From Department of Neurobiology, Care Sciences and
Society
Karolinska Institutet, Stockholm, Sweden

QUALITY OF LIFE IN FAMILY CAREGIVERS TO PERSONS WITH BREAST CANCER IN IRAN- METHODOLOGICAL AND CLINICAL ASPECTS

Sedigheh Khanjari

Stockholm 2012

ABSTRACT

Background: In Iran, cancer is the third cause of death and breast cancer is the most common cancer among women. Nursing care should focus on the entire family (and not only the patient) as one unit of care. The overall aim of this thesis was to investigate quality of life (QoL) and coping capacity of caregivers of family members with breast cancer in Iran.

Method: This thesis is based on four studies, two methodological studies and two longitudinal studies that included six standardized instruments. Study I & II focused on translation into the Persian language and tested the psychometric properties of the Health Index (HI), Sense of Coherence (SOC) scale, Brief Religious Coping (RCOPE) scale, Spirituality Perspective Scale (SPS) in a healthy sample (n=333) and Caregiver Quality of Life Index-Cancer (CQOLC) scale in a sample of family caregivers (n=150). In Study III the five questionnaires (CQOLC, SOC, SPS, RCOPE, and HI) were assessed in the sample of family caregivers at the time of diagnosis (T1) and 6 months later (T2). In study IV consequences that were due to the breast cancer experience were investigated through semi-structured interviews at T1 and T2 using the Swedish version of the Schedule for the Evaluation of Individual Quality of Life-Direct Weighting.

Results: The reliability of the instruments as measured by Cronbach's alpha values and intra-class correlations was highly satisfying. In addition, the majority of the hypotheses posed for validity were confirmed. A confirmatory factor analysis of the CQOLC showed a similar four-factor structure to that of the original CQOLC instrument, although with somewhat different item loadings. Hierarchical multiple regression analysis confirmed validity in that SOC was the strongest predictor of well-being and QoL in both samples. Other predictors contributing to the variance were negative religious coping, education, and severity of breast cancer. Family caregivers rated statistically significantly lesser mental burden and lifestyle disruptiveness between T1 and T2. During the same period, positive adaptation, sense of coherence, spirituality, coping were rated statistically significantly worse. None of these changes was of clinical relevance as estimated by effect size except negative religious coping. Over 50% of the family caregivers had a stable overall QoL, 15% decreased in QoL, and 34% increased their overall QoL. The multiple regression analyses of the ratings of QoL at T1 showed that negative religious coping, SOC, and severity of breast cancer explain 64% of the variance of change in overall QoL. The most frequent categories important for the QoL of family caregivers both at T1 and T2 were health in general, relationships, financial status, education, and religion. Psychological impact of disease, concerns about disease, religion, and financial situation were the most frequent categories nominated as influencing life in relation to having a family member with breast cancer. Further, positive aspects in the form of a new view of life and positive effects of relationships were mentioned.

Conclusion: Being a caregiver to a family member with breast cancer affected the life of the caregiver at both T1 and T2. Our findings indicate that some family caregivers have more difficulties than other family caregivers with adjusting to the situation, which may lead to lower QoL. Standardized instruments sometimes fail to capture all areas of importance in the life of caregivers to family members with breast cancer. This thesis calls attention to the need for nursing care to assist and support family caregivers of family members with breast cancer. This support should occur early in the disease process.

Key words: quality of life, family caregivers, breast cancer, sense of coherence, spirituality, religious coping

To my family

LIST OF PUBLICATIONS

This doctoral thesis is based on the following papers, referred to in the text by their roman numerals:

I. Rohani, C., Khanjari, S., Abedi, H-A., Oskouie, F., & Langius-Eklöf, A. (2010). Health index, sense of coherence scale, brief religious coping scale and spiritual perspective scale: psychometric properties. *Journal of Advanced Nursing*, *66*(12), 2796-2806.

II. Khanjari, S., Oskouie, F., Langius-Eklöf A. (2011). Psychometric testing of the Caregiver Quality of Life Index-Cancer scale in an Iranian sample of family caregivers to newly diagnosed breast cancer women. *Journal of Clinical Nursing*, *21*(3-4), 573-584.

III. Khanjari S., Oskouie F., & Langius-Eklöf A. (2011). Lower sense of coherence, negative religious coping and disease severity as indicators of a decrease in quality of life in Iranian family caregivers of relatives with breast cancer during the first six months after diagnosis. *Cancer Nursing*, DOI: 10.1097/NCC.0b013e31821f1dda

IV. Khanjari, S., Oskouie, F., Sundberg, K., & Langius-Eklöf, A. Family caregivers of persons with breast cancer and their perception on quality of life and how it is affected by the disease: a prospective study in Iran. (Manuscript)

CONTENTS

LIST OF ABBREVIATIONS

QoL	Quality of life
HI	Health Index
SOC	Sense of Coherence
RCOPE	Religious Coping
SPS	Spiritual Perspective Scale
CQOLC	Caregiver Quality of Life Index-Cancer
CQOLC-P	Caregiver Quality of Life Index Cancer- Persian version
CFA	Confirmatory Factor Analysis
SPSS	Statistical Package for Social Science
LISREL	Liner structural relationships analysis
SEIQoL-DW	The Schedule for the Evaluation of Individual Quality of Life - Directed Weighted
GFI	Goodness-of-fit index
NNFI	Non-normed fit indices
SRMR	Standardized root mean square residual
RMSEA	Square error of approximation
ML	Maximum likelihood

1   INTRODUCTION

Cancer is the most important cause of death in developed countries and the second most important cause of death in developing countries (GLOBOCAN, 2008). Approximately 12.7 million cancer cases and 7.6 million cancer deaths are estimated to have occurred in 2008: of these, 56% of the cases and 64% of the deaths occurred in the developing world (GLOBOCAN, 2008). Breast cancer is the most frequently diagnosed cancer and the leading cause of cancer death among females (GLOBOCAN, 2008).

The most prevalent malignancy in women is breast cancer (Parkin et al., 2005). Cancer is the third cause of death in Iran and breast cancer is the most common cancer in Iranian women (Mousavi et al., 2009). The mortality rate of breast cancer in women in Iran is 24 per 100 000 (Mousavi et al., 2009). Over 30 000 deaths occur annually in Iran because of cancer with an incidence of above 70 000 new cases (Asadi-Lari et al., 2008). The most common primary female cancer is breast cancer in Iran (Goya, 2007). Although the incidence of breast cancer is still low compared with Western countries (23.65 per 100 000 Caucasian women in Iran vs. 140.8 per 100 000 Caucasian women in the USA), the number of patients with newly diagnosed breast cancer increase (Harirchi et al., 2011).

The growing number of persons living with chronic diseases, earlier hospital discharges, and greater dependence on outpatient care has increased demands away from professional caregivers toward family caregivers (van den Bos, 1995). In the care of a patient with cancer it is therefore vital to involve and provide care for the family caregiver as well (Wagner et al., 2011, Zahlis & Lewis, 2010). Overall, little is known about how family caregivers of patients with breast cancer perceive their situation.

2 BACKGROUND

2.1 FAMILY NURSING

Family nursing has witnessed a growth due to in increased attention on health promotion, increased prevalence of chronic illness, and increased awareness of concerned family (Friedman et al., 2003). Family nursing focuses on the family as a unit of care, addressing the needs of a family in response to a member's illness or threat to health, also focusing on the individual (St John, & Flowers, 2009). The definition of family nursing contains delivery of care to families and family members in health and illness situations (Friedman et al., 2003).

There are a variety of tools and approaches used in family nursing and family assessment. One such tool is the Calgary Family Assessment Model which contains three main areas of assessment: family structures, stage of family development (stages, tasks, and attachments), and functional status, which includes instrumental (activities of daily living) and expressive components (communication, beliefs, problem solving, roles, alliances, power, and coalitions) (Wright, & Leahey, 2005). The use of a family system nursing approach was found to increase family-nurse relationships (Legrow & Rossen, 2005). Nurses consider families as a resource and as a part of their work of great importance (Benzein et al., 2008).

2.2 FAMILY CAREGIVER

National Family Caregivers Association (2011) declares family caregivers could be spouses, partners, adult children, relatives, or friends. The participation of the family caregiver in the health care team might have an important role in improving the patient's health and QoL. Family caregivers provide unexpected care that is physically, emotionally, socially, and financially demanding and might result in the neglect of their own needs (Schubart et al., 2007).

In the past, family caregivers have often been left out by inflexible visiting hours, not understanding the clinical language, and with a sense that their efforts were not appropriate to the caregiving task (Blum, & Sherman, 2010). Historically, the majority of family caregivers have been female family members who did not work outside the home. Nowadays, women have both a job and a caregiving responsibility (Talley, & Crews, 2007). Additionally, many working women are caring for their children and their parents simultaneously, and this and other variations of care may put increasing pressure on the home care system and the women in the homes (Talley, & Crews, 2007). On the other hand, advances in health care have been extended and the number of people with chronic disease has decreased.

Family caregivers of patients with cancer may experience a host of problems, such as depression, anxiety, anger, fear, lack of sleep, severe fatigue, physical problems, and financial problems (Siegel et al., 1991, Harrington et al., 1996, Kilpatrick 1998, Inconomou et al., 2001, Perz et al., 2011). They may also experience primary stressors that stem from the patients' daily needs (e.g., bathing, dressing, feeding, taking medication, and managing finances) and secondary stressors (giving emotional support, transportation to clinics, and concern regarding monitoring symptoms in the patients) (Wagner et al., 2011, Bigatti et al., 2011). Family caregiving may also lead to feelings of anger and resentment, especially when they sense that the loved one is giving up

despite the caregivers' efforts (Blum, & Sherman, 2010). For a patient and their family members, cancer can be related to fear of death, recurrence, uncertainty, disruptions in lifestyle, distress, and mood disturbances (Iconomou et al., 2001, Kim et al., 2011).

Experience of distress in family caregivers from the burdens of providing care may have a negative effect on their ability to care for the patients (Weitzner et al., 1999). In addition, family caregivers may not receive enough support from other family members and friends (Kilpatrick, 1998). Family caregivers with many responsibilities need and ought to have support from the nation's public health system to maintain their own health. However, evidence shows that health care providers often ignore this need (Northouse, 1998). The unmet psychological needs of family caregivers' of patients with cancer have been found to be related to poor mental health and QoL (Kim, & Spillers, 2010).

2.3 FAMILY CAREGIVING AND BREAST CANCER

The attention to family caregiving has increased in the world and studies have been published from different countries, for example Korea (Rhee et al., 2005), Turkey (Aslan et al., 2009), Sweden (Broberger et al., 2005), Lebanon (Doumit et al., 2008), Taiwan (Chen et al., 2009, Tang 2006). Studies in different cancer types have also increased for example breast cancer (Northouse et al., 2001, Zahlis, & Lewis, 2010), lung cancer (Bakas et al., 2001), ovarian cancer (Ferrell et al., 2002) and brain cancer (Sherwood et al., 2006) (Fletcher et al., 2011).

Family caregiving normally involves a significant expenditure of time, energy, and money over potentially long periods and engages tasks that may be unpleasant and uncomfortable, as well as psychologically stressful and physically exhausting (Schulz, & Martire, 2004). The influence of family caregiving has been suggested to be typically measured in terms of psychological distress, burden, psychiatric and biological morbidity, and economic impacts (e.g., reduced work hours or leaving a job to provide care) (Grunfeld et al., 2004, Nijboer et al., 2001).

The growing number of persons living with chronic diseases, earlier hospital discharges, and greater dependence on outpatient care has prompted demands away from professional caregivers toward family caregivers (van den Bos, 1995). Furthermore, increased life expectancy and age in the population, changes in health care repayment, and advances in medical technology have meant that family caregiving is becoming increasingly important (Schulz, & Martire, 2004). Improvements in early detection together with advanced and individualized treatments have resulted in the fact that more women with breast cancer are living longer (Shulman et al., 2010).

To be a family caregiver may lead to physical stress and a greater risk of mortality (Blum, & Sherman, 2010). Therefore, in the care of a patient with breast cancer it is vital to involve and provide care and support for the family caregiver as well (Wagner et al., 2011).

Additionally, negative aspects may not always follow caregiving experiences. Thus, caregiving may also be perceived as a positive feature in family caregivers of cancer patients (e.g., enhanced self-esteem and self-efficacy, and achievement of a greater purpose and meaning in life and forgiving, empathy, appreciation, and positive self-view (Hunt 2003, Nijboer et al., 1999, Blum, & Sherman, 2010). In addition, family

caregivers of persons with breast cancer have reported an increasing bond, love, and closeness to their family member (Wagner et al., 2011, Zahils, & Lewis, 2010).

2.4 IRANIAN CONTEXT

2.4.1 Population and demography

Iran is 1,648,000 km^2 and located in Southwest Asia. Iran ranks 16th in size among the countries of the world and its climate ranges from subtropical to subpolar (Geography of Iran). Iran has a population of 70 million people, with more than 13 million living in the capital city of Tehran (Statistical center of Iran, 2009). One quarter of its people are 15 years of age or younger while 7.26% of the population are aged 60 years or over (Statistical center of Iran, 2009). Iran is a country composed of different ethnic groups, including Persian (51%), Azeri (24%), Gilaki and Mazandarani (8%), Kurd (7%), and Arab (3%) (Geography of Iran). The majority of the people are Muslims (98%) and the official language is Persian (Statistical center of Iran 2009).

2.4.2 Family

Family is generally defined as "two or more persons who are joined together by bonds of sharing and emotional closeness and who identify themselves as being part of a family" (Friedman et al., 2003, p10). This definition of family is very broad and permits people to define who is important to them and whom they want to involve in their life (Diem & Moyer, 2005). Traditional definitions of family contain what is referred to as a nuclear family consisting of a father, a mother and one or more children or an extended family that includes grandparents, aunts, uncles, and cousins (Friedman et al., 2003).

In the Iranian context the family is defined as two or more individuals who are joined together by marriage or who are biologically related. All couples who have been legally married have certain rights and responsibility to one another.

The Iranian family structure has changed radically in recent years. For instance, nowadays, both men and women work but household chores are still regarded as women's work. This means that women are more educated, which leads to better job prospects. Furthermore, today couples are older at their first marriage, the divorce rates increases, the age at first births increases and the employment rates of women in Iran rise (Abbasi-Shavazi et al., 2009). An increase in the level of literacy in women (from 36% in 1976 to 80% in 2006) has led to a decrease in births (from over six births in 1985 to 1.9 births in 2006) (Abbasi-Shavazi et al., 2009). However, the Iranian culture still emphasizes the mother's primary role as homemaker while the main responsibility of the father is to be the primary worker and provide for the housing, food, and clothing for his family, even though many Iranian wives contribute to the family income. Today's Iranian family is a family in transition, from extended structure to nuclear family structure.

2.4.3 Healthcare delivery system

The healthcare system in Iran is primarily managed by the government. Planning, monitoring, and supervision of health-related activities in public and private sectors are under the supervision of the Ministry of Health and Medical Education (MOHME)

(Mehrdad, 2009). The public sectors in Iran provide primary health care, treatment, and rehabilitation. The Iranian government emphasizes primary health care (Mehrdad, 2009). Almost 65% of all hospital beds are run by medical universities that are connected to the MOHME. Health care is financed via a combination of public expenditures, consumer co-payments, and revenue that are raised from special contracts between health insurance organizations and medical universities. There are four major health insurance organizations and 90% of the population is under the coverage of one kind of health insurance (Mehrdad, 2009).

