of their own schedules and the time required to help the patient.	*Delete this item. Because it is redundant with item No.3.*	*Delete this item.*	*Delete this item.*	*Delete this item.*

Original items from Phase 1 that sent to experts in Phase 2	Items as a result of content validity in Phase 2	Items as a result of discussing with a Medial Center Editor	Items as a result of the pilot test	Items from the suggestion of the committees and final items to collect data in Phase 3
7. The openness with which my family talks about cancer.	the openness with which your family talks about cancer? *For family member version:* the openness with which your family talks about cancer?	Combine this item and item No.8 together and modify it to be "how openly your family talks about cancer, and your treatment and its side effects?" *For family member version:* how openly your family talks about your family member's cancer, treatment and its side effects?	Combine this item and item No.8 together and modify it to be "how openly your family talks about cancer, and your treatment and its side effects?" *For family member version:* how openly your family talks about your family member's cancer, treatment and its side effects?	Combine this item and item No.8 together and modify it to be "how openly your family talks about cancer, and your treatment and its side effects?" *For family member version:* how openly your family talks about your family member's cancer, treatment and its side effects?
8. Family discussions about cancer, medical treatments, and their side effects.	your family's discussions about your medical treatment and side effects? *For family member version:* your family's discussions about your family member's cancer treatment and side effects?	Combine this item with item No. 7.	Combine this item with item No. 7.	Combine this item with item No. 7.

Original items from Phase 1 that sent to experts in Phase 2	Items as a result of content validity in Phase 2	Items as a result of discussing with a Medial Center Editor	Items as a result of the pilot test	Items from the suggestion of the committees and final items to collect data in Phase 3
9. The openness with which family members express their feelings about my situation. *For Family Member version:* The openness with which family members express their feelings about the patient's situation.	how family members express their feelings about your situation? *For family member version:* how family members express their feelings about your family member's cancer?	how family members share their feelings about your situation? *For family member version:* how family members share their feelings about your family member's cancer?	how family members share their feelings about your situation? *For family member version:* how family members share their feelings about your family member's cancer?	how family members share their feelings about your situation with cancer? *For family member version:* how family members share their feelings about your family member's cancer?
10. The frequency with which family members ask me how I am doing.	how often family members ask you how you're doing? *For family member version:* how often family members ask you how you're doing?	how often family members ask you how you're doing? *For family member version:* how often family members ask you how you're doing?	how often family members ask you how you're doing? *For family member version:* how often family members ask you how you're doing?	how often family members ask you how you are doing? *For family member version:* how often family members ask you how you are doing?

Original items from Phase 1 that sent to experts in Phase 2	Items as a result of content validity in Phase 2	Items as a result of discussing with a Medial Center Editor	Items as a result of the pilot test	Items from the suggestion of the committees and final items to collect data in Phase 3
11. The amount of time that my family spends with me.	the time that your family spends with you?	the time that your family spends with you? *Move to General Question*	the time that your family spends with you? *Move to General Question*	the time that your family spends with you? *Move to General Question*

Overall Subdomains

How satisfied are you with…

Original items from Phase 1 that sent to experts in Phase 2	Items as a result of content validity in Phase 2	Items as a result of discussing with a Medial Center Editor	Items as a result of the pilot test	Items from the suggestion of the committees and final items to collect data in Phase 3
1. Interactions in your family.	the interactions in your family and the relationships among members of your family?	the interactions in your family (how family members relate to each other)?	the interactions in your family (how family members relate to each other)?	the interactions among your family (how family members relate to each other)?
2. Distribution of responsibilities in your family.	the sharing of responsibilities in your family?	the sharing of responsibilities in your family?	the sharing of responsibilities in your family?	the sharing of responsibilities in your family?
3. Communication among members of your family.	communication among members of your family?	communication among members of your family?	communication among members of your family?	communication among members of your family?
4. The emotional support that people in your family give each other.	the emotional support that people in your family give each other?	the emotional support that people in your family give each other?	the emotional support that people in your family give each other?	the emotional support that people in your family give each other?

