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PROTECTIVE FACTORS OF BURDEN OF CARE AMONG CAREGIVERS OF PATIENTS WITH CANCER

By

HALA RABIH NAFFAH

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By

HALA RABIH NAFFAH

Approved by:

Fatima al- Jamil, Assistant Professor
Department of Psychology
Advisor

Nidal Najjar Daou, Assistant Professor
Department of Psychology
Member of Committee

Nadiya Slobodenyuk, Assistant Professor
Department of Psychology
Member of Committee

Date of thesis defense: May 8, 2014

AMERICAN UNIVERSITY OF BEIRUT

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AN ABSTRACT OF THE THESIS OF

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Due to the large number of people being annually diagnosed with cancer in Lebanon (approximately 7,000 people as reported by the World Health Organization (World Health Organization, Regional office for the Eastern Mediterranean, 2010) and the high dependency of cancer patients on their caregivers, it became important to investigate the resources that help caregivers of cancer patients in Lebanon to cope with their burden of care. Several research studies have demonstrated a significant association between social support and burden of care as well as mutuality and similar constructs to burden of care. The current study investigated the extent to which spirituality, mutuality, and greater social support, predicted lower levels of burden of care among 111 caregivers of patients with cancer who were recruited from the Naef K. Basile Cancer Institute at the American University of Beirut Medical Center in Lebanon. The Hierarchal Regression analysis results revealed that after controlling for the socio-demographic variables; spirituality, social support, and mutuality were found to be significant predictors of burden of care. Among the socio-demographic variables only time since diagnosis was significantly associated with burden of care. The clinical implications, limitations, and recommendations for future research are discussed.

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Chapter I

BURDEN OF CARE

Family caregivers including spouses, parents, siblings or children are often referred to as informal caregivers, since they provide unpaid care services to their sick relatives (Gunes, Calisir, Ozkan, &Orhan, 2012; Palos et al., 2011). Sharpe, Butow, Smith, Mcconnell, and Clarke (2005) reported that individuals are considered caregivers when they are responsible for handling over 50% of the patients' needs during the entire illness period. The tasks carried out for the patients by the caregivers can consist of activities such as bathing, dressing, handling the finances, carrying out shopping errands, escorting them to hospital appointments, assisting them through their treatments, attending to their nutritional needs and providing them with emotional support. Carretero, Garces, Rodenas, and Sanjose (2009) reported that the chronic nature of caregiving and the inability to anticipate the finalization of the caregiving role negatively impact the caregivers' psychological and physical well-being. Emanuel, Fairclough, Slutsman, and Emanuel (2000) also found that the caregiving role negatively impacts family and social relationships, and creates a financial burden, such that an average of 10% of the family's monthly income is spent on treatment costs.In Comparison to the United States, financial burden on caregivers in Lebanon can be higher based on several differences, such as the minimum wage in the country, the costs of treatment and the health insurance system.

The general effects of such psychological, physical, social, and financial demands have been given various labels in the literature. Among these labels are role strain, strain, caregiver difficulty, caregiver reactions (caregiver experiences), and burden of care (Garlo, O'Leary, Van Ness, & Fried, 2010; Gunes et al., 2012, Nijboer, Tempelaar, Sanderman, Triemstra, Spruijt,& van den Bos,1998; Schumacher, Stewart, Archbold, Caparro, Mutale, &Agrawal 2008).The current study was interested in examining the negative factors of caregiving and thus burden of care was more relevant to the study than caregiver reactions. Burden of care was also selected over role strain because it is the more comprehensive construct of caregiving, as it encompasses the widest range of areas associated with the difficulties of caregiving including the caregiver's psychosocial and financial problems. Nevertheless, while burden of care was the construct that was examined in the following study, role strain, strain, caregiver reactions, and caregiver difficulty were mentioned interchangeably in accordance with the construct examined in each study.

In addition, researchers have examined other constructs such as quality of life and psychological or emotional distress in relation to the caregiving role. While these studies were reviewed below, the constructs were not examined in the current study.

Schumacher et al. (2008) explained that role strain can be understood in two ways, the first is the difficulty of fulfilling caregiving tasks; this type of role strain is referred to as caregiving difficulty. The second encompasses the level of overall stress resulting from the caregiving experience; this global level of role strain is referred to as strain. As stated by Schumacher et al. (2008), the two aspects of role strain are different, since a caregiver can rate the overall caregiving situation as stressful yet carry out his/her caregiving tasks with no difficulty and vice versa.

Caregiver reactions and burden of care are similar and overlapping constructs. Caregiver reactions is multidimensional and looks at both the negative and positive aspects of caregiving (Nijboer et al., 1998). According to Given, Given, Stommel, Collins, King, and Franklin (1992), caregiver reactions, or what is also referred to as caregiver experiences, include four negative dimensions of caregiving in addition to one positive dimension. The first dimension assesses the extent to which the caregiver's daily schedule is disrupted and the level of restriction of the caregiver's social activities due to the caregiving role. The second dimension examines the amount of financial problems that arise as a result of caregiving and whether or not the caregiver is strained by them. The third dimension investigates the level of support provided to the caregiver by the family and specifically whether the caregiver is left to care for the patient alone, and the fourth dimension assesses the extent to which the caregiver's physical health is negatively affected by the caregiving role. In contrast to those negative aspects of caregiving, caregiver reactions also include one positive dimension of caregiving which is self-esteem. According to Nijboer et al. (1998), the self-esteem dimension assesses the caregiver's positive emotions related to his/her caregiving role, such as increased feelings of pride, satisfaction, and self-worth. Such positive reactions, as stated by Nijboer et al., would be a result of the newchallenges that the caregiver faces and the emotional satisfaction that he/she receives from the role he/she is playing.