The private sector has an important role in the provision of health care, especially secondary and tertiary health care in urban areas (Mehrdad, 2009). There are many non-governmental organizations (NGOs), which are principally active in special fields such as cancer, diabetes, and thalassemia (Mehrdad, 2009).

Cancer services are primarily organized through the medical universities and delivered by multidisciplinary teams within specialized cancer centers. Health personnel have a main role in making the initial contact and referral to test woman with cancer who wish to use public health services (Moradian et al., 2011). It is also possible for patients to visit specialist consultants and other professionals, first for tests and then for surgical and other treatment and services (Moradian et al., 2011).

2.5 THEORETICAL CONCEPTS

2.5.1 Quality of life

The concept of quality of life (QoL) is a scientific construct which has various meanings based on the area of application (O'Boyle, 1997, Fayers & Machine, 2007). Defining the QoL concept is difficult because of its complexity and that it encompasses several dimensions (e.g., physical functioning, emotional functioning, role functioning, social functioning, general health, and psychological aspects) (Fayers & Machine, 2007). There is a consensus about QoL being subjective and multidimensional (Cella, 1994, O'Boyle, 1997, King & Hinds, 2003). The concept of health-related quality of life (HRQoL) contains those aspects of overall QoL that can be clearly shown to affect physical and mental health (Fayers & Machine, 2007). The reason for measuring HRQoL is that it can help determine the burden of disease, injury, and disability (CDC 2011).

QoL is influenced by one's personal background, health, social situation, culture, environment, and age (King & Hinds, 2003). Standardized instruments have been used to measure HRQoL and the impact that illness/treatment has on the QoL of women with cancer and their family caregivers. These instruments can be generic, disease-specific, or symptom-specific (Bowling, 1995). However, every individual has his or her own philosophy of life that contains a unique combination of different components (Lindblad et al., 2002). Calman (1984) elaborates that persons have certain aims and expectations in life and that QoL reflects differences and gaps between the hopes and expectations in different people. Therefore, QoL could be described in individual terms according to the personal explanation in their own terms (Calman 1984, Lindblad et al., 2002, Fayers & Machine, 2007). Dijkers (2003) has categorized instruments of QoL on a continuum from standardized questionnaires with predefined categories to individualized instruments that allow the respondents to define the categories. There are individual QoL instruments for that purpose and one of the most known is the Schedule

for the Evaluation of Individual Quality of Life -Direct Weighting (SEIQoL-DW). The SEIQoL-DW is a self-report instrument for measuring various areas considered by individual patients as important to their QoL (O'Boyle, 1994). Determining areas of QoL by respondents that cover all aspects of life enables researchers to specify important problems and priorities from the perspective of the respondents (Bowling, 1995, Hickey et al., 1996).

To cover different aspects of QoL the use of multiple instruments is required (O'Connor, 2004, Fayers & Machine, 2007). In this thesis a subjective view of QoL is based on standard instruments and an individual's reported perception of QoL.

2.5.2 Coping capacity

Coping mechanisms could be defined as "any efforts directed at stress management" (Stuart & Laraia, 2001, p.68). Coping resources include social supports, relationship between the individual, family and group, viewing oneself positively, problem-solving abilities, knowledge and intelligence (Stuart & Laraia, 2001). Having the capacity to form self through a developmental process that is a positive move of person through challenging life events can be called inner strength (Roux et al., 2002, 2003, Lundman et al., 2010). Inner strengths can be defined by several concepts and measured with different scales, such as resilience scale (Wagnild & Young, 1993), sense of coherence scale (Antonovsky, 1987), hardiness scale (Maddi, 2002), purpose in life scale (Crumbaugh & Maholick, 1964) and self-transcendence scale (Reed, 1986). Statistically significant correlations were found between scores on the resilience scale, the sense of coherence scale, the purpose in life scale, and the self-transcendence scale (Nygren et al., 2005).

Spirituality, religiosity, and personal beliefs have been suggested to be important and relevant to QoL. Thus, they should be included when assessing QoL in order to have a holistic approach to measurement (O'Connell & kevington, 2005, O'Connell 2002). Furthermore, several studies have demonstrated that SOC could act as predictor of QoL in patients with cancer, including breast cancer (Gibson & Parker, 2003, Bruscia et al., 2008, Kenne Sarenmalm et al., 2011). In this thesis, spirituality, religious coping, and SOC were chosen to explore relationships among inner strengths and QoL in family caregivers of patients with breast cancer in Iran.

2.5.2.1 Sense of coherence (SOC)
How to manage a threatening situation will differ between people. Antonovsky explained SOC as "A global orientation that expresses the extent to which one has a pervasive enduring though dynamic feeling of confidence that (1) The stimuli deriving from one's internal and external environments in the course of living are structured, predictable, and explicable, (2) the resources are available to one to meet the demands posed by these stimuli, (3) these demands are challenges, worthy of investment and engagement" (Antonovsky, 1987 p 41). Antonovsky labeled these three components as comprehensibility, manageability, and meaningfulness. The theory of SOC suggests that people with a high SOC may cope well in an unstable situation (Antonovsky, 1987). The SOC is a multidimensional concept and refers to a number of internal and external resources (e.g., social, historical and cultural background, childhood, and social roles) called generalized resistance resources (GRR). These resources supply energy and help people to cope with daily problems. The theory was operationalized by Antonovsky who developed the SOC scale to assess the degree of SOC. Antonovsky (1987) claimed that a person's SOC should be fully developed and stabilized by the age

of 30 years and remains stable if there are no dramatic changes in life. However, the stability of the SOC scale has been questioned (Nilsson et al., 2003, Feldt et al., 2003), whereas others have confirmed its stability (Schnyder et al., 2000, Langius-Eklöf & Samuelsson, 2009, Feldt et al., 2000). The SOC scale has been suggested to be stable as long as the changes do not reach a change of 10% (Karlsson et al., 2000). In several studies a higher level of SOC was found to be related to better QoL and perceived health (Eriksson & Lindström, 2006, 2007). Some studies have reported that SOC is related to anxiety and depression. In these studies, persons with a higher degree of SOC have shown less depression (Skärsäter et al., 2009, Kenne Sarenmalm, 2011). Furthermore, a longitudinal study showed that SOC was associated with recovery from depression (Skärsäter et al., 2009).

Individuals with higher SOC try to perceive situations as manageable, meaningful, and comprehensible and these abilities reduce the tension caused by stressors (Antonovsky, 1987). Furthermore, SOC played a role as predictor of QoL in caregivers of post-stroke patients (Van Puymbroeck & Rittman, 2005) as well as a moderator and mediator of QoL in family members of patients with serious mental illness (Suresky et al., 2008).

2.5.2.2 *Religious coping*

The word "religion" comes from the Latin "religio", which is usually translated as "obligation" or bond" in the Oxford English Dictionary (OED). Religion represents the "human recognition of superhuman controlling power and especially of a personal God or gods entitled to obedience and worship" (Fontana, 2003, p. 6). Religion might facilitate coping with illness by providing an indirect form of control that helps to break up the cycle of anxiety and depression (Sherman, 2010 p 15). An important coping resource for patients and family caregivers with life-threatening illnesses might be religion (Abraido-Lanzan et al., 2004). Religion provides a number of ways for coping with illness, such as the promotion of active coping with health problems, fostering emotional well-being, establishing and maintaining social support, and facilitating the process of meaning-making (Cummings & Pargament, 2010). Through religion, persons have a sense of purpose and meaning to deal with inarticulate events or chronic difficulty (Taylor et al., 1999). Pargament, et al. (1988) conceptualized and measured three ways in which people can use religious coping in the search for control: Self-directing (control through oneself), Deferring (control through God), and collaborative (control through a relationship with God). The scale contains 105 items intended to represent five theoretical dimensions of religious coping (finding meaning, gaining control, gaining comfort and closeness to God, gaining intimacy with others, and achieving a life transformation) (Pargament et al., 1998, 2000). From this scale, the Brief Religious Coping (brief RCOPE) scale was created consisting of 14 items characterizing positive and negative religious coping styles (Pargament et al., 1998 2000).

Religious coping is a coping strategy described as having different importance in different cultures. For instance, a sample of Swedish chronic pain patients reported that 37% of the patients totally denied praying for an end to their pain or relying on faith in God or a higher power (Andersson, 2008). In a study on 198 women with breast cancer negative religious coping methods were found to predict worse mental health and life satisfaction (Hebert et al., 2009). Findings from a German hospital setting showed that the patients' faith was a strong source when fronting a hard situation. They believed in a higher power, that God would help them, and they used prayer as a coping strategy (Büssing et al., 2009).

2.5.2.3 Spirituality

Although the terms spirituality and religion are often used interchangeably in everyday discussions, spirituality is seen as a broader concept than religiosity (Sherman, 2010). The word spirituality comes from the Latin word spiritus meaning breath (Fontana, 2003, p.11). Spirituality is the lens through which persons interpret their world and their reality in their effort to understand themselves, their needs, and their relationship to self, others, nature, and God (Sherman, 2010). Moreover, spirituality appears to be a more abstract concept than religion and can be described as that which gives life meaning (Dunn, Handley, & Dunkin, 2009).

Reed (1986) has developed a middle-range theory on self-transcendence, a human development theory that is particularly relevant to persons who are experiencing significant life events such as end-of-life. Meaning in life is one aspect of spirituality (Vachon, 2008) and is an essential component of positive mental health (Ferguson & Goodwin, 2010). In times of crisis and illness spirituality plays a crucial role in helping people cope with loss, grief, and death (Weaver, Flannelly, & Flannelly, 2001). Koenig (2004) observed that patients who reported to be both spiritual and religious were more likely to have more social support and better psychosocial and physical health outcomes than patients who did not consider themselves spiritual and religious.

In the Iranian culture most people believe God is a higher power in their life. In Europe, over 50% of the people believe there is a God (52%) and 27% insists there is some sort of spirit or life force. Only 18% of persons believe that there is no spirit, God, or life force (European commission June 2005).

Sherman (2010, p14) describes that spirituality can be a dynamic force that helps patients to understand their disease and way of coping. A person with a life-threatening illness may question the purpose of their life. Such persons may seek to transcend their suffering and thus health care providers need to be aware of the spiritual interests and needs of patients.

2.6   RATIONALE

The main persons responsible for taking care of patients with breast cancer in Iran at home are the family members. Family units are the cornerstone of society and are strongly valued according to ancient and religious cultures. Moreover, home care services are not widely available for breast cancer patients and only a limited numbers of private agencies exist in some Iranian cities. Family nursing has been given high attention during the last decade and no studies have been done in Iran focusing on the perspective of family caregivers to persons with breast cancer in Iran. To support family caregivers and the family as a unit of care there is a need to understand how they deal with their situation and how their QoL is influenced by having a family member with breast cancer.

3 AIMS

The overall aim was to investigate QoL and coping capacity of family caregivers of family members newly diagnosed with breast cancer in Iran to improve the understanding of their need of support.

The specific aims were to:

1. Translate the HI, SOC scale, Brief RCOPE scale and SPS into the Persian language (Farsi) and to test their validity and reliability within the Iranian culture (study I).

2. Translate the CQOLC into the Persian language (Farsi), evaluate the factor structure of the CQOLC in a sample of Iranian family caregivers to patients with newly diagnosed breast cancer using confirmatory factor analysis (CFA), and examine the validity and internal consistency of measures based on the obtained factor structure (study II).

3. Describe QoL aspects, degree of SOC, spirituality, and religious coping and explore factors that could predict changes in QoL in a sample of family caregivers to patients with breast cancer in Iran at time of diagnosis and 6 months later (study III).

4. Describe important areas to QoL in family caregivers of breast cancer patients in Iran and to determine which areas in life are influenced by the disease and how these areas change over time (study IV).

4 METHODS

4.1 STUDY DESIGN

The studies presented in this thesis have a longitudinal, descriptive, and predictive design. Five self-rated questionnaires and one semi-structured interview questionnaire are used for data collection. Two studies involve methodological testing of psychometric properties of the questionnaires used for the Persian language in samples in Iran. One study is clinical comprising of a sample of family caregivers in Iran followed from the time of diagnosis (T1) and 6 months later (T2). Study I is descriptive, study II is descriptive and explorative, study III longitudinal, descriptive and predictive, and study IV is a longitudinal and descriptive study.

Table 1. Overview of design, number of participants, time of data collection, data collection, and data analyses included in the thesis

Study	Design/research approach	Number of participants & time of data collection		Data collection	Data analyses
		T1	T2		
I	Descriptive and cross-sectional, psychometric evaluation and cross-cultural adaptation	333 Jun 2006	293 Aug 2006	Questionnaires administered by self-report SOC, HI, RCOPE, SPS	Descriptive statistic, chi-square statistic, unpaired t-test, correlation coefficient, stepwise forward multiple linear regression, item analysis, Kolmogorov-Smirnov, Cronbach's alpha
II	Descriptive and explorative, psychometric evaluation and cross-cultural adaptation	166 Oct 2006	-	Questionnaires administered by self-report and medical records CQOLC,SOC, HI, RCOPE, SPS	Descriptive statistic, chi-square statistic, unpaired t-test, correlation coefficient, Kolmogorov-Smirnov, CFA using LISREL software and SAS software, Cronbach's alpha
III	Longitudinal, descriptive and predictive	150 Oct 2006 to Jan 2008	115 Apr 2007 to July 2008	Questionnaires administered by self-report and medical records CQOLC-P, SOC, HI, RCOPE, SPS	Descriptive statistic, chi-square statistic, paired t-test, unpaired t-test, correlation coefficient, simultaneous multiple linear regression, Kolmogorov-Smirnov, Cronbach's alpha, effect size
IV	Descriptive and Longitudinal	129 Oct 2006 to Jan 2008	88 Apr 2007 to July 2008	A semi-structured interview with interview guide Swedish version of SEIQOL-DW	Deductive content analysis, descriptive statistic, chi-square statistic

4.2   SAMPLES

4.2.1 Healthy people

The sample in this study (n = 375) was a convenience sample of healthy women and men employees working in two universities (n = 136), one private company (n = 29), and nine urban health centers (n = 210) in Tehran. Of the 375 participants, 333 (88.8%) returned the questionnaires at baseline and 298 (79.5%) at the 1-month follow-up. Hence, the final sample consisted of the 298 persons who participated at both T1 and T2.

4.2.1   Family caregivers

First 20 patients were asked for consent asking their family caregiver for participating in the procedure of face validity of one of the questionnaires. All of them consented but 4 did not fulfill the whole questionnaire. From 175 newly diagnosed patients with breast cancer who were eligible 25 declined their family caregiver to participate leaving 150 family caregivers who all consented to participate in the study at the time of diagnosis. To increase the power of the study the 16 family caregivers recruited for face validity who did fulfill the questionnaire were included in the study II (in total n=166) (figure 1).

Of the 150 family caregivers participating at the time of diagnosis (T1) 35 did not return the questionnaires 6 months later (T2) Twenty-six refused further participation, 7 caregivers did not receive the questionnaires through the mail and one patient and one caregiver had deceased. Thus, the final sample consisted of 115 participants at both T1 and T2 in study III (figure 1).