Overall Family Quality of Life

Original items from Phase 1 that sent to experts in Phase 2	Items as a result of content validity in Phase 2	Items as a result of discussing with a Medial Center Editor	Items as a result of the pilot test	Items from the suggestion of the committees and final items to collect data in Phase 3
Overall, how satisfied are you with your family life?	Overall, how satisfied are you with your family life? *Note*: Separate this item from other dimensions.	Overall, how satisfied are you with your family life?	Overall, how satisfied are you with your family life?	Overall, how satisfied are you with your family life?

Appendix E

The Family Quality of Life Questionnaire---Patient Version

The Family Quality of Life Questionnaire---Patient Version

Please think about your life with your family **over the past month**, then rate how satisfied you are for each of the areas described below. When making these ratings, please rate your satisfaction rather than the amount of the activity. For instance, in item #2 (*… the contact that family members have with each other in person, or on the phone, etc.?),* if family members only have A Little contact with each other, but you are Very Much satisfied with this contact, then you would pick "Very Much" for this item.

(Please Circle One Number on Each Line)

How satisfied are you with…	**How satisfied are you with your family life in this area?**				
	Not at All	**A Little**	**Some-what**	**Quite a Bit**	**Very Much**
1. how willing family members are to help when someone in the family needs extra help?	1	2	3	4	5
2. the contact that family members have with each other in person, or on the phone, etc.?	1	2	3	4	5
3. the help that family members give each other in their lives?	1	2	3	4	5
4. how often family members do things together either at home or going out?	1	2	3	4	5
5. your sex life with your partner? *If this is not applicable or you prefer not to answer, please check this box* ☐	1	2	3	4	5
6. how willing family members are to care for someone who gets sick?	1	2	3	4	5
7. the help family members give each other around the house?	1	2	3	4	5
8. how your family shares responsibilities, such as taking care of children or pets, or shopping for food?	1	2	3	4	5

(Please Circle One Number on Each Line)

How satisfied are you with…	**How satisfied are you with your family life in this area?**				
	Not at All	**A Little**	**Some-what**	**Quite a Bit**	**Very Much**
9. your family's financial situation?	1	2	3	4	5
10. how your family handles the problems that come up?	1	2	3	4	5
11. how honestly your family discusses the future?	1	2	3	4	5
12. how family members show feelings such as sadness, happiness, or disappointment?	1	2	3	4	5
13. how optimistic or positive your family is?	1	2	3	4	5
14. the love and affection family members show each other?	1	2	3	4	5
15. how much family members encourage and support each other?	1	2	3	4	5
16. how family members show concern for each other?	1	2	3	4	5
17. how family members talk about important things that come up?	1	2	3	4	5
18. the time that your family spends with you?	1	2	3	4	5

Again, please think about your life with your family **over the past month**, then rate how satisfied you are for each of the areas described below. When making these ratings, please think about how **the cancer** has affected **your life** in the family. Also, as with the previous questions, please rate your satisfaction rather than the amount of the activity.

(Please Circle One Number on Each Line)

How satisfied are you with…	**How satisfied are you with your family life in this area?**				
	Not at All	**A Little**	**Some-what**	**Quite a Bit**	**Very Much**
1. how willing family members are to go with you to the doctor or the hospital?	1	2	3	4	5
2. how well family members find the time to take care of their own responsibilities as well as to help take care of you?	1	2	3	4	5
3. how well family members are able to adjust their own activities and work in response to your illness?	1	2	3	4	5
4. how well your family adjusts to changes in your activity level and abilities because of your cancer?	1	2	3	4	5
5. how openly your family talks about cancer, and your treatment and its side effects?	1	2	3	4	5
6. how family members share their feelings about your situation with cancer?	1	2	3	4	5
7. how often family members ask you how you are doing?	1	2	3	4	5
8. The encouragement and support that family members give you to help you cope with cancer?	1	2	3	4	5
9. how close your family members have become because of your cancer?	1	2	3	4	5

Again, thinking about your life with your family **over the past month**, please rate your level of satisfaction with each of these areas:

(Please Circle One Number on Each Line)