Of the 150 family caregivers participating in study III and answering the questionnaires at T1 129 participated in the semi-structured interview at T1 and 88 participated at both T1 and T2 which constituted study IV (figure 1). The 41 drop-outs consisted of 39 family care givers who refused further participation and one family caregiver and one patient died.
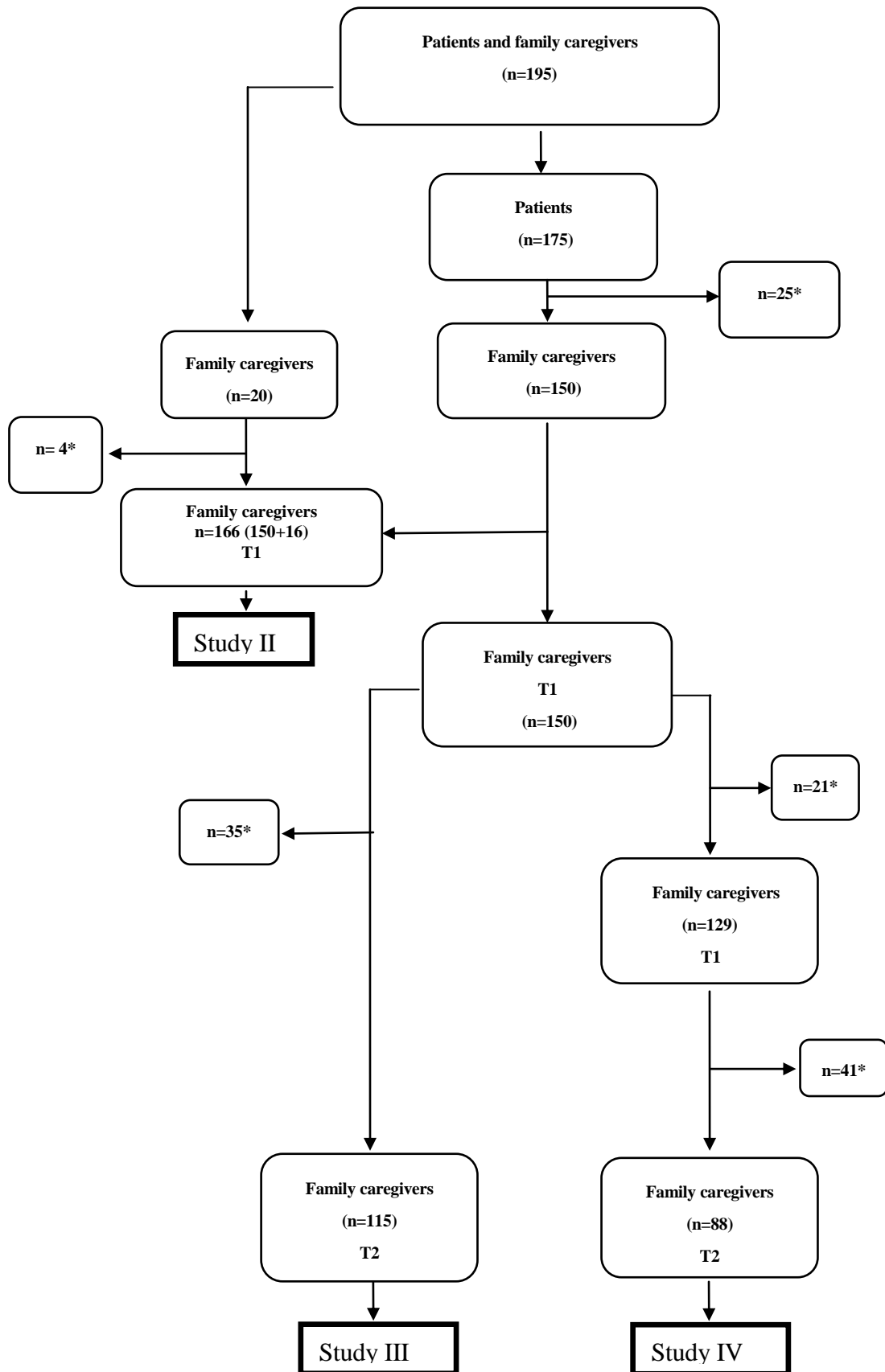
Figure 1. Overview of the samples in study II-IV.
* Dropout

4.3 DATA COLLECTION

Data collection consisted of five self-administered questionnaires and one interview-based questionnaire. Further, demographic data (age, marital status, occupation status, level of education, and relationship to patients) were collected by single questions. Data on the breast cancer patients' age, occupational status, level of education, and types of treatment were obtained by medical record review.

4.3.1 Measures

4.3.1.1 CQOLC (study II & III)

The Caregiver Quality of Life Index-Cancer (CQOLC), originally developed in the United States, was designed to assess QoL of family caregivers of cancer patients (Weitzner et al., 1997). CQOLC, developed by in-depth interviews, was selected because it is a multidimensional tool that captures the caregivers' perceptions of QoL. Additionally, the reliability and validity of the CQOLC were verified in several countries (USA, Korea, and Taiwan) (Weitzner et al., 1999, Rhee et al., 2005, Tang et al., 2009).

The CQOLC consists of 35 items. Each item is rated on a 5-point scale from 0 (not at all) to 4 (very much). The original CQOLC has four subscales that can be calculated from 27 of the 35 items: Burden, Disruptiveness, Positive adaptation, and Financial concerns (Weitzner, unpublished manual, personal communication). The other eight items did not load on any of the four subscales. All 35 items are included in a complete CQOLC score (overall QoL). The highest total score for this instrument is 140 and the lowest score is zero, with higher scores indicating better QoL.

The CQOLC was translated into the Persian language following standardized guidelines and psychometric properties of the scale were supported as reported in study II. However, the slight different sub-scales obtained in the factor analysis in study II constituted a Persian version labeled CQOLC-P. In CQOLPC-P 4 subscales can be calculated from 34 of the items: Mental/emotional burden, Lifestyle disruption, Positive adaptation, and Financial concerns. One additional item concerns family interest in caregiving and is not a part of any subscale but is included with the other items in the total CQOLC-P score (overall QoL). The maximum total score for the instrument is 140. The maximum scores for each of the subscales in CQOLC-P are 56 (mental/emotional burden), 36 (lifestyle disruption), 32 (positive adaptation), and 12 (financial concerns).

4.3.1.2 SOC (study I-III)

The SOC scale was developed by Antonovsky (1987) to measure the concept of sense of coherence. It is defined as an individual's global view of life based on how comprehensible, manageable, and meaningful life appears to them. The degree of SOC was measured with the 13-item short form version of the SOC (Antonovsky, 1987). The SOC scale has been widely used and found to be reliable, as well as a valid measure of a person's general view of (Eriksson & Lindström, 2005) life. The scale ranges from 1 to 7 points, with 2 anchoring responses. The respondents are asked to choose the answer that best represents their idea by choosing a number between the 2 anchoring responses (e.g., 1 = never to 7 = very often). Higher scores represent higher SOC.

4.3.1.3 SPS (study I-III)

The Spirituality Perspective scale was developed by Reed (1986, 1987). The SPS is a 10-item questionnaire that uses a 6-point Likert-type scale to measure the importance of spiritual views in a person's life. Individuals were asked to respond to the items that measure the importance of spiritual views in their lives. The highest score is 60 and the lowest is 10, with higher scores representing higher levels of spiritual perception and activity. The validity and reliability of the SPS in different samples (e.g., older, terminally ill, acutely ill, and healthy adults) have been confirmed (Reed, 1986, 1987, Jesse & Reed, 2004, Dailey & Stewart, 2007).

4.3.1.4 Brief RCOPE (study I-III)

For measuring religious coping, Pargament et al., (2000) proposed the RCOPE scale. Later, a short version, the Brief Religious Coping (RCOPE) scale with 14 items was developed to give researchers a broader view of the extent to which individuals engage in positive and negative forms of religious coping (Pargament et al., 1998). The Brief RCOPE scale consists of 7 items that reflect positive religious coping (positive RCOPE Scale) and 7 items that reflect negative religious coping (negative RCOPE Scale). The scoring range for each scale is from 7 to 28 points, with higher scores indicating stronger positive and negative religious coping. The psychometric properties have been supported by high internal consistency, confirmatory factor analysis, and hierarchical regression analysis (Pargament et al., 1998, 2000).

4.3.1.5 HI (study I-III)

The HI has been developed and tested in Sweden (Nordström et al., 1992, Forsberg & Björvell, 1993). The respondents are asked to rate their health status from the previous week by responding to each item on a 4-point scale (1- 4). The 9 items are summed into an index score (9-36 points), with higher scores corresponding to a more positive perception of general well-being. Validation of HI has been tested in different populations with satisfactory results (Nordström et al., 1992, Forsberg & Björvell, 1993, Sjöström et al., 2004).

4.3.1.6 SEIQoL-DW (study IV)

A Swedish evaluated, extended, and modified version of the SEIQoL-DW was used in this study that included a generic (SEIQoL-G) and a disease-related part (SEIQoL-DR) (Wettergren et al., 2003, 2005, 2009). In SEIQoL-G respondents' respond to an open-ended question about the most important things in their current life: "If you think about your life as a whole, what are the most important things, both good and bad, in your life at present that are crucial to your quality of life?" Although the respondents are allowed to mention as many areas as they want, only up to five main areas were listed. In the SEQoL-DR part the respondents were asked, "If you think about the fact that your relative has breast cancer, what in your life is influenced, both positively and negatively, by breast cancer?" The respondents could mention as many areas as they wanted but only up to five were actually listed.

4.3.1.7 Demographic and medical variables

Demographic variables included age, sex, level of education), marital and occupation status in all studies and number of children, and relationship with patient in study II-IV. In addition, breast cancer stage and treatment procedure were used to assess medical variables of the family caregivers' member with breast cancer.

4.4   PROCEDURE

For study I an announcement was placed on the walls at the different settings to recruit participants. The announcement was directed to the recruitment of healthy people and the aim of the study, voluntariness and confidentiality were stressed. After showing interest to participate written information in detail was handed to the participants and written informed consent was obtained. The participants in study I could get the questionnaires at an appointed place and thereafter leave a fulfilled questionnaire to the same place or to the researcher. For study II-IV, initially, the researcher approached the eligible patients with information about the study and asked for their consent to contact their primary family caregiver. The family caregivers were then informed about the study and written consent was obtained from those who volunteered.

In this thesis the primary family caregivers were defined according to the perspective of the Iranian context by posing questions to the patients such as 'Who provides and/or manages your care? 'Whom do you rely on most for help at home?' or 'Is your primary family caregiver your husband, daughter, son, father, mother, brother, or sister'?
The data collection took place in study I at baseline (T1) and one month later (T2) and for study III-IV at the time of diagnosis (T1) and 6 months later (T2). Study II only consisted of the participants at T1. In study I the questionnaires were posted by regular mail to all participants at both T1 and T2. In study III and IV at T1, the caregivers completed the questionnaires at the hospital. At T2, the participants received the questionnaires via regular mail that included a prepaid envelope to return the material my mail. The interviews in study were collected face-to-face interview at the time of diagnosis and by telephone interviews 6 months later.

4.4.1   Translation procedure, face and content validity

A special guideline was used for translation and cultural adaptation of the instruments from English or Swedish into the Persian language. This model includes simultaneous translations and blind back-translations, followed by group consultations with bilingual experts. Translators in these studies had different academic backgrounds in nursing and education. All versions of the translations and back-translations of the instruments were reviewed by the research group. For face and content validity, the instruments were submitted to two expert panels consisting of 7 and 3 members at two universities of medical sciences in Iran. They were experts in research methodology and specialists in nursing. Twenty volunteers (10 healthy persons and 10 patients with breast cancer) were included in the study to assess the face validity of the instruments. They were asked to read and evaluate the content of the instruments and judge the items for readability and clarity. A further 20 family caregivers assessed the face validity of the CQOLC. Figure 2 illustrates the different steps in the translation and cultural adaptation process used in this thesis.
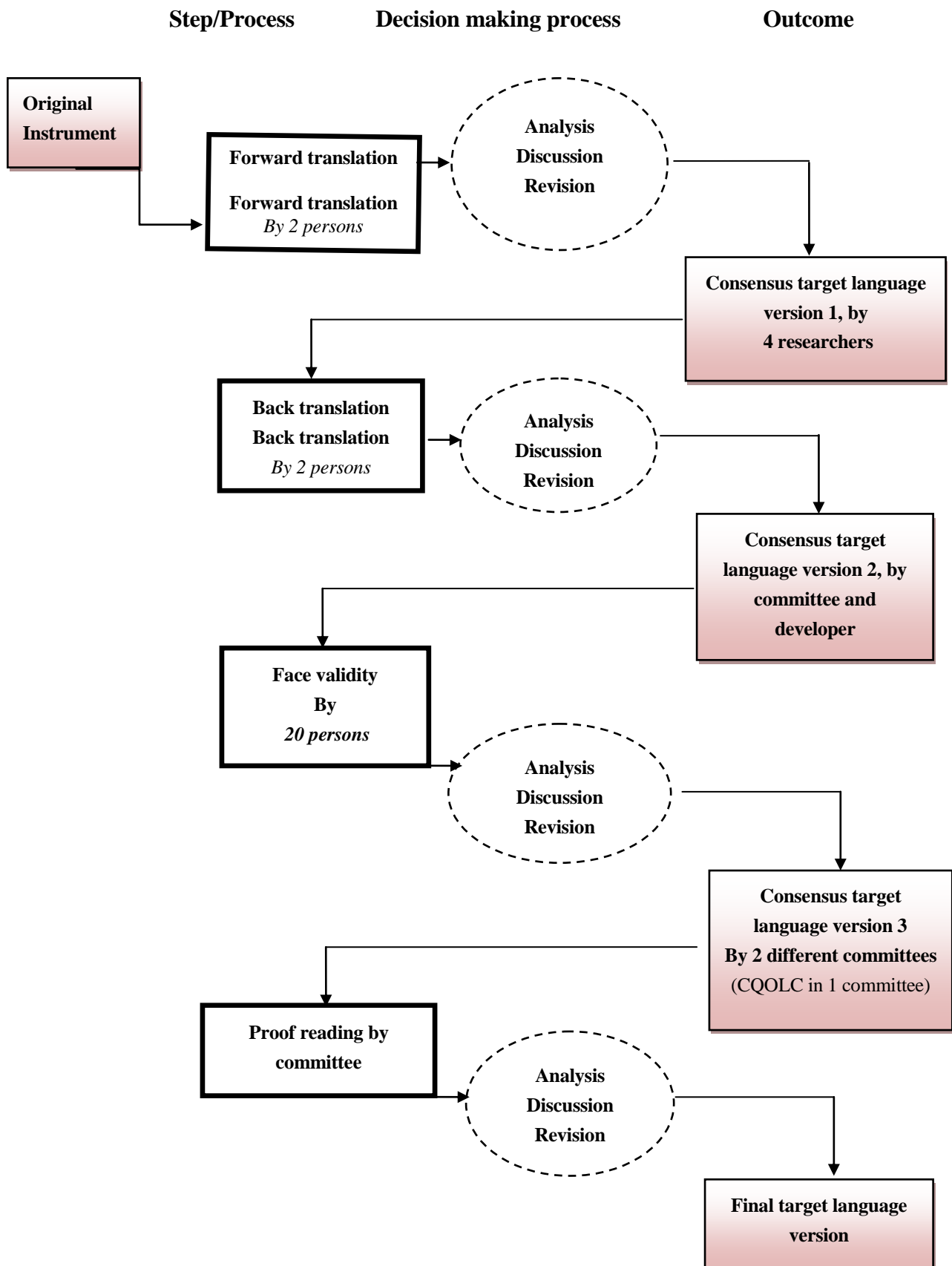
Step/Process **Decision making process** **Outcome**

Original Instrument

Forward translation

Forward translation
By 2 persons

Analysis
Discussion
Revision

Consensus target language version 1, by 4 researchers

Back translation
Back translation
By 2 persons

Analysis
Discussion
Revision

Consensus target language version 2, by committee and developer

Face validity
By
20 persons

Analysis
Discussion
Revision

Consensus target language version 3
By 2 different committees
(CQOLC in 1 committee)

Proof reading by committee

Analysis
Discussion
Revision

Final target language version

Figure 2. The translation and cultural adaptation process used in studies I and II.

17

4.5 DATA ANALYSES

Descriptive analyses were performed on the respondents' background characteristics (study I- IV). Chi-square statistics and Fisher's exact test (two-sided) were conducted when comparing independent groups for nominal data and Student's paired and unpaired t tests when comparing groups for continuous data. In all statistical analysis a p-value of <0.05 was considered statistically significant. The statistical analyses were performed using the statistical Package for Social Sciences software (SPSS) 14.0 for windows.

4.5.1 Study I

Cronbach's alpha coefficient was used for assessment of internal consistency. The inter-item correlation analysis was performed by computing the corrected item-total correlation for the items in the instruments (a result of 0.30 or above was regarded as acceptable) (Ferketich, 1991). Evaluation of the test-retest reliability was performed using the intra-class correlation coefficient. Values of the intra-class correlation coefficient differ from 0 (totally unreliable) to 1 (perfectly reliable), and values overhead 0.80 were considered as evidence of excellent reliability (Nunnally & Bernstein, 1994).

For criterion-related validity, three main hypotheses were determined and seven exploratory hypotheses were stated. Furthermore, hierarchical multiple regression analyses were performed to determine criterion-related validity. HI scores were used as the dependent variable while SOC, SPS, positive and negative RCOPE scores together with demographic data were selected as independent variables. Independent variables were arranged into five categories: demographic variables (age, sex, education, job and marital status), SOC, negative RCOPE, positive RCOPE, and SPS scores. The demographic variables were entered first and the order of entry of the remaining variables into the models was based on a higher correlation coefficient with HI scores.

4.5.2 Study II

The underlying dimensions of the CQOLC were examined by CFA using LISREL 8.53. The LISREL program creates several goodness-of-fit indices as a synopsis appraisal of the instrument's validity. In this study the degree of model fit was assessed by (a) the ratio of chi-square test statistics (χ^2) to its associated degrees of freedom (df), (b) the RMSEA and SRMR, and (c) the NFI, NNFI, and CFI (Kline 2005, Hu & Bentler 1999). The RMSEA and CFI are less sensitive to sample size (< 200) than other statistics (Fan, et al. 1999). A model fit is suggested to be acceptable if the χ^2/df ratio is lower than 2, if both the CFI and NNFI are higher than 0.90, and if the SRMR and RMSEA are both lower than 0.08 (Hu & Bentler, 1999, Kline 2005, Tabachnick & Fidell, 2007). Calculation of power was performed (Hancock & Freeman 2001) and with a power >0.80 a sample size of 115 persons is considered adequate (Cohen, 1988). For evaluation of convergent validity, the Pearson correlation coefficient was used in which a correlation below 0.20 was considered low and more than 0.86 very high (Cohen et al. 2000). Five explorative hypotheses based on earlier studies were posed. In addition, a hierarchical multiple regression analysis was applied to evaluate the ability of SOC, SPS, and positive and negative RCOPE scales to predict QoL. The overall CQOLC score was used as a dependent variable and SOC, SPS, and positive and negative RCOPE scores as independent variables because they are relatively stable. Variables were arranged into five categories: demographic variables of the patients and the family caregivers (age, sex, education level, marital and occupational status,

relationship with patient and breast cancer stage), SOC, negative RCOPE, positive RCOPE, and SPS scores. The demographic variables were entered first and the order of entry of the remaining model entry variables was based on an upper correlation coefficient with the CQOLC score. The internal consistency of the scale and various subscales were analyzed by Cronbach's alpha. A Cronbach's alpha coefficient ≥ 0.70 was considered satisfactory (Nunnally & Bernstein, 1994).

4.5.3 Study III

Effect size was calculated for estimation of, a clinically significant change in overall QoL (CQOLC). The number of family caregivers changing their ratings on the overall score of the CQOLC-P was divided into three groups (stable, increased, and deteriorated) by using a cut off score of change of <10% (stable) and >10% (improved and deteriorated, respectively) between baseline and 6 months later (Osoba et al., 2005).

Pearson's correlation coefficients were used to examine relationships between the variables. Simultaneous multiple regression analyses were used to predict changes in overall QoL scores (CQOLC). The dependent variable was the change score (minus and plus) in the overall CQOLC-P score. The independent variables were the family caregivers' demographic variables (age, sex, education level, occupational status, marital status, number of children, and relationship with patient) and the patients' demographic and medical variables (age, education level, occupational status, marital status, number of children, breast cancer stage, type of surgery, chemotherapy, and radiotherapy). The total CQOLC-P score at T1, as well as the SOC, negative RCOPE, positive RCOPE, and SPS scores at T2 served as independent variables. All these independent variables were entered into the model simultaneously. A power calculation with an alpha of 0.05 and a power of 0.90 shows the sample size of 112 persons to be sufficient (Zar, 1998).

4.5.4 Study IV

Family caregivers' answers were written and analyzed according to the deductive content analysis method of Elo & Kyngäs (2008). During the interview, the interviewer wrote down the answers of family caregivers and later the text was written in a computer word processing program. The analysis of the transcripts was performed by reading it several times to identify units made of single words or short phrases (by the first author) and then units were coded and categorized. The two Persian-speaking authors discussed the categorization of the units until final agreement was reached between the two authors. Eventually, units and categories were translated into English and discussed and modified together with the other authors. Examples of categorization of statements reported by family caregivers are listed in Table 2 and 3.

Table 2. Categories with examples of descriptors describing generic categories in QoL (SEIQoL-G) reported by family caregivers of persons with breast cancer

Category	Category descriptors
Relationship	Appropriate relationship with family and others, maintain good relationship, honesty in relationship with others
Healthy family	Being happy in life, joy in the family, having a warm family, satisfaction of family life, family happiness

Table 3. Categories with examples of descriptors reported by family caregivers of persons with breast cancer describing disease-related QoL (SEIQoL-DR)

Category	Category descriptors
Psychological impact	Depression, stress, fear, sadness, insomnia, fear, un-concentrated, confused
Concerns about disease	Treatment process, reducing pain, future of family members, survival, fear of recurrence

5 ETHICAL CONSIDERATIONS

All four studies (I-IV) in this thesis followed the Helsinki Declaration and were approved by the national Ethical Board of Research at the Ministry of Health and Medical Education as well as the Iran University of Medical Sciences. All the participants and their family caregivers were given verbal and written information about the study that included the focus, aim, methods and procedures and its confidentiality, voluntarism, and the name of the researcher. For all studies the participants signed a written informed consent form. In the informed consent the participants were assured about the confidentiality and that they were allowed to withdraw from the study at any time. For maintaining privacy and preventing identification, collected data were assigned code numbers. All information was kept in locked boxes at the university. Overall, the studies were considered to be safe with low risk. One ethical dilemma could be that the patients were asked to identify their primary family caregiver. The family caregivers of patients with breast cancer who did not consent the researcher to contact their family caregivers to participate were excluded. These family caregivers might possibly have been interested in contributing to the study but did not get that opportunity. However, it was found to be more ethical to first ask the patient for permission and then the family caregiver to avoid potential conflicts. On the other hand, some of the family caregivers might feel obliged to participate because their family member with breast cancer wished participation. The information very clearly declared voluntariness and some family caregivers actually declined participation.

Another ethical dilemma could be asking patients in a vulnerable position about their primary family caregivers that needs special attention to the situation of patient and family caregiver. Approaching the patients was done sensitive to avoid pressure and the overall impression is that the patients found the study important and therefore gave their consent.

6 RESULTS

6.1 CHARACTERISTICS OF THE SAMPLES

6.1.1 Healthy sample (study I)

The age of participants ranged from 18 to 70 years (mean = 38.2, SD = 10.8) and most were female (78%). Fifty percent had a university degree, more than 70% were married, and 63% were employed.

6.1.2 Patient group and family caregivers (study II-IV)

The mean age of the family caregiver sample in study II was 40.7 years (range 18–75, SD 13.1), study III 40.1 years (range 18–75, SD 13.4) and study IV 41.1 years (range 18–75, SD 13.9). Most of the participants were women, married, employed, and highly educated. Furthermore, approximately 22% were 18–27 years of age, 10% were students, and 34% were daughters to the patients. The mean age of the patients with breast cancer was 45.8 years (range 19 – 68, SD 10), and the majority of them (77%) were married and housewives (57%). In addition, 73 (45%) of the patients were classified having stage II, 34 (21%) stage III, and 32 (20%) stage I.

Demographic characteristics of the family caregivers in study III-IV and the dropouts are summarized in Table 4.

Table 4. Characteristics of family caregivers of persons with breast cancer who participated at diagnosis (T1) and 6 months later (T2) and the dropouts in study III and IV

Variables	Study III			Study IV		
	Total n=115	Dropouts n=35	p-value[a]	Total n=88	Dropouts n=41	p-value[a]
Marital status n (%)			ns[b]			ns[b]
Married	85 (74)	28 (80)		63 (72)	30 (73)	
Single	30 (26)	7 (20)		25 (28)	11 (27)	
Occupational Status n (%)			ns[b]			ns[b]
Employee	60 (53)	12 (34)		39 (44)	26 (63)	
Housewife	32 (28)	11 (31)		30 (34)	7 (17)	
Retired	12 (10)	10 (29)		11 (12)	3 (7)	
Student	11 (9)	2 (6)		8 (10)	5 (12)	
			ns[b]			
Level of education n (%)						
Secondary/high school	18 (16)	5 (14)		16 (18)	6 (15)	
Diploma	40 (35)	15 (43)		29 (33)	17 (42)	
University	57 (49)	15 (43)		43 (49)	18 (44)	
			ns[b]			ns[b]
Relationship to patient n (%)						
Husband	42 (37)	15 (43)		28 (31)	18 (44)	
Daughter	43 (37)	4 (11)		32 (36)	12 (29)	
Sister	21 (18)	7 (20)		21 (23)	5 (12)	
Mother	5 (4)	4 (11)		6 (7)	2 (5)	
Son/brother	4 (4)	5 (15)		1 (1)	4 (10)	

a. between total group and dropout group
b. Chi-square test

6.2 PSYCHOMETRIC EVALUATION

6.2.1 HI, SOC, SPS, and RCOPE Scale (study I)

Cronbach's alpha and test-retest coefficients of the instruments ranged from 0.82 - 0.77 and 0.78 - 0.80, respectively. The item analysis of all items in each instrument was acceptable, except for item 1 of the SOC scale ('Do you have the feeling that you don't really care about what goes on around you?') and item 7 of the negative RCOPE Scale ('Questioned the power of God'). Almost all main hypotheses were accepted. The hypothesis about a low positive correlation between the positive and negative RCOPE scales was not accepted, but the correlation coefficient of 0.24 was very close to the hypotheses posed. All exploratory hypotheses were accepted, except for a moderate positive correlation between the SOC and positive RCOPE, a slight positive correlation between the HI and positive RCOPE, a moderate inverse correlation between the SPS and negative RCOPE, and a slight positive correlation between the SPS and the HI. The hierarchical multiple regression analyses revealed that the SOC, positive RCOPE,

negative RCOPE, and SPS scores significantly predicted the HI scores at T1. Meanwhile, only SOC scores and negative RCOPE significantly predicted the HI scores at T 2.

All hypothesis posed in study I were also examined in study III, and almost all hypotheses posed in study I were confirmed in the family caregivers at T1 and T2 (Table 5).

Table 5. Correlation coefficients between SOC, negative RCOPE, positive RCOPE, HI, and SPS in healthy people (Study I) and in family caregivers of persons with breast cancer (Study III) based on the hypotheses[a] posed in Study I

Variables	Study I Healthy people (n=293)	Study III FCG[a]T1 (n=150)	FCG[a] T2 (n=115)
SOC & n-RCOPE	- 0.37	- 0.31	- 0.43
SOC & p-RCOPE	0.11	0.07	0.09
SOC & SPS	0.25	0.23	0.35
SPS & n-RCOPE	- 0.03	- 0.14	-0.30
SPS & p-RCOPE	0.60	0.54	0.58
HI & SOC	0.59	0.54	0.45
HI & SPS	0.07	0.06	0.16
HI & p-RCOPE	- 0.01	- 0.05	0.16
HI & n-RCOPE	- 0.33	- 0.26	-0.46
NRC & p-RCOPE	0.24	0.09	- 0.05

[a] Family caregivers

* Hypothesis:

1. There is a slight positive correlation between the SOC scale and the SPS (Gibson & Parker, 2003).
2. There is a moderate positive correlation between the SOC scale and the positive RCOPE scale (Pargament 1999a, 1999b).
3. There is a moderate inverse correlation between the SOC scale and the negative RCOPE scale (Pargament 1999a, 1999b).
4. There is a moderate inverse correlation between the SPS and the negative RCOPE scale (Pargament et al., 2004, Trevino et al., 2010).
5. There is a moderate positive correlation between the SPS and the positive RCOPE scale (Pargament et al., 2004, Trevino et al., 2010).
6. There is a low positive correlation between the positive and negative RCOPE scales (Pargament et al., 1998).
7. There is a moderate positive correlation between the SOC scale and the HI (Forsberg & Björvell, 1993, Cederfjäll et al., 2001, Sjöström et al., 2004).
8. There is a slight positive correlation between the SPS and the HI (Reed 1986, 1987, Runquist & Reed, 2007).
9. There is a slight positive correlation between the HI and the positive RCOPE scale (Pargament et al., 2000, 2004).
10. There is a slight inverse correlation between the HI and the negative RCOPE scale (Pargament et al., 1998, 2004).

6.2.2 CQOLC-P scale (study II)

The results of the CFA showed the RMSEA criterion to be 0.06 [confidence interval (CI): 0.053 - 0.068)], SRMR 0.07, $\chi2/df$ 1.60 (864.88/539, $p < 0.0$), CFI 0.95, NNFI 0.94, and IFI 0.95, representing acceptable fit indexes for the model structure. All items loaded to four factors ($p<0.05$, $p<0.001$), except item 35. In this thesis 27 of 35 items loaded to four factors (mental/emotional Burden, Disruptiveness, Positive adaptation, and Financial concerns) as suggested by Weitzner. The major difference appeared for items 2, 4, 13, and 15, which in the present study also loaded on Burden, whereas these items did not load on any factor in the study by Weitzner. Furthermore, items 30 and 32 loaded on Disruptiveness in our study but did not load on this factor in Weitzner. Finally, item 23 loaded on Positive adaptation, whereas in Weitzner this item did not load any factor.

Convergent validity of the CQOLC-P scale was verified. The stepwise hierarchical multiple regression analyses further supported this as the scores of SOC, negative RCOPE, higher education, and severity of breast cancer to statistically predicted the overall CQOLC-P score, accounting for 41% of the explained variance. Thus, better overall QoL was associated with a higher degree of SOC, less negative religious coping, higher education, and lower severity of breast cancer.

6.3 CQOLC-P, SOC, SPS AND RCOPE SCALE IN FAMILY CAREGIVERS (STUDY III)

6.3.1 Changes over time

The family caregivers scored statistically significantly better on overall CQOLC-P and well-being and showed lesser burden and disruptiveness at T2 than at T1. Further, they scored significantly lower on score of positive adaptation, SOC, spirituality, and negative RCOPE at T2. Changes on all the scales for each group are presented in Table 6. The effect size of the negative RCOPE score was (0.49), but the effect sizes of other scales were overall small (0.14-0.33). Less than 50% (n=56) of the family caregivers changed their overall perception of QoL by 10%. Of these 56 participants, 39 (33.9%) showed better QoL and 17 (14.8%) showed worse QoL.