How satisfied are you with…	**How satisfied are you with your family life in this area?**				
	Not at All	**A Little**	**Some-what**	**Quite a Bit**	**Very Much**
1. the interactions among family members (how family members relate to each other)?	1	2	3	4	5
2. the sharing of responsibilities in your family?	1	2	3	4	5
3. communication among members of your family?	1	2	3	4	5
4. the emotional support that people in your family give each other?	1	2	3	4	5

Finally, thinking about your life with your family **over the past month**, please rate your level of satisfaction in your family life in overall:

(Please Circle One Number on Each Line)

Item	**Not at All**	**A Little**	**Some-what**	**Quite a Bit**	**Very Much**
Overall, how satisfied are you with your family life?	1	2	3	4	5

Appendix F

The Family Quality of Life Questionnaire---Family Member Version

The Family Quality of Life Questionnaire---Family Member Version

Please think about your life with your family **over the past month**, then rate how satisfied you are for each of the areas described below. When making these ratings, please rate your satisfaction rather than the amount of the activity. For instance, in item #2 (*… the contact that family members have with each other in person, or on the phone, etc.?),* if family members only have A Little contact with each other, but you are Very Much satisfied with this contact, then you would pick "Very Much" for this item.

(Please Circle One Number on Each Line)

How satisfied are you with…	**How satisfied are you with your family life in this area?**				
	Not at All	**A Little**	**Some-what**	**Quite a Bit**	**Very Much**
1. how willing family members are to help when someone in the family needs extra help?	1	2	3	4	5
2. the contact that family members have with each other in person, or on the phone, etc.?	1	2	3	4	5
3. the help that family members give each other in their lives?	1	2	3	4	5
4. how often family members do things together either at home or going out?	1	2	3	4	5
5. your sex life with your partner? *If this is not applicable or you prefer not to answer, please check this box* ☐	1	2	3	4	5
6. how willing family members are to care for someone who gets sick?	1	2	3	4	5
7. the help family members give each other around the house?	1	2	3	4	5
8. how your family shares responsibilities, such as taking care of children or pets, or shopping for food?	1	2	3	4	5

(Please Circle One Number on Each Line)

How satisfied are you with…	**How satisfied are you with your family life in this area?**				
	Not at All	**A Little**	**Some-what**	**Quite a Bit**	**Very Much**
9. your family's financial situation?	1	2	3	4	5
10. how your family handles the problems that come up?	1	2	3	4	5
11. how honestly your family discusses the future?	1	2	3	4	5
12. how family members show feelings such as sadness, happiness, or disappointment?	1	2	3	4	5
13. how optimistic or positive your family is?	1	2	3	4	5
14. the love and affection family members show each other?	1	2	3	4	5
15. how much family members encourage and support each other?	1	2	3	4	5
16. how family members show concern for each other?	1	2	3	4	5
17. how family members talk about important things that come up?	1	2	3	4	5
18. the time that your family spends with you?	1	2	3	4	5

Again, please think about your life with your family **over the past month**, then rate how satisfied you are with each of the areas described below. When making these ratings, please think about how **the cancer** has affected **your life** in the family, how the strain that the cancer may have caused for you has affected your satisfaction with your family life. For instance, in item #1 *(… how willing family members are to go the doctor or the hospital with the person who has cancer?)* think about how satisfied you are with how willing other family members are to go with the patient to the doctor.

(Please Circle One Number on Each Line)

How satisfied are you with…	**How satisfied are you with your family life in this area?**				
	Not at All	**A Little**	**Some-what**	**Quite a Bit**	**Very Much**
1. how willing family members are to go the doctor or the hospital with the person who has cancer?	1	2	3	4	5
2. how well family members find the time to take care of their own responsibilities as well as to help take care of the family member with cancer?	1	2	3	4	5
3. how well family members are able to adjust their own activities and work in response to your family member's illness?	1	2	3	4	5
4. how well your family adjusts to changes in the activity level and abilities of your family member who has cancer?	1	2	3	4	5
5. how openly your family talks about your family member's cancer, treatment and its side effects?	1	2	3	4	5
6. how family members share their feelings about your family member's cancer?	1	2	3	4	5
7. how often family members ask you how you are doing?	1	2	3	4	5
8. The encouragement and support that family members give each other to cope with the situation?	1	2	3	4	5