Table 6. Family caregivers of persons with breast cancer and their ratings on the scales before diagnosis (T1) and 6 months later (T2) (n = 115)

Variables	T1 Mean (SD)	T2 Mean (SD)	p-value
CGQOL-P (0-140)	91.7 (20.5)	95.6 (19.3)	0.00
Mental/emotional			
Burden (0-56)	32.3 (12.5)	35.8 (11.4)	0.00
Lifestyle disruption (0-36)	27.5 (6.5)	29.5 (5.1)	0.00
Positive adaptation (0-32)	22.4 (5.4)	20.6 (5.4)	0.00
Financial concerns (0-12)	7.7 (3.4)	8.2 (3.1)	0.11
SOC (13-91)	61.7 (13.3)	59.4 (12.5)	0.03
SPS (10-60)	50.7 (6.6)	49.4 (7.1)	0.01
RCOPE			
Positive RCOPE (7-28)	22.7 (4.4)	22.1 (4.5)	0.08
Negative RCOPE (7-28)	12.0 (4.9)	9.6 (3.7)	0.00
HI (9-36)	27.1 (4)	27.8 (3.9)	0.03

6.3.2 Predictors of CQOLC-P

The overall baseline CQOLC-P score, SOC, negative RCOPE, and severity of breast cancer were the strongest predictors of a change in overall CQOLC-P scores. Thus, the greater decline in overall QoL rating, the lower the baseline QoL score, the lower degree of SOC, the higher use of negative religious coping, and the more severe stage of breast cancer. Together, these predictors accounted for 64% of the explained variance in the change of the overall CQOLC-P score (Table 7).

Table 7. Final result of the regression analysis in family caregivers of persons with breast cancer (n = 115)

Dependent variable	Independent variable	time	ß	*P*	R2
Difference of	overall CQOLC-P	T1	0.792	0.00	0.64
overall CQOLC-P	SOC	T2	-0.310	0.00	
between T1	RCOPE (-)	T2	0.315	0.00	
and T2	Severity of breast cancer		0.167	0.04	

6.4 SEIQOL (STUDY IV)

6.4.1 SEIQoL-G

The most frequently mentioned descriptors at both T1 and T2 (approximately 70% of the participants) were categorized as Health in general. In addition, more than half of the nominated important descriptors were categorized as Relationships, Financial situation, and Education at T1. At T2, Religion/spirituality (51%) and Relationships (47%) were the most frequent categories. Over time, the category Financial situation was significantly less (p= 0.049) often mentioned as being more important at T2 than at T1. In contrast, Courteous was significantly (p= 0.053) more often mentioned at T2 than at T1.

6.4.2 SEIQoL-DR

The determined descriptors affecting the life of the family caregivers were categorized as shown in Table 8. The category Psychological impact of disease was most frequently mentioned at both T1 and T2 (>70%). Furthermore, important categories found to be influenced by disease were Relationships, Concerns about disease, Religion/spirituality, and Financial situation. At T1, 20% and at T2, 23% of the family caregivers reported a positive view to life (e.g., create a positive vision of life, empathy for others, optimism, happy life, increased kindness, increased love); the corresponding figure at T2 was 23%. There were no significant differences between the categories mentioned as being more important at T1 and T2.

Table 8. Categories of disease-related QoL (SIEQoL-DR) in family caregivers to persons with breast cancer at the time of diagnosis (T1) and 6 months later (T2) Numbers and percentage are presented (n=82)[a]

	T1	T2
Categories	n (%)	n(%)
Psychological impact	59 (71.9)	58 (70.7)
Relationships	34 (41.5)	27 (32.9)
Concerns about disease	32 (39.0)	33 (40.2)
Religion/spirituality	28 (34.1)	32 (39.0)
Financial situation	26 (31.7)	32 (39.0)
Concerns about the future	22 (26.8)	17 (20.7)
Peace and comfort	22 (26.8)	16 (19.5)
Health in general	21 (25.6)	20 (24.4)
Healthy family	21 (25.6)	19 (23.2)
Working /occupation	17 (20.7)	11 (13.4)
Positive view to life	16 (19.5)	19 (23.2)
Own & family's health	12 (14.6)	9 (11.0)
Learning & development	11 (13.4)	14 (17.1)
Education	8 (9.8)	3 (3.7)
Social life/hobby	6 (7.3)	2 (2.4)
Marriage		4 (4.9)

[a]Percentage exceeds 100% because each respondent could choose more than one category

7 DISCUSSION

The focus of this thesis was QoL and coping in family caregivers to patients with breast cancer in Iran. However, there were no existing questionnaires in the Persian language for measuring QoL and coping strategies of family caregivers. Validity and reliability are typically viewed as essential elements for determining the quality of any questionnaire. Already existing questionnaires must be translated in each culture in which they are going to be used, but the translation and validation procedures are a crucial and a multi-step process aiming to achieve equivalence between the original and the translated instrument (Beaton, et al. 2000, Corless, et al. 2001, Bowden & Fox-Rushby, 2003). In this thesis six instruments were translated following a special guideline and later validated.

7.1 PSYCHOMETRIC PROPERTIES OF THE QUESTIONNAIRES

7.1.1 HI, SOC, SPS and RCOPE scale

Overall, our results provide support for the reliability of the HI, SOC scale, Brief RCOPE scale and SPS in the Iranian culture, regarding both internal consistency and stability. Item analysis of all items in each instrument demonstrated satisfactory results.

The regression model strengthened support for the validity of the scales. The SOC scale was the strongest variable explaining the variance in HI scores (well-being) as shown previously (Cohen & Dekel, 2000, Kivimäki, et al., 2000, Suominen et al, 2001, Pallant, & Lae, 2002, Sjöström et al,. 2004). The positive and negative RCOPE scales and the SPS also contributed to the prediction of well-being, confirming hypothesised relationships. Furthermore, the SOC scale appeared to be a stronger predictor of well-being than religious and spiritual coping, as measured by the RCOPE scales and the SPS. The minor positive correlation between the scale of SOC and the SPS, is in agreement with previous studies on the SOC scale and the SPS as well as other concepts of spirituality (Strang & Strang, 2001, Gibson & Parker 2003, Nygren et al., 2005, Delgado, 2007). This might indicate that both spirituality and SOC might reflect different sources of inner strength (Lundman et al., 2010). Stronger relation between the SOC and SPS or other spirituality concepts has also been affirmed (Coward, 1996, Gibson & Parker, 2003). However, in this thesis minor positive correlation between the scale of SOC and the SPS has been confirmed.

A slight positive correlation was found between positive and negative RCOPE scales indicating a divergence between the two scales. However, no significant association was found in positive and negative RCOPE scales at either T1 or T2 in study III. In other studies similar findings (no significant association in positive and negative RCOPE) have been reported in adults undergoing cardiac surgery (Ai, et al. 2009) and in family caregivers of terminally ill cancer patients (significant association in positive and negative RCOPE) (Pearce et al. 2006). In a recent literature review Pargament, reported that most studies did not show a significant association between positive RCOPE and negative RCOPE (Pargament, et al. 2011). It is rather obvious that these two concepts are distinct from each other and the reason for the slight difference between studies could be the type of stress.

7.1.2   Factor structure of CQOLC

The factor structure of the CQOLC in the sample of family caregivers had a similar factor structure as the original version but there are some differences worth mentioning. Weitzner reported eight items not belonging to any factor. However, in the present study seven of these eight items loaded on different factors (subscales) that we further used in the analyses and labelled CQOLC-P (Persian version). In this study only item "It bothers me that other family members have not shown interest in taking care of my loved one" failed to load on any of the factors, which also was the case in the original American version. However, this item loaded on the Disruptiveness factor in Tang et al.'s (2009) study. The expert panel and laypersons recruited in this thesis did not find anything particularly strange with this item. Thus, to exclude this item based on one study is not advisable. Deleting this item from the analysis did not change the reliability of the overall CQOLC-P score. The differences between the original factor analysis by Weitzner (Weitzner, et al. 1999) and the other study made in Taiwan (Tang, et al. 2009) might depend on the different samples or the time point in the patients' disease course. Our data were collected during the period that was near to diagnosis and in the study of Tang family caregivers of patients with terminal illness were included and constituted a more heterogeneous sample of patients with different diagnoses (Tang, et al. 2009). Therefore, it is crucial that more studies are conducted not only in Iran but also in other countries as well to test the factor structure of the CQOLPC, especially since it seems sensitive to the study sample.

7.2   FAMILY CAREGIVERS' QUALITY OF LIFE AT DIAGNOSIS AND 6 MONTHS LATER

Overall QoL and well-being were rated significantly higher and mental/emotional burden and lifestyle disruption significantly lower in family caregivers 6 months after the diagnosis. Comparing findings of the QoL of family caregivers according to the CQOLC-P instrument and the interview (SEIQOL) showed that the items of the subscales mental/emotional burden and lifestyle disruption are similar to the descriptors in the categories of "psychological impact of disease" and "concerns about disease". For example, in the category of psychological impact of disease and concerns about disease descriptors could be "frustration, nervousness, impact of illness on family, adverse effects of treatment, disruption of sleep, mental strain, and management of the patient's pain". Particularly noteworthy was that more than 70% of family caregivers at T1 (diagnosis) and T2 (6-month follow-up) nominated psychological impact of the disease, which is somewhat of contradictory when compared with the results of the CQOLC-P. Furthermore, concerns about disease were mentioned by more than 40% of family caregivers at both T1 and T2. According to the CQOLC-P, the scores of the sub-scales mental burden and disruptiveness decreased 6 months after diagnosis, but the number of family caregivers that determined psychological impact of the disease and concerns about disease did not decrease during the same time. These results, together with the fact that positive effects of the situation were mentioned, indicate that the CQOLC might not capture all issues that may come with being a family caregiver to a family member with newly diagnosed breast cancer and highlight the need to further evaluate the best way to assess the consequences of being a family caregiver to a person with breast cancer.

On the question of what is important in life considering QoL in general, descriptors such as feeling healthy, mentally well and not physically dependent on others (bodily),

and being physically independent were categorized as health in general and determined by the majority of the family caregivers both at diagnosis (67%) and 6 months later (73%). In a person-centered perspective the values and beliefs of persons should be respected and therefore each individual is given the opportunity to bring their meaning of health into nursing care (Wright & McCormack, 2001). The proportion of family caregivers reporting health in general as important to QoL is similar to that reported in previous studies of family caregivers of patients with amyotrophic lateral sclerosis (Olsson et al. 2010, Lo Coco et al. 2005) and in samples of healthy people (Wettergren, et al. 2003).

Overall, the changes in scores of the CQOLC-P were not estimated as clinically significant as calculated with effect size. However, when utilizing a 10% change, as suggested by Osoba et al. (2005), half of the family caregivers showed a stable QoL, about 30% of the family caregivers improved in QoL, and 15% showed a reduction in their overall QoL. Hence, although QoL does not seem to be negatively influenced in most family caregivers during the time frame from diagnosis time of breast cancer and 6 months later, it can be questioned if a stable QoL is the optimal outcome. Therefore, a challenge for nursing could be to improve QoL in conjunction with preventing further decline.

7.2.1 Relationship

Many of the family caregivers reported a negative impact from the disease onset on the relationship among family members. For instance, the family caregivers reported that the disease changed their relationship with their family member with cancer and that the disease tended to increase these problems, findings in line with Zahlis & Lewis, (2010). On the other hand, many family caregivers reported a positive impact of the disease on their relationship (improved relationship with spouse, improved family communications, and improved relationship with the relative who is ill). Some of these findings (e.g., that the relative's breast cancer brought them closer and strengthened their relationship) are in accordance with the results of Zahlis & Lewis, (2010). Good family relationships have been shown to be associated with less distress than poorer family relationships (Francis, et al. 2011).

7.2.2 Financial concerns

Financial concerns as measured by the SEIQoL-G were important to QoL. They were significantly less important at the 6-month follow-up than at the time of diagnosis (from 54.5 to 39.8%). However, financial concerns as measured by the CQOLC-P did not significantly change from T1 to T2, nor did the proportion of family caregivers that determined that the financial situation influenced their QoL because of their family member's disease (SEIQoL-DR). The financial situation might be an important topic in Iran in that Iran does not have a full financed healthcare system and relies instead on insurance systems that are not available for all inhabitants. About one third of the family caregivers stated financial concerns related to the disease (e.g., increased economic pressure and being forced to discontinue treatment because of financial difficulties). High expenditures produce additional hardships and economic burdens may add to the negative psychological impact of caregiving for patients and their family caregivers (Grunfeld, et al. 2004, Arozullah, et al. 2004). Moreover, patients may delay in seeking care because of high treatment costs. Thus, awareness of financial issues should be recognized following a diagnosis of breast cancer, especially in lower income women (Arozullah, et al. 2004).

7.2.3 Positive views

In study IV, the family caregivers reported a deeper appreciation of life and self, changed values and empathy for others, optimism, pleased life, and increased kindness and love. Meaning in life relates to the value and purpose of life, main life goals, and for some, spirituality (Breitbart, 2003, Jim, et al. 2006). However, cancer often challenges or threatens the existing beliefs of a person (Vachon, 2008). That a person can grow with facing a cancer diagnosis has been described previously. The person might rethink life goals, make a decision that is possible to achieve and therefore some persons may realize a new sense of personal control and self -affirmation throw re-examination of their self-identity (Vachon, 2008). Caring for a member with cancer might be an opportunity for the family caregiver to look at their own life and to value their life more than they did before the event (Wells, et al. 2008). Jim et al. (2006) reported that less meaning in life is related to negative emotions in persons with cancer. Optimism was significantly correlated with spiritual well-being, anxiety, depression, and HRQOL in newly diagnosed cancer patients (Mazanec et al., 2010). It is possible that encountering a life-threatening illness will make a family caregiver more alert to life and lead to a desire to invest in a more meaningful view of life.

Religion and spirituality are two dimensions important for Muslims and were among the most important areas for having QoL. In the present thesis, religion and spirituality were found to influence some of the family caregivers in a positive way. Although religion and spirituality in the Iranian cultural context are important, other areas for example, relationship, financial situation, were more important in the life of family caregivers to a person with breast cancer.

7.3 PREDICTORS OF QUALITY OF LIFE

The overall rating of QoL at the time of diagnosis was the strongest predictor in the rating of QoL change 6 months after diagnosis. This finding suggests it is important to assess the level of QoL of family caregivers of breast cancer patients at the time of diagnosis. The time of diagnosis is the most vulnerable phase in a patient's cancer trajectory despite the source of cancer diagnosis (Pitceathy, et al. 2003, Nijboer, et al. 1999). Other predictors of change for overall QoL were SOC, negative religious coping, and the severity of breast cancer. These results are in agreement with studies of patients with advanced cancer, patients with cancer and their healthy partners and family caregivers of terminally ill cancer patients (Tarakeshwar et al. 2006, Bruscia et al., 2008, Tang et al., 2006, Kim et al., 2007b). Research has shown that negative religious coping predicts worse mental health and life satisfaction in women with breast cancer (Hebert, et al. 2009). In this thesis SOC was found to be the strongest coping capacity predicting QoL. Consistent with other studies, SOC has been a predictor of QoL in family caregivers of post-stroke patients (Van Puymbroeck & Rittman, 2005), serious mental illness (Suresky et al., 2008) and cancer patients (Gustavsson-Lilius et al. 2011). The severity of a disease is an important factor for an individual's QoL. Kim, et al. (2007b) reported that family caregivers of breast cancer patients with a more severe type of breast cancer show a greater level of psychological distress than those with a less severe type of breast cancer.

7.4   COPING RESOURCES

Family caregivers rated overall QoL higher at 6 months after the time of diagnosis and during the same time, coping aspects changed in terms of scoring a lower SOC and lesser feeling of spirituality, positive adaptation, and more negative religious coping. This pattern of increased perception of QoL along with a weakness to cope with the situation seems rather surprising. Several factors might influence the QoL of family caregivers' perception, including the caregiver's personality and his or her ability to manage (coping capacity), life in a new and uncertain situation together with other individual characteristics (e.g., sex and level of education) (Wrosch & Scheier, 2003). The stability of the SOC scale has been questioned (Schnyder, et al. 2000, Nilsson et al. 2003, Feldt et al. 2011). The SOC scale has been suggested to be stable as long as the changes do not reach a level of 10% (Karlsson, et al. 2003). However, temporary fluctuations in SOC are expected (e.g. when experiencing a life-threatening event). Such a situation may be less comprehensive, manageable, and meaningful, but in the long term this does not necessarily change the person's enduring degree of SOC. A well-documented finding confirmed in our study is that a decrease in SOC and negative religious coping scores was most apparent in those family caregivers who significantly deteriorated in QoL scores. Additionally, the SOC score was stable in those family caregivers who had a stable or improved QoL.

Reducing a negative religious coping style might play an important role in helping family caregivers in Iran adapt to stressors associated with caregiving because negative coping strategies might be linked to poorer adjustment (Hills et al. 2005).

In the SEIQOL-G approximately half of the family caregivers and in SEIQOL-DR approximately 40% of the family caregivers considered religion as important and influencing their life. In this thesis positive religious coping did not change over time but the degree of spirituality decreased after 6 months. It is important to emphasize that the study sample is derived from a culture in which religion and spirituality are important in daily life. In person-centered nursing it is essential to develop a clear picture of what patients' value about their life and how they make sense of what is happening. The results of this thesis indicate how important it is for nurses to integrate persons' values into the decision-making process and in their field of practice (McCormack & McCance, 2010). McCormack stated that persons or families' beliefs about a disease might determine how they will cope (McCormack & McCance, 2010).

7.5   METHODOLOGICAL CONSIDERATIONS

The best strategy for enhancing internal validity is to use a strong research design that includes the use of control mechanisms (Polit & Beck, 2012). The strength of this thesis is its longitudinal design and that both standardized self-administrated questionnaires and semi-structured interviews were used for data collection. The longitudinal design increases the validity of the findings. However, the samples were non-random selections of healthy people and family caregivers of patients with breast cancer, which might influence the risk of bias. Although the non-random sample in Study I was from different study locations, many of the participants were healthy, rather well-educated, and women. Thus, to some extent the sample was not a representative sample of the Iranian population. This may limit the external validity of the findings, and these results should be considered with some concern.

External validity in study II-IV is strengthened by including all family caregivers of patients with breast cancer of different ages from 19 -75 years of age (Polit & Beck, 2012). When planning a study that includes a test-retest, it is important that the answers on a questionnaire are not related to the participants' responses on the first test occasion. Therefore, we decided to have a 1-month interval between the measurement times in the healthy sample (Polit & Beck, 2012). However, The CQOLC-P needs additional testing in family caregivers to confirm the content of its subscales in different settings and time frames.

In study III there are several factors that limit the generalizability of the findings. First, the ratings of QoL, SOC, spirituality, and well-being at the time of diagnosis for those who did not participate at T2 were significantly lower than those who did participate. Although we don't have enough evidence, it seems that the family caregivers who declined participation or who did not complete the T2 phase of the study were more negatively influenced in the role of family caregiver, which, on the other hand, strengthens our conclusion for the early identification of family caregivers in need of support. This possibility is supported by the sample selection bias in our study, i.e. the participants belonged to higher socioeconomic groups than the general population in Iran (the participants were more educated than the general Iranian population, with 50% of the participants having a higher education). Iran does not have a mammography screening program and therefore women must seek mammography examination on their own accord in Iranian. Mammography screening units in Iran are more common in urban areas. It seems that seeking a mammography is dependent on socioeconomic variables (e.g., women from lower socioeconomic groups tend to attend less often to breast cancer screening programs than women from higher socioeconomic groups) (Louwman et al., 2007, Montazeri et al., 2008).

 The family caregivers' mean age in this study was lower than that in other studies, which is perhaps because younger people in Iran have breast cancer than in other countries (Nijboer et al., 1999, Grunfeld et al., 2004). Additionally, and probably for the same reason, the percentage of female caregivers and daughters of patients was higher than that of other studies (Grunfeld et al., 2004).

The strength of this thesis is that it utilized widely used validated instruments that underwent a rigorous validation process with healthy people and family caregivers. However, some limitations need to be addressed. One limitation is that the samples were non-randomly selected. Thus, our sample was more educated than the general Iranian population and was generally from higher socioeconomic groups than those living in rural areas. Iranian women must look for mammography examination by themselves, and mammography units in Iran are more common in urban areas. It seems looking for a mammography dependent on socioeconomic variables (Louwman et al., 2007, Montazeri et al., 2008). In this thesis sample were collected from an urban area (Tehran) and, therefore, most probably overall more belonging to higher socioeconomic groups than those living in rural areas. Nonetheless, this is the first study in an Iranian population of this kind and for this reason is of scientific value. Still, the study should be replicated using samples that are more representative.

It was decided to perform the follow-up interview by telephone after 6 months using the SEQoL in that this was more convenient for both the family caregivers and the researcher. The attrition rate might be higher because the researcher or participants do not have to travel for face-to-face interviews. Telephone interviews with SEIQoL have been performed successfully (Sundberg et al., 2010). The telephone interview is also suggested as an effective method of data collection in research (Musselwhite et al., 2007). Consequently, a limitation might be that the interviewer cannot control for environmental factors that could distract the attention of the participants during the interview. However, it does permit greater anonymity and a more relaxed atmosphere.

The advantage of choosing the SEIQOL-DR is that, the semi-structured interview is suitable for comparing the result of standard questionnaires with individual measures not using predetermined variables.

8   NURSING IMPLICATIONS

Philosophy of care has been defined from traditional biomedical science models to a more holistic perspective. In the biomedical model the person is viewed as the sum of bio-psychosocial parts and emphasis is primarily on physical care (Landers & McCarthy, 2007). However, this thesis acknowledges the person-centered orientation as a humanistic philosophical perspective for practice and organization of nursing care, where the values and beliefs of patients and family caregivers are respected (McCormack & McCance, 2010). Moreover, a practice when everything seems to come together and the outcome is deemed satisfying (called 'person-centered moments) must increase to become an everyday cultural pattern or norm for nurses and the health team personnel (McCormack & McCance, 2010). According to McCormack (2004), persons exist as individuals (being with self) with a right for respect and dignity. Person-centered nursing therefore involves care that emphasizes respect and dignity of the individual patients. The focus of care is on the person, i.e. not only on the disease process (McCormack, 2004). To deliver person-centered nursing one must know the person, i.e. know his or her (patient/family caregiver) anxieties, fears, and needs (Davis & Kumar, 2003). McCormack & McCance (2010) described person-centered care as a rich understanding of the patients, including their environment which focuses on the context in which care is delivered. However, patients and family caregivers build various explanations around the disease.

An important role for nurses is to provide support to promote health and QoL of the patients and the family caregivers. In order to achieve this goal the nurse requires knowledge about the needs and views of the patients and family caregivers. Applying person-centered nursing facilitates communion between nurses and persons with cancer (Clarke, Hanson, & Ross, 2003) and family caregivers. It may also enable family caregivers to persons with cancer to feel proud about themselves and their patients, which can lead to a higher ability to provide care. There is an expectation that practitioners accept person-centered principles in their practice and organizations are expected to respect the values of the service user (McCormack & McCance, 2010).

The finding that coping of family caregivers of persons with breast cancer decreased after 6 months indicates the need for guidance and support from nurses. This thesis shows that family caregivers to persons with breast cancer in Iran need specific attention regarding psychological distress and their concerns about diagnose and coping ability. This could be done by implementing interventions that strengthen the individual's adjustment to the situation together with education about the disease and treatment. Other studies suggest problem solving and individual package information focused on needs of being family caregiver (Bucher et al., 1999), and education programs as beneficial ways to help family caregivers decrease their stress level when caring for a relative with breast cancer (Kim et al., 2007a).

Our findings also indicate the importance of including family caregivers in the care process and that such incorporation should start already at the time of diagnosis. One approach above using standardized questionnaires is to include a biographic account of a value history (McCormack & Tanya, 2010). By including the value history as a routine part of the person's history, nurses can help family caregivers and patients identify their beliefs, values, and attitudes about the health care process. Findings from

this thesis in conjunction with other findings show the importance of nurses being able to provide holistic care for patients and family caregivers. Assisting the family caregiver to find meaning in care could be of help to the person with disease.

9 CONCLUSIONS

The questionnaires SOC, HI, SPS, and RCOPE were found psychometric suitable to be used in Iran for both healthy people and family caregivers of patients with breast cancer.

Family caregivers to family members with breast cancer describe the disease to influence psychological state, relationship within the family, concerns about disease, religious coping, and their financial situation at time of diagnosis and 6 months later. Importantly, some family caregivers also describe positive consequences like changed view of life and an enhanced relationship in family. Overall the QoL as measured with CQOLC-P improved from the time of diagnosis to 6 months later.

The strongest predictors of QoL were the degree of SOC and negative religious coping. The rating of overall QoL at the time of diagnosis was also a strong predictor for a change of overall QoL and 6 months later. Therefore, it is important to assess the level of QoL of family caregivers already at the time diagnosis together with overall coping ability.

This thesis indicated that in standardized instruments some areas of importance in life are included in the instruments and some areas are not. Thus, the combination of a standardized instrument with individual measures or open-ended questions is recommended when investigating the QoL of family caregivers.

Taken together our results indicate that family caregivers to persons with breast cancer in Iran might have problems adjusting to the situation, which may eventually lead to decreased QoL.

10 FUTURE RESEARCH

Further studies could build on knowledge form this thesis by conducting intervention studies that support coping capacity by an education program including information about the disease and support in how to manage the situation.

The present studies focused on family caregivers at time of diagnosis and six months later and follow up studies are recommended concerning QoL in family caregivers of patients at different stage of cancers also including later stages and end of life.

Future studies are recommended to investigate the validity and reliability of the instruments in different populations and setting. Furthermore, research with a qualitative approach will contribute to the knowledge about the family caregivers life world.

11 ACKNOWLEDGEMENTS

12 REFERENCES

Abbasi-Shavazi, M. J., Morgan, S. P., Hossein-Chavoshi, M., & McDonald, P. (2009). Family change and continuity in Iran: birth control use before first pregnancy. *Journal of Marriage Family, 7*1(5), 1309-1324.

Abraído-Lanzan, A. F., Vasquez, E., & Echeverría, S. E. (2004). Religious and other forms of coping among Latinos with arthritis. *Journal of Consulting and Clinical Psychology, 72*(1), 91-102.

Ai, A. L., Seymour, E. M., Tice, T. N., Kronfol, Z. & Bolling, S. F. (2009). Spiritual struggle related to plasma interleukin-6 prior to cardiac surgery. *Psychology of Religion and Spirituality, 1*, 112-128.

Andersson, G. (2008). Chronic pain and praying to a higher power: Useful or useless? *Journal of Religion & Health, 47*, 176-187.

Antonovsky, A. (1987). *Unraveling the Mystery of Health: How People Manage Stress and Stay Well*. San Francisco: Jossey-Bass Publishers.

Arozullah, A. M., Calhoun, E. A., Wolf, M., Finley, D. K., Fitzner, K. A., Heckinger, E., … Bennett, C. L., (2004). The financial burden of cancer: estimates from a study of insured women with breast cancer. *The Journal of Supportive Oncology, 2*(3), 271-278.

Asadi-Lari, M., Madjd, Z. & Akbari, M. (2008). The need for palliative care services in Iran; an introductory commentary. *Iranian Journal of Cancer Prevention, 1*, 1-5.

Aslan, O., Sanisoglu, Y., Akyol, M., & Yektin S. (2009). Quality of sleep in Turkish family caregivers of cancer patients. *Cancer Nursing, 32(5)*, 370-377.

Bakas, T., Lewis, R. R., & Parsons, J. E. (2001). Caregiving tasks among family caregivers of patients with lung cancer. *Oncology Nursing Forum, 28*, 847-854.

Beaton, D. E., Bombardier, C., Guillemin, F. & Ferraz, M. B. (2000). Guidelines for the process of cross-cultural adaptation of self-report measures. *Spine, 25*(24), 3186–3191.

Benzein, E., Johansson, P., Arestedt, K.F., & Saveman, B.I. (2008). Nurses' attitudes about the importance of families in nursing care: a survey of Swedish nurses. *Journal of Family Nursing, 14*(2),162-80.

Bigatti, S. M., Brown, L. F., Steiner, J. L., & Miller, K. D. (2011). Breast cancer in a wife: how husbands cope and how well it works. *Cancer Nursing, 34* (3), 193-201.

Blum, K., & Sherman, D. W. (2010). Understanding the experience of caregivers: a focus on transitions. *Seminars in Oncology Nursing, 26*(4), 243-58.

Bowden, A. & Fox-Rushby, J. A. (2003). A systematic and critical review of the process of translation and adaptation of generic health-related quality of life measures in Africa, Asia, Eastern Europe, the Middle East, South America. *Social Science and Medicine*, *57*(7), 1289–1306.

Bowling, A. (1995). What things are important in people's lives? A survey of the public's judgments to inform scales of health related quality of life. *Social Science & Medicine, 41*, 1447-1462.

Breitbart, W. (2003). Reframing hope: meaning-centered care for patients near the end of life. Interview by Karen S. Heller. *Journal of Palliative Medicine, 6*(6), 979-988.

Broberger, E., Tishelman, C., & von Essen, L. (2005). Discrepancies and similarities in how patients with lung cancer and their professional and family caregivers assess symptom occurrence and symptom distress. *Journal of Pain and Symptom Management, 29*, 572-583.

Bruscia, K., Shultis, C., Dennery, K. & Dileo, C. (2008). Predictive factors in the quality of life of cancer inpatients. *Journal of Psychosocial Oncology, 26*, 75–90.

Bucher, J. A., Houts, P. S., Nezu, C. M., & Nezu, A. M. (1999). Improving problem solving skills of family caregivers through group education. *Journal of Psychosocial Oncology, 16*(3-4), 73-84.

Büssing, A., Fischer, J., Ostermann, T., & Matthiessen, P. F. (2009). Reliance on God's help as a measure of intrinsic religiosity in healthy elderly and patients with chronic diseases Correlations with health related quality of life? *Applied Research in Quality of Life, 4*, 77-90.

Calman, C. K. (1984). Quality of life in cancer patients. A hypothesis. *Journal of Medical Ethics, 10*(3), 124-127.

Cederfjäll, C., Langius-Eklöf, A., Lidman, K. & Wredling, R. (2001). Gender differences in perceived health-related quality of life among patients with HIV infection. *AIDS Patient Care and STDS, 15*, 31–39.

Cella, D.F. (1994). Quality of life: concepts and definition. *Journal of Pain and Symptom Management, 9*(3), 186-192.

Center for Disease Control and Prevention (CDC). *Healthy Living*, cdcinfo@cdc.gov, 2011.