(Please Circle One Number on Each Line)

How satisfied are you with…	**How satisfied are you with your family life in this area?**				
	Not at All	**A Little**	**Some-what**	**Quite a Bit**	**Very Much**
9. how close your family members have become because of the cancer?	1	2	3	4	5

Again, thinking about your life with your family **over the past month**, please rate your level of satisfaction with each of these areas:

(Please Circle One Number on Each Line)

How satisfied are you with…	**How satisfied are you with your family life in this area?**				
	Not at All	**A Little**	**Some-what**	**Quite a Bit**	**Very Much**
1. the interactions among family members (how family members relate to each other)?	1	2	3	4	5
2. the sharing of responsibilities in your family?	1	2	3	4	5
3. communication among members of your family?	1	2	3	4	5
4. the emotional support that people in your family give each other?	1	2	3	4	5

Finally, thinking about your life with your family **over the past month**, please rate your level of satisfaction in your family life in overall:

(Please Circle One Number on Each Line)

Item	**Not at All**	**A Little**	**Some-what**	**Quite a Bit**	**Very Much**
Overall, how satisfied are you with your family life?	1	2	3	4	5

Appendix G

The SF-36$^{®}$ Health Survey

The SF-36® Health Survey

The questions below ask about your health and how it affects your life. Please read all of the questions and circle the answer that best describes your health or your situation.

(Please Circle One Number on Each Line)

Item	**Excellent**	**Very good**	**Good**	**Fair**	**Poor**
1. In general, would you say your health is:	1	2	3	4	5

(Please Circle One Number on Each Line)

Item	**Much better**	**Somewhat better**	**About the same**	**Somewhat worse**	**Much worse**
2. Compared to **one year ago**, how would you rate your health in general **now**?	1	2	3	4	5

The following items are about activities you might do during a typical day. Does **your health now limit you** in these activities? If so, how much?

(Please Circle One Number on Each Line)

Activities	**Yes, Limited a Lot**	**Yes, Limited a Little**	**No, Not Limited at All**
3. **Vigorous activities**, such as running, lifting heavy objects, participating in strenuous sports	1	2	3
4. **Moderate activities**, such as moving a table, pushing a vacuum cleaner, bowling, or playing golf	1	2	3
5. Lifting or carrying groceries	1	2	3
6. Climbing **several** flights of stairs	1	2	3
7. Climbing **one** flight of stairs	1	2	3
8. Bending, kneeling, or stooping	1	2	3
9. Walking **more than a mile**	1	2	3
10. Walking **several blocks**	1	2	3

Activities	Yes, Limited a Lot	Yes, Limited a Little	No, Not Limited at All
11. Walking **one block**	1	2	3
12. Bathing or dressing yourself	1	2	3

During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of your physical health**?

(Please Circle One Number on Each Line)

Items	Yes	No
13. Cut down the **amount of time** you spent on work or other activities	1	2
14. **Accomplished less** than you would like	1	2
15. Were limited in the **kind** of work or other activities	1	2
16. Had **difficulty** performing the work or other activities (for example, it took extra effort)	1	2

During the **past 4 weeks**, have you had any of the following problems with your work or other regular daily activities **as a result of any emotional problems** (such as feeling depressed or anxious)?

(Please Circle One Number on Each Line)

Items	Yes	No
17. Cut down the **amount of time** you spent on work or other activities	1	2
18. **Accomplished less** than you would like	1	2
19. Didn’t do work or other activities as **carefully** as usual	1	2

(Please Circle One Number on Each Line)

Item	Not at all	Slightly	Moderately	Quite a bit	Extremely
20. During the **past 4 weeks**, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors, or groups?	1	2	3	4	5

Item	None	Very mild	Mild	Moderate	Severe	Very severe
21. How much **bodily** pain have you had during the **past 4 weeks**?	1	2	3	4	5	6

Item	Not at all	Slightly	Moderately	Quite a bit	Extremely
22. During the **past 4 weeks**, how much did **pain** interfere with your normal work (including both outside the home and housework)?	1	2	3	4	5

The following questions are about how you feel and how things have been with you during the **past 4 weeks**. For each question, please give the one answer that comes closest to the way you have been feeling.