Chen, C. Y., Liu, C. Y., & Liang, H. Y. (2009). Comparison of patient and caregiver assessments of depressive symptoms in elderly patients with depression. *Psychiatry Research, 166*(1), 69-75.

Clarke, A., Hanson, E. J., & Ross, H. (2003). Seeing the person behind the patient: enhancing the care of older people using a biographical approach. *Journal of Clinical Nursing, 12*(5), 697-706.

Cohen, J. (1988). *Statistical Power Analysis for the Behavioral Sciences*, (2nd ed.). ISBN 0-8058-0283-5.

Cohen, O. & Dekel, R. (2000). Sense of coherence, ways of coping, and well-being of married and divorced mothers. *Contemporary Family Therapy: An International Journal, 22*, 467–486.

Cohen, L., Morrison, K. & Manion, L. (2000). *Research Methods in Education*. London: Falmer Press.

Corless, I. B., Nicholas, P. K. & Nokes, K. M. (2001). Issues in cross cultural quality of life research. *Journal of Nursing Scholarship, 33*(1), 15–20.

Coward, D. D. (1996). Self-transcendence and correlates in a healthy population. *Nursing Research*, *45*(2), 116–121.

Crumbaugh, J. C., & Maholick, L. T., (1964). An experimental study in existentialism: the psychometric approach to Frankl's concept of noogenic neurosis. *Journal of Clinical Psychology*, *20*(2), 200–207.

Cummings, P. J. & Pargament, K. I., (2010). Medicine for the Spirit: Religious Coping in Individuals with Medical Conditions, *Religions, 1*, 28-53.

Dailey, D. E. & Stewart, A. L. (2007). Psychometric characteristics of the spiritual perspective scale in pregnant African- American women. *Research in Nursing and Health, 30*, 61–71.

Davis, K., & Kumar, D., (2003). Pelvic floor dysfunction: A conceptual framework for collaboration patient-centred care. *Journal of Advanced Nursing, 43*(6), 555-568.

Delgado, C. (2007). Sense of coherence, spirituality, stress and quality of life in chronic illness. *Journal of Nursing Scholarship, 39*, 229–234.

Diem & Moyer, (2005). *Community Health Nursing projects*. Philadelphia, Lippincott William & Wilkins.

Dijkers, M. P. (2003). Individualization in quality of life measurement: instruments and approaches. *Archives of Physical Medicine and Rehabilitation*, *84*(4 Suppl 2), 3-14.

Doumit, M. A., Huijer, H. A., Kelley, J. H. & Nassar, N. (2008). The lived experience of Lebanese family caregivers of cancer patients. *Cancer Nursing, 31*(4), E36-42.

Dunn, L. L., Handley, M.C., & Dunkin, J. W. (2009). The provision of spiritual care by registered nurses on a maternal-infant unit. *Journal of Holistic Nursing, 27*(1), 19-28.

Elo, S. & Kyngäs, H. (2008). The qualitative content analysis process. *Journal of Advanced Nursing*, *62*(1), 107-115.

Eriksson, M. & Lindström, B. (2005). Validity of Antonovsky's sense of coherence scale: a systematic review. *Journal of Epidemiology & Community Health*, *59*, 460-6.

Eriksson, M. & Lindström, B. (2006). Antonovsky's sense of coherence scale and the relation with health: a systematic review. *Journal of Epidemiology & Community Health*, *60*, 376-81.

Eriksson, M. & Lindstrom, B. (2007). Antonovsky's sense of coherence scale and its relation with quality of life: a systematic review. *Journal of Epidemiology & Community Health, 61*, 938-44.

Fan, X., Thompson, B. & Wang, L. (1999). The effects of sample size, estimation methods and model specification on SEM fit indices. *Structural Equation Modelling*, *6*, 56–83.

Fayers, P. M. & Machine, D. (2007). *Quality of Life: The Assessment, Analysis and Interpretation of Patient-Reported Outcomes*. West Sussex, UK: John Wiley & Sons Ltd.

Feldt, T., Leskinen, E., Kinnunen, U., & Mauno, S. (2000). Longitudinal factor analysis models in the assessment of stability of sense of coherence. *Personality and Individual Differences, 28*, 239–257.

Feldt, T., Leskinen, E., Kinnunen, U., & Ruoppila, I. (2003). The stability of sense of coherence: Comparing two age groups in a 5-year follow-up study. *Personality and Individual Differences, 35*, 1151–1165.

Feldt, T., Leskinen, E., Koskenvuo, M., Suominen, S., Vahtera, J., & Kivimäki, M. (2011). Development of sense of coherence in adulthood: a person-centered approach. The population-based HeSSup cohort study. *Quality of Life Research*, *20*(1), 69-79.

Ferguson, S. J., & Goodwin, A. D. (2010). Optimism and well-being in older adults: the mediating role of social support and perceived control. *International Journal of Aging and Human Development, 71*(1), 43-68.

Ferketich, S. (1991). Focus on psychometrics: aspects of item analysis. *Research in Nursing & Health, 14*(2), 165–168.

Ferrell, B., Ervin, K., Smith, S., Marek, T., & Melancon, C. (2002). Family perspectives of ovarian cancer. *Cancer Practice, 10*, 269-276.

Fletcher, B. S., Miaskowski, Ch., Given, B. & Schumacher, K. (2011). The cancer family caregiving experience: An updated and expanded conceptual model. *European Journal f Oncology Nursing,* 1-12.

Fontana, D. (2003). Psychology, religion, and spirituality, USA: Blackwell publishing.

Forsberg, C., & Björvell, H. (1993). Swedish population norms for the GHRI, HI, and STAI-ste. *Quality of Life Research, 2*(5), 349-356.

Francis, L. E., Bowman, K. F., Kypriotakis, G., & Rose, J. H. (2011). Relationships and emotional wellbeing among African American and White advanced cancer caregivers. Patient Education & Counseling, *85* (3), 446-53.

Friedman, M., Bowden, R., & Jones, E. (2003). *Family Nursing: Research, Theory, and Practice*. 5th ed. Upper Saddle River, NJ: Julie Levin Alexander.

Geography of Iran: facts and figures. (n.d.) *Iran Chamber Society*. Retrieved December, 21, 2011, from http://www.iranchamber.com

Gibson, L. M. & Parker, V. (2003). Inner resources as predictors of psychological well-being in middle-income African American breast cancer survivors. *Cancer Control, 10*, 52–59.

GLOBOCAN (2008). Cancer Incidence and Mortality Worldwide: IARC CancerBase No. 10 Lyon, France: International Agency for Research on Cancer, retrived December 9, 2010, from http://globocan.iarc.fr

Goya, M. (2007). *Iranian Annual Cancer Registration Report 2005/2006.* Ministry of Health and Medical Education, Health Deputy, Center for Disease Control and Prevention (In Persian). Tehran, Iran.

Grunfeld, E., Coyle, D., Whelan, T., Clinch, J., Reynol, L., Earlee, C.C., ... Glossop, R. (2004). Family caregiver burden: results of a longitudinal study of breast cancer patients and their principal caregivers. *Canadian Medical Association Journal, 170*(12), 1795-801.

Gustavsson-Lilius, M., Julkunen, J., Keskivaara, P., Lipsanen, J., & Hietanen, P. (2011). Predictors of distress in cancer patients and their partners: The role of optimism in the sense of coherence construct. *Psychological Health, 3*, 1-18.

Hancock, R. & Freeman, J. M. (2001). Power and sample size for the root mean square error of approximation test of not close fit in structural equation modeling. *Educational and Psychological Measurement, 61*, 741–758.

Harirchi, I., Kolahdoozan, S., Karbakhsh, M., Chegini, N., Mohseni, S. M., Montazeri, A., … Ebrahimi, M. (2011). Twenty years of breast cancer in Iran: downstaging without a formal screening program. *Annals Oncology, 22* (1), 93-7.

Harrington, V., Lackey, N. R. & Gates, M. F. (1996). Needs of caregivers of clinic and hospice cancer patients. *Cancer Nursing, 19*, 118–125.

Hebert, R., Zdaniuk, B., Schulz, R., & Scheier, M. (2009). Positive and negative religious coping and well-being in women with breast cancer. *Journal of Palliative Medicine, 12*(6), 537-545.

Hickey, A. M., Bury, G., O'Boyle, C. A., Bradley, F., O'Kelly, F. D. & Shannon, W. (1996). A new short form individual quality of life measure (SEIQoL-DW): application in a cohort of individuals with HIV/AIDS. *BMJ: British Medical Journal, 6313* (7048), 29-33.

Hills, J., Paice, J. A., Cameron, J. R., & Shott, S. (2005). Spirituality and distress in palliative care consultation. *Journal of Palliative Medicine, 8*(4), 782-8.

Hu, L., & Bentler, B. M. (1999). Cut off criteria for fit indexes in covariance structure analysis: conventional criteria versus new alternatives. *Structural Equation Modeling, 6*, 1–55.

Hunt, K. C. (2003). Concepts in caregiver research. *Journal of Nursing Scholarship*, *35*(1), 27-32.

Iconomou, G., Viha, A., Kalofonos, H. P., & Kardamakis, D. (2001). Impact of cancer on primary caregivers of patients receiving radiation therapy. *Acta Oncologica, 40*(6), 766–771.

Jesse, D. E., & Reed, P. G. (2004). Effects of spirituality and psychological wellbeing on health risk behaviors in Appalachian pregnant women. *Journal of Obstetric Gynecologic and Neonatal Nursing, 33,* 739–747.

Jim, H.S., Purnell, J. Q., Richardson, S.A., Golden-Kreutz, D., & Andersen, B.L. (2006). Measuring meaning in life following cancer. *Quality of Life Research*, *15*, 1355-1371.

Karlsson, I., Berglin, E., & Larsson, P. A. (2000). Sense of coherence: quality of life before and after coronary artery bypass surgery-a longitudinal study. *Journal of Advanced Nursing*, *31*(6), 1383-1392.

Kenne Sarenmalm, E., Browall, M., Persson, L.O., Fall-Dickson, J., & Gaston-Johansson, F. (2011). Relationship of sense of coherence to stressful events, coping strategies, health status, and quality of life in women with breast cancer. *Psycho-Oncology,* doi: 10.1002/pon.2053

Kilpatrick, M. G., Kristjanson, L. J., Tataryn, D. J. & Fraser, V. H. (1998). Information needs of husbands of women with breast cancer. *Oncology Nursing Forum, 25*(9), 1595-1601.

Kim, Y., Carver, C. S., Spillers, R. L., Love-Ghaffari, M., & Kaw, C. K. (2011). Dyadic effects of fear of *Life Research,* Jun 21 [Epub, ahead of print].

Kim, Y., Kashy, D. & Evans, T. (2007a). Age and attachment style impact stress and depressive symptoms among caregivers: a prospective design. *Journal of Cancer Survivorship, 1*, 35-43.

Kim, Y., & Spillers, R. L. (2010). Quality of life of family caregivers at 2 years after a relative's cancer diagnosis. *Psycho-Oncology*, *19*(4), 431-440.

Kim, Y., Wellisch, D. K., Spillers, R. L., & Crammer, C. (2007b). Psychological distress of female cancer caregivers: effects of type of cancer and caregivers' spirituality. *Support Care Cancer*, *15*(12), 1367-1374.

King, R. C. (2003). Overview of quality of life and controversial issues. In King RC, Hinds PS, eds. Quality of Life: From Nursing and Patient Perspectives: Theory, Research, Practice, (2nd ed). Boston: Jones and Bartlett Publishers, 28-37.

King, R. C., & Hinds, P. S. (2003). *Quality of Life: from Nursing and Patient, Perspectives, Theory, Research, Practices*. Toronto, Jones and Bartlett Publishers, 26-17.

Kivimäki, M., Feldt, T., Vahtera, J. & Nurmi, J.-E. (2000). Sense of Coherence and health: evidence from two cross-lagged longitudinal samples. *Social Science & Medicine, 50*, 583–597.

Kline, B. R. (2005). *Principals and Practice of Structural Equation Modeling*, (2nd ed). New York: Guilford Press.

Koenig, H. G. (2004). Religion, spirituality, and medicine: research findings and implications for clinical practice. *Southern Medical Journal, 97*(12), 1194-1200.

Landers, M. G., & McCarthy, G. M. (2007). Person-centered nursing practice with older people in Ireland. *Nursing Science Quarterly, 20* (1), 78-84.

Langius-Eklöf, A. & Samuelsson, M. (2009). Sense of coherence and psychiatric morbidity in terms of anxiety and depression in patients with major depression before and after electric convulsive treatment. *Scandinavian Journal of Caring Sciences, 23*(2), 375-9.

Legrow, K., Rossen, B. E. (2005). Development of professional practice based on a family systems nursing framework: nurses' and families' experiences. *Journal of Family nursing, 11*(1):38-58.

Lindblad, Å. K., Ring, L., Glimelius, B., & Hansson, M. G. (2002). Focus on the Individual. *Acta Oncologica*, *41*(6), 507-516.

Lo Coco, G., Lo Coco, D., Cicero, V., Oliveri, A., Lo Verso, G., Piccoli, F., & La Bella V. (2005). Individual and health-related quality of life assessment in amyotrophic lateral sclerosis patients and their caregivers. *Journal of Neurology Science, 15*, 238(1-2), 11-7.

Louwman, W. J., van de Poll-Franse, L. V., Fracheboud, J., Roukema, J. A. & Coebergh, J. W. (2007). Impact of a program of mass mammography screening for breast cancer on socioeconomic variation in survival: a population- based study. *Breast Cancer Research and Treatment, 105*, 369–375.

Lundman, B., Aléx, L., Jonsén, E., Norberg, A., Nygren, B., Santamäki Fischer, R., & Strandberg, G. (2010). Inner strength a theoretical analysis of salutogenic concepts. *International Journal of Nursing Studies, 47*(2), 251-260.

Maddi, S. R., (2002). The story of hardiness: twenty years of theorizing, research, and practice. *Consulting Psychology Journal: Practice and Research, 54* (3), 173-185.

Mazanec, S. R., Daly, B. J., Douglas, S. L., & Lipson, A. R. (2010). The relationship between optimism and quality of life in newly diagnosed cancer patients. *Cancer Nursing, 33*(3), 235-243.

McCormack, B. (2004). Person-centeredness in gerontological nursing: An overview of the literature. *International Journal of Older People Nursing, 13*, 31-38.

McCormack, B., & McCance, T. (2010). *Person-centred Nursing: Theory and Practice.* Oxford: Wiley-Blackwell.

Mehrdad, R. (2009). Health system in Iran. *International Medical Community Journal*, *52*(1), 69-73.

Montazeri, A., Vahdaninia, M., Harirchi, I., Harirchi, A. M., Sajadian, A., Khaleghi, F., et al. (2008). Breast cancer in Iran: need for greater women awareness of warning signs and effective screening methods. *Asian Pacific Family Medicine, 7*, 1–7.

Moradian, S., Aledavood, S. A., & Tabatabaee, A. (2011). Iranians cancer patients and their perspectives: a qualitative study, *European Journal of Cancer Care,* doi: 10.1111/j.1365-2354.2011.01293.x.

Mousavi, S.M., Zheng, T., & Dastgiri, S. (2009). Miller AB Age distribution of breast cancer in the middle East, implications for screening. *Breast Journal, 15*(6), 677-679.

Musselwhite, K., Cuff, L., McGregor, L. & King, K. M., (2007). The telephone interview is an effective method of data collection in clinical nursing research: a discussion paper. *International Journal of Nursing Studies, 44*, 1064-1070.

National Family Caregivers Association (n.d.). retrieved November 28, 2011, from www.cancer.gov/pdq/caregivers/.../page1availabel

Nijboer, C., Tempelaar, R., Triemstra, M., van den Bos, G. A., & Sanderman, R. (2001).The role of social and psychological resources in caregiving of cancer patients. *Cancer, 91*(5), 1029-1039.

Nijboer, C., Triemstra, M., Tempelaar, R., Sanderman, R., & van den Bos, G. A. (1999). Determinants of caregiving experiences and mental health of partners of cancer patients. *Cancer*, *86*(4), 577-588.

Nilsson, B., Holmgren, L., Stegmayr, B., & Westman, G. (2003). Sense of coherence--stability over time and relation to health, disease, and psychosocial changes in a general population: a longitudinal study. *Scandinavian Journal of Public Health*, *31*(4), 297-304.

Nordström G., Nyman C. R. & Theorell T. (1992). Psychosocial adjustment and general state of health in patients with ileal conduit urinary diversion. *Scandinavian Journal of Urology and Nephrology, 26*, 139–147.

Northouse, L., Templin, T., & Mood, D. (2001). Couples' adjustment to breast disease during the first year following diagnosis. *Journal of Behavioral Medicine, 24*(2), 115-136.

Northouse, L. L., Templin, T., Mood, D., & Oberst, M. (1998). Couples' adjustment to breast cancer and benign breast disease: a longitudinal analysis. *Psycho-Oncology, 7*(1), 37-48.

Nunnally, J. C. & Bernstein, I. H. (1994). *Psychometric Theory*. New York: McGraw-Hill.

Nygren, B., Ale´x, L., Jonse´n, E., Gustafson, Y., Norberg, A. & Lundman, B. (2005). Resilience, sense of coherence, purpose in life and self-transcendence in relation to perceived physical and mental health among the oldest old. *Aging and Mental Health, 9*(4), 354–362.

O'Boyle, C. A., (1994). The Schedule for the Evaluation of Individual Quality of Life. *International Journal of Mental Health, 23*, 3-23.

O'Boyle . A., & Waldron, D. (1997). Quality of life issues in palliative medicine. *The Journal of Neurology*, 244 Suppl 4, S18-25.

O'Connell, K. A. (2002). Spirituality, religion and personal beliefs: A dimension of quality of life? Doctoral Thesis, University of Bath, UK.

O'Connor, R. (2004). *Measuring Quality of Life in Health*. Edinburgh: Churchill Livingstone.

O'Connell, K. A. & Skevington, M. S. (2005). The relevance of: Themes from focus groups in Britain. *British Journal of Health Psychology, 10*, 379–398.

Olsson, A. G., Markhede, I., Strang, S., & Persson, L. I. (2010). Differences in quality of life modalities give rise to needs of individual support in patients with ALS and their next of kin. *Palliative & Supportive Care, 8*(1), 75-82.

Osoba, D., Bezjak, A., Brundage, M., Zee, B., Tu, D., & Pater, J. (2005). Analysis and interpretation of health-related quality-of-life data from clinical trials: basic approach of the National Cancer Institute of Canada Clinical Trials Group. *European Journal of Cancer, 41*(2), 280-287.

Oxford dictionary (7th ed). (2000). Hinsdale, IL: Penguin Press.

Pallant, J. F. & Lae, L. (2002). Sense of coherence, well-being, coping and personality factors: further evaluation of the sense of coherence scale. *Personality and Individual Differences, 33*(1), 39–48.

Pargament, K. I. (1999a). Meaning. In Multidimensional Measurement of Religiousness/Spirituality for use in Health Research (Fetzer Institute, National Institute on Aging Working Group, ed.), John E. Fetzer Institute, Kalamazo, MI, pp. 19–24.

Pargament, K. I. (1999b). Religious/spiritual coping. In Multidimensional Measurement of Religiousness/Spirituality for use in Health Research (Fetzer Institute, National Institute on Aging Working Group, ed.), John E. Fetzer Institute, Kalamazo, MI, pp. 43–56.

Pargament, K., Feuille, M., & Burdzy, D. (2011). The Brief RCOPE: Current Psychometric Status of a Short Measure of Religious Coping, *Religions*, *2*(1), 51-76.

Pargament, K. I., Kennell, J., Hathaway, W., Grevengoed, N., Newman, J., & Jones, W. (1988). Religion and the problem-solving process: Three styles of coping. *Journal for the Scientific Study of Religion, 27*, 90-104.

Pargament, K. I., Koenig, H. G. & Perez, L. M. (2000). The many methods of religious coping: development and initial validation of the RCOPE. *Journal of Clinical Psychology, 56*(4), 519–543.

Pargament, K. I., McCarthy, S., Shah, P., Ano, G., Tarakeshwar, N., Wachholtz, A., et al. (2004). Religion and HIV: a review of the literature and clinical implications. *Southern Medical Journal, 97*(12), 1201–1209.

Pargament, K. I., Smith, B. W., Koeing, H. G. & Perez, L. (1998). Patterns of positive and negative religious coping with major life stressors. *Journal for the Scientific Study of Religion, 37*(4), 711–725.

Parkin, D. M., Bray, F., Ferlay, J., & Pisani, P. (2005). Global cancer statistics, 2002. *CA: a Cancer Journal for Clinicians, 55*(2), 74-108.

Pearce, M. J., Singer, J. L., & Prigerson, H. G. (2006). Religious coping among caregivers of terminally ill cancer patients: Main effects and psychosocial mediators. *Journal of Health Psychology, 11*, 743-759.

Perz, J., Ussher, J. M., Butow, P. & Wain, G. (2011). Gender differences in cancer carer psychological distress: an analysis of moderators and mediators. *European Journal of Cancer Care, 20,* 610-619.

Pitceathly, C., & Maguire, P. (2003). The psychological impact of cancer on patients' partners and other key relatives: a review. *European Journal of Cancer*, *39*(11), 1517-1524.

Polit, F. D., & Beck, T. C. (2012). *Nursing Research Generating and Assessing Evidence for Nursing Practice*. CITY, Lippincott Williams & Wilkins.

Reed, P. G. (1986). Religiousness among terminally ill and healthy adults. *Research in Nursing and Health*, *9*, 35–42.

Reed, P. G. (1987). Spirituality and well-being in terminally ill hospitalized adults. *Research in Nursing and Health, 10*, 335–344.

Rhee, Y. S., Shin, D. O., Lee, K. M., Yu, H. J., Kim, J. W., Kim, S. O., … Yun, Y.H. (2005). Korean version of the caregiver quality of life index cancer (CQOLC-K). *Quality of Life Research, 14*, 899–904.

Roux, G. Dingley, C., & Bush, H. (2002). Inner strength in women: Meta synthesis of qualitative findings in theory development. *Journal of Theory Construction & Testing, 6*(1), 4-15.

Roux, G. Lewis, K. Younger, J. & Dingley, C. (2003). Development and testing of Inner Strength Questionnaire. *Journal of Cultural Diversity*, *10* (1), 4–5

Runquist, J. R. & Reed, P. G. (2007). Self-transcendence and wellbeing in homeless adults. *Journal of Holistic Nursing, 25*(1), 5–13.

Schubart, J., Kinzie, M., & Farace, E. (2007). Caring for the brain tumor patient: family caregiver burden and unmet needs. *Neuro-Oncology, 10*, 61–72.

Schulz, R., & Martire, L. M. (2004). Family caregiving of Persons with dementia Prevalence, Health Effects, and Support Strategies. *American Journal of Geriatric Psychiatry, 12*(3), 240-249.

Schnyder, U., Büchi, S., Sensky, T., & Klaghofer, R. (2000). Antonovsky's sense of coherence: trait or state? *Psychotherapy & Psychosomatics, 69*(6), 296-302.

Sherman, D. W. (2010). Spiritually and culturally competent palliative care. In Matzo M, (Eds), *Palliative Care Nursing: Quality Care to the End of Life*, (3rd ed), New York, NY: Springer Publishing Company.

Sherwood, P. R., Given, B. A., Given, C. W., Schiffman, R. F., Murman, D. L., Lovely, M., … Remer, S. (2006). Predictors of distress in caregivers of persons with a primary malignant brain tumor. *Research in Nursing & Health*, *29(2)*, 105-120.

Shulman, L. N., Willett, W., Sievers, A., & Knaul, F. M. (2010). Breast cancer in developing countries: opportunities for improved survival. *Journal of Oncology,* 12, doi:10.1155/2010/595167

Siegel, K., Raveis, V. H., Houts, P., Mor, V. (1991). Caregiver burden and unmet needs. *Cancer*, *68*, 11-40.

Sjöström, H., Langius-Eklöf, A. & Hjertberg, R. (2004), Well-being and sense of coherence during pregnancy. *Acta Obstetricia et Gynecologica Scandinavica*, *83*, 1112–1118.

Skärsäter, I., Rayens, M. K., Peden, A., Hall, L., Zhang, M., Agren, H., & Prochazka, H. (2009). Sense of coherence and recovery from major depression: a 4-year follow-up. *Archives of Psychiatric Nursing, 23*(2), 119-127.

Strang, S. & Strang, P. (2001). Spiritual thoughts, coping and sense of coherence in brain tumor patients and their spouses. *Palliative Medicine, 15*, 127–134.

St John, W., & Flowers, K. (2009). Working with families: from theory to clinical nursing practice, *Collegian* (Royal college of Nursing Australia), *16*(3), 131-138.

Statistical Centre of Iran. Statistical Centre of Iran [http://www.sci.org.ir] website 2009. The Results of Census 2006.

Stuart, W. G. & Laraia, M. T. (2001). *Principles and Practice of Psychiatric Nursing*. (7th ed). St Louis, USA: C.V.: Mosby.

Sundberg, K. K., Doukkali, E., Lampic, C., Eriksson, L. E., Arvidson, J., & Wettergren, L. (2010). Long-term survivors of childhood cancer report quality of life and health status in parity with a comparison group. *Pediatric Blood & Cancer*, *55*(2), 337-343.

Suominen, S., Helenius, H., Blomberg, H., Uutela, A. & Koskenvuo, M. (2001). Sense of coherence as a predictor of subjective state of health-results of 4 years of follow-up of adults. *Journal of Psychosomatic Research, 50*, 77–86.

Suresky, M. J., Zauszniewski, J. A, & Bekhet, A. K. (2008). Sense of coherence and quality of life in women family members of the seriously mentally ill. *Mental Health Nursing*, *29*(3), 265-278.

Tabachnick, G. B. & Fidell, S. L. (2007). *Using Multivariate Statistics*, (5th ed). Boston: Pearson.

Talley, R. C., & Crews, J. E. (2007). Framing the public health of caregiving. *American Journal of Public Health*, *97*(2), 224-228.

Tang, S. T., (2006). Concordance of quality-of-life assessments between terminally ill cancer patients and their primary family caregivers in Taiwan. *Cancer Nursing, 29*, 49-57.

Tang, W. R., Tang, S. T. & Kao, C. Y. (2009). Psychometric testing of the caregiver quality of life index-cancer on a Taiwanese family caregiver sample. *Cancer Nursing, 32*, 220–229.

Tarakeshwar, N., Vanderwerker, L. C., Paulk, E., Pearce, M. J., Kasl, S. V. & Prigerson, H. G. (2006). Religious coping is associated with the quality of life of patients with advanced cancer. *Journal of Palliative Medicine, 9*, 646–657.

Taylor, E. J., Outlaw, F. H., Bernardo, T. R., & Roy, A. (1999). Spiritual conflicts associated with praying about cancer. *Psycho-Oncology*, *8*(5), 386-394.

Trevino, K. M., Pargament, K. I., Cotton, S., Leonard, A. C., Hahn, J., Caprini-Faigin, C. A., & Tsevat, J. (2010). Religious coping and physiological, psychological, social, and spiritual outcomes in patients with HIV/AIDS: Cross-sectional and longitudinal findings. *AIDS and Behavior*, *12* (2), 379-389.

Vachon, M. L. (1998). Psychosocial needs of patients and families. *Journal of Palliative Medicine, 14* (3), 49-56.

Vachon, M. L. (2008). Meaning, spirituality, and wellness in cancer survivors. *Seminars in Oncology Nursing, 24*(3), 218-225.

van den Bos, G. A. (1995). The burden of chronic diseases in terms of disability, use of health care and healthy life expect. *The European Journal of Public Health, 5*, 29–34.

Van Puymbroeck, M., & Rittman, M. R. (2005). Quality-of-life predictors for caregivers at 1 and 6 months post stroke: Results of path analyses. *Journal of Rehabilitation Research and Development, 42*(6), 747-760.

Wagner, C. D., Tanmoy Das, L., Bigatti, S. M., & Storniolo, A. M. (2011). Characterizing burden, caregiving benefits, and psychological distress of husbands of breast cancer patients during treatment and beyond. *Cancer Nursing, 34*(4), 21-30.

Wagnild, G. M, & Young, H. M. (1993). Development and psychometric evaluation of the Resilience Scale. *Journal of Nursing Measurement, 1*, 165-178.

Weaver, A. J., Flannelly, L. T., & Flannelly, K. J. (2001). A review of research on religious and spiritual variables in two primary gerontological nursing journals: 1991 to 1997. *Journal of Gerontological Nursing, 27*(9), 47-54.

Weitzner, M. A., Jacobsen, P. B., Wagner, H. J. r., Friedland, J. & Cox, C. (1999). The Caregiver Quality of Life Index-Cancer (CQOLC) scale: development and validation of an instrument to measure quality of life of the family caregiver of patients with cancer. *Quality of Life Research, 8*, 55–63.

Weitzner, M. A., & McMillan, S. C. J. (1999). The caregiver quality of life index-cancer (CQOLC) scale: revalidation in a home hospice setting. *Palliative Care, 15*(2), 13-20.

Weitzner, M. A., Meyers, C. A., Steinbruecker, S., Saleeba, A. K. & Sandifer, S. D. (1997). Developing a caregiver quality of life instrument preliminary steps. *Cancer Practice, 5*, 25–31.

Wells, J. N., Cagle, C. S., Bradley, P., & Barnes, D. (2008). Voices of Mexican American caregivers for family members with cancer: On becoming stronger. *Journal of Transcultural Nursing, 19(*3), 223-233.

Wettergren, L., Björkholm, M., & Axdorph, U. (2003). Individual quality of life in long-term survivors of Hodgkin's lymphoma, a comparative study. *Quality of Life Research, 12*, 545-554.

Wettergren, L., Björkholm, M., & Langius-Eklöf, A. (2005). Validation of an extended version of the SEIQoL-DW in a cohort of Hodgkin lymphoma' survivors, *Quality of Life Research, 14*, 2331-2335.

Wettergren, L., Kettis-Lindblad, A., Sprangers, M., & Ring, L. (2009). The use, feasibility and psychometric properties of an individualized quality-of-life instrument: a systematic review of the SEIQoL-DW. *Quality of Life Research*, *18*(6), 737-746.

Wright, J., & McCormack, B. (2001). Practice development: individualized care. Nursing standard, *15*(36), 37-42.

Wright, L. & Leahey, M. (2005). *Nurses and Families a Guide to Family Assessment and Intervention* (4th ed.). Philadelphia: F.A Davis.

Wrosch, C., & Scheier, M.F. (2003). Personality and quality of life: the importance of optimism and goal adjustment. *Quality of Life Research*, *12 Suppl, 1*, 59-72.

Zahlis, E. H., & Lewis, F. M. (2010). Coming to grips with breast cancer: the spouse's experience with his wife's first six months. *Journal of Psychosocial Oncology*, *28*(1), 79-97.

Zar, H. J. (1998). *Biostatistical Analysis*. (2nd ed.), NJ: Prentice Hall.