(Please Circle One Number on Each Line)

How much of the time during the past 4 weeks:	All of the Time	Most of the Time	A Good Bit of the Time	Some of the Time	A Little of the Time	None of the Time
23. Did you feel full of pep?	1	2	3	4	5	6

How much of the time during the past 4 weeks:	**All of the Time**	**Most of the Time**	**A Good Bit of the Time**	**Some of the Time**	**A Little of the Time**	**None of the Time**
24. Have you been a very nervous person?	1	2	3	4	5	6
25. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
26. Have you felt calm and peaceful?	1	2	3	4	5	6
27. Did you have a lot of energy?	1	2	3	4	5	6
28. Have you felt downhearted and blue?	1	2	3	4	5	6
29. Did you feel worn out?	1	2	3	4	5	6
30. Have you been a happy person?	1	2	3	4	5	6
31. Did you feel tired?	1	2	3	4	5	6

(Please Circle One Number on Each Line)

Item	**All of the time**	**Most of the time**	**Some of the time**	**A Little of the time**	**None of the time**
32. During the **past 4 weeks**, how much of the time has your **physical health or emotional problems** interfered with your social activities (like visiting with friends, relatives, etc.)?	1	2	3	4	5

How TRUE or FALSE is **each** of the following statements for you?

(Please Circle One Number on Each Line)

Items	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
33. I seem to get sick a little easier than other people.	1	2	3	4	5
34. I am as healthy as anybody I know.	1	2	3	4	5
35. I expect my health to get worse.	1	2	3	4	5
36. My health is excellent.	1	2	3	4	5

Appendix H

The Functional Assessment of Cancer Therapy - General version (FACT-G)

The Functional Assessment of Cancer Therapy - General version (FACT-G)

Below is a list of statement that other people with your illness have said are important. By circle one number per line, please indicate how true each statement has been for you **<u>during the past 7 days</u>**.

	PHYSICAL WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GP1	I have a lack of energy.	0	1	2	3	4
GP2	I have nausea.	0	1	2	3	4
GP3	Because of my physical condition, I have trouble meeting the needs of my family.	0	1	2	3	4
GP4	I have pain.	0	1	2	3	4
GP5	I am bothered by side effects of treatment.	0	1	2	3	4
GP6	I feel ill.	0	1	2	3	4
GP7	I am forced to spent time in bed.	0	1	2	3	4

By circle one number per line, please indicate how true each statement has been for you **<u>during the past 7 days</u>**.

	SOCIAL/FAMILY WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
GS1	I feel close to my friends.	0	1	2	3	4
GS2	I get emotional support from my family.	0	1	2	3	4
GS3	I get support from my friends.	0	1	2	3	4
GS4	My family has accepted my illness.	0	1	2	3	4
GS5	I am satisfied with family communication about my illness.	0	1	2	3	4
GS6	I feel close to my partner (or the person who is my main support).	0	1	2	3	4
Q1	*Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please check this box ☐ and go to the next section.*					

SOCIAL/FAMILY WELL-BEING		Not at all	A little bit	Some-what	Quite a bit	Very much
GS7	I am satisfied with my sex life.	0	1	2	3	4

By circle one number per line, please indicate how true each statement has been for you **during the past 7 days**.

EMOTIONAL WELL-BEING		Not at all	A little bit	Some-what	Quite a bit	Very much
GE1	I feel sad.	0	1	2	3	4
GE2	I am satisfied with how I am coping with my illness.	0	1	2	3	4
GE3	I am losing hope in the fight against my illness.	0	1	2	3	4
GE4	I feel nervous.	0	1	2	3	4
GE5	I worry about dying.	0	1	2	3	4
GE6	I worry that my condition will get worse.	0	1	2	3	4

By circle one number per line, please indicate how true each statement has been for you **during the past 7 days**.

FUNCTIONAL WELL-BEING		Not at all	A little bit	Some-what	Quite a Bit	Very much
GF1	I am able to work (include work at home).	0	1	2	3	4
GF2	My work (include work at home) is fulfilling.	0	1	2	3	4
GF3	I am able to enjoy life.	0	1	2	3	4
GF4	I have accepted my illness.	0	1	2	3	4
GF5	I am sleeping well.	0	1	2	3	4
GF6	I am enjoying the things I usually do for fun.	0	1	2	3	4
GF7	I am content with the quality of my life right now.	0	1	2	3	4

Appendix I

The Functional Assessment of Cancer Therapy - General version (FACT-G)

(Family Caregiver Version)

The Functional Assessment of Cancer Therapy - General version (FACT-G)
(Family Caregiver Version)

Below is a list of statement that other people with your illness have said are important. By circle one number per line, please indicate how true each statement has been for you **during the past 7 days**.

PHYSICAL WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
P1. I have a lack of energy.	0	1	2	3	4
P2. I have nausea.	0	1	2	3	4
P3. Because of my physical condition, I have trouble meeting the needs of my family.	0	1	2	3	4
P4. I have pain.	0	1	2	3	4
P5. Are you currently taking any medication or receiving other medical treatments? ☐ No. ☐ Yes. If yes, I am bothered by side effects of my treatment.	0	1	2	3	4
P6. I feel ill.	0	1	2	3	4
P7. I am forced to spent time in bed.	0	1	2	3	4

By circle one number per line, please indicate how true each statement has been for you **during the past 7 days**.

SOCIAL/FAMILY WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
S1. I feel close to my friends.	0	1	2	3	4
S2. I get emotional support from my family.	0	1	2	3	4
S3. I get support from my friends.	0	1	2	3	4
S4. My family has accepted the illness.	0	1	2	3	4
S5. I am satisfied with family communication about the illness.	0	1	2	3	4

SOCIAL/FAMILY WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
S6. I feel close to my partner (or the person who is my main support).	0	1	2	3	4
Q. *Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please check this box* ☐ *and go to the next section.*					
S7. I am satisfied with my sex life.	0	1	2	3	4

By circle one number per line, please indicate how true each statement has been for you **during the past 7 days**.

EMOTIONAL WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
E1. I feel sad.	0	1	2	3	4
E2. I am satisfied with how I am coping with my family member's illness.	0	1	2	3	4
E3. I am losing hope in the fight against my family member's illness.	0	1	2	3	4
E4. I feel nervous.	0	1	2	3	4
E5. I worry about my family member dying.	0	1	2	3	4
E6. I worry that my family member's condition will get worse.	0	1	2	3	4

By circle one number per line, please indicate how true each statement has been for you **<u>during the past 7 days</u>**.

FUNCTIONAL WELL-BEING	**Not at all**	**A little bit**	**Some-what**	**Quite a bit**	**Very much**
F1. I am able to work (include work at home).	0	1	2	3	4
F2. My work (include work at home) is fulfilling.	0	1	2	3	4
F3. I am able to enjoy life.	0	1	2	3	4
F4. I have accepted my family member's illness.	0	1	2	3	4
F5. I am sleeping well.	0	1	2	3	4
F6. I am enjoying the things I usually do for fun.	0	1	2	3	4
F7. I am content with the quality of my life right now.	0	1	2	3	4

Appendix J

The Family Interaction and Emotional Well-Being Subscales of the Beach Center Family Quality of Life Scale

The Family Interaction and Emotional Well-Being Subscales of the Beach Center Family Quality of Life Scale

Please think about your family life **over the past month** and circle the number that best describes your satisfaction of family interaction and emotional well-being.

How satisfied am I that…	**Very Dissatisfied**	**Dissatisfied**	**Neither**	**Satisfied**	**Very Satisfied**
1. My family enjoys spending time together.	1	2	3	4	5
2. My family has the support we need to relieve stress.	1	2	3	4	5
3. My family members have friends or others who provide support.	1	2	3	4	5
4. My family members talk openly with each other.	1	2	3	4	5
5. My family members have some time to pursue our own interests.	1	2	3	4	5
6. Our family solves problems together.	1	2	3	4	5
7. My family members support each other to accomplish goals.	1	2	3	4	5
8. My family members show that they love and care for each other.	1	2	3	4	5
9. My family has outside help available to us to take care of special needs of all family members.	1	2	3	4	5
10. My family is able to handle life's ups and downs.	1	2	3	4	5

Appendix K

The Balanced Cohesion Subscale of the Flexibility and Cohesion Evaluation Scales (FACES IV)

The Balanced Cohesion Subscale
of the Flexibility and Cohesion Evaluation Scales (FACES IV)

Please read all questions and circle the number that best describes your family.

DOES NOT describe our family at all…………………… 1
SLIGHTLY describes our family at all…………………... 2
SOMEWHAT describes our family at all……………….….. 3
GENERALLY describes our family at all……………….. 4
VERY WELL describes our family at all………………… 5

Items	Does Not Describe	Slightly Describes	Somewhat Describes	Generally Describes	Very Well Describes
1. Family members are involved in each others lives.	1	2	3	4	5
2. Family members feel very close to each other.	1	2	3	4	5
3. Family members are supportive of each other during difficult times.	1	2	3	4	5
4. Family members consult other family members on personal decisions.	1	2	3	4	5
5. Family members like to spend some of their free time with each other.	1	2	3	4	5
6. Although family members have individual interests, they still participate in family activities.	1	2	3	4	5
7. This family has a good balance of separateness and closeness.	1	2	3	4	5

Appendix L

The Family Communication Scale

The Family Communication Scale

Please read all questions and circle the number that best describe your family communication.

DOES NOT describe our family at all…………………… 1

SLIGHTLY describes our family at all…………………... 2

SOMEWHAT describes our family at all……………..….. 3

GENERALLY describes our family at all……………….. 4

VERY WELL describes our family at all………………… 5

Items	**Does Not Describe**	**Slightly Describe**	**Somewhat Describe**	**Generally Describe**	**Very Well Describe**
1. Family members are satisfied with how they communicate with each other.	1	2	3	4	5
2. Family members are very good listeners.	1	2	3	4	5
3. Family members express affection to each other.	1	2	3	4	5
4. Family members are able to ask each other for what they want.	1	2	3	4	5
5. Family members can calmly discuss problems with each other.	1	2	3	4	5
6. Family members discuss their ideas and beliefs with each other.	1	2	3	4	5
7. When family members ask questions of each other, they get honest answers.	1	2	3	4	5
8. Family members try to understand each other's feelings.	1	2	3	4	5

Items	Does Not Describe	Slightly Describe	Somewhat Describe	Generally Describe	Very Well Describe
9. When angry, family members seldom say negative things about each other.	1	2	3	4	5
10. Family members express their true feelings to each other.	1	2	3	4	5

Appendix M

The Family Satisfaction Scale (FSS)

The Family Satisfaction Scale (FSS)

Please read all questions and circle the number that best describe your family satisfaction.

How satisfied you are with these aspects of your family relationship?	**Very Dissatisfied**	**Somewhat Dissatisfied**	**Generally Satisfied**	**Very Satisfied**	**Extremely Satisfied**
1. The degree of closeness between family members.	1	2	3	4	5
2. Your family's ability to cope with stress.	1	2	3	4	5
3. Your family's ability to be flexible.	1	2	3	4	5
4. Your family's ability to share positive experiences.	1	2	3	4	5
5. The quality of communication between family members.	1	2	3	4	5
6. Your family's ability to resolve conflicts.	1	2	3	4	5
7. The amount of time you spend together as a family.	1	2	3	4	5
8. The way problems are discussed.	1	2	3	4	5
9. The fairness of criticism in your family.	1	2	3	4	5
10. Family members concerns for each other.	1	2	3	4	5

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