The construct of burden of care also examines the above five dimensions while looking at the self-esteem subscale from a negative perspective, that is, it assesses the extent to which the caregiver resents caring for the patient and how much he/she views the caregiving role as unimportant to him/her.[1]

A. The Difficulty of Caregiving for Cancer Patients

Caregiving for patients with cancer can be very challenging due to several factors,

including the severity of the patients' disease and its threat to life (American Cancer Society, 2014), the high risk of relapse and metastasis (Esselen, Rodriguez, Growdon, Krasner, Horowitz, and Campos, 2012; Sugiyama et al., 2012), and the side effects of treatment (Andreyev, Davidson, Gillespie, Allum, &Swarbrick, 2012; Barasch& Coke, 2007; Pitello, Treon, Jones, & Kiel, 2010; Thomas et al., 2010). The American Cancer Society (2014) reported that cancer is the second most common cause of mortality after cardiac disease in the United States, contributing to one out of four deaths. According to the American Cancer Society, 1,665,540 Americans are expected to be diagnosed with cancer in 2014, out of which 585,720 are expected to die as a result of the disease, equivalent to 1600 deaths per day. Cancer was also found to be the second most common cause of death among diseases in Lebanon after cardiovascular disease, contributing to 19% of mortality as reported by the World Health Organization in 2011. The Lebanese National Cancer Registry (2003) stated that 7,888 people were diagnosed with cancer in 2003; while according to the World Health Organization in 2010, approximately 7,000 people in Lebanon are diagnosed with cancer every year. Shamseddine et al. (2014) reported that during the period ranging between 2008 and 2018, cancer prevalence rates are projected to

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[1] According to several research studies, a total burden of care score can be calculated by reversing theself-esteem subscale (Chen et al., 2009; Given et al., 2004; Shieh, Tung, &liang, 2012).

increase from 225.7 to 296.0 and from 243.9 to 339.5 cases per 100,000 for males and females respectively.

The relatively high risk of cancer recurrence is also a very stressful matter for caregivers. Sugiyama et al.'s (2012) study revealed that 29.3% of patients with esophageal cancer had a cancer relapse after undergoing an esophagectomy. Moreover, Han, Deneve, and Gonzalez (2012) reviewed several studies on the recurrence of Gastrointestinal Stromal Tumors, during which they reported the percentages of patients with cancer relapse. According to the review study, the lowest percentage of disease recurrence was 28.57%, while the highest percentage of disease recurrence was 83.05% of patients who underwent the resection. As for the recurrence of ovarian, fallopian tube, or peritoneal cancer, Esselen et al. (2012) showed that out of the 143 patients who underwent surgery, 62.9% had a relapse.

An additional factor that differentiates cancer from other types of diseases is the side effects of its treatments. The side effects differ depending on the type of treatment as well as the type of cancer. Patients undergoing chemotherapy, radiotherapy, or hormonal therapy may suffer from vomiting, nausea, pain, fatigue, insomnia, dermatitis, xerostomia, gastrointenstinal symptoms, and/or oral symptoms, such as mucositis, bleeding, and taste disorders (Andreyev et al., 2012; Barasch& Coke, 2007; Pitello et al., 2010; Thomas et al., 2010).

B. Caregivers of Cancer Patients in Lebanon

Research studies on the experiences of caregivers of cancer patients in Lebanon are very scarce; however, a qualitative study conducted in Lebanon on the topic, has provided important background information on the caregiving experience in the country (Doumit, Huijer, Kelley, &Nassar, 2008). In Lebanon, due to the cultural expectations and traditions as well as the close family ties that also stretch to the individuals' extended families, Doumit et al. (2008) found that the Lebanese family provides immense support when one of its members becomes ill. Such support includes escorting patients to their recurrent hospital visits and providing extensive care for them at home. Similarly, according to Adib and Hamadeh (1999) some Lebanese families go as far as keeping the patients uninformed of the truth about their disease in an attempt to protect them from distress.

Such high family involvement in times of illness can also increase the financial, physical, and psychological burden felt by caregivers of patients with cancer (Doumit et al., 2008). On the financial level, Doumit et al. revealed that caregivers complained of the high costs of treatment. Doumit et al. also emphasized the psychological burden of the caregivers in the study as they revealed feelings of uncertainty, fear, loss of happiness, psychological pain, hopelessness and frustration. The physical burden felt by the caregivers was highlighted as well, as one of the elderly participants reported that she had to carry out all the chores for her sick daughter such as cleaning, cooking, and ironing, in addition to attending to her grandchildren's needs. On the social level, Doumit et al. reported that the caregivers who participated in the study were living in a state of emergency, because they had to be available for the patients around the clock. One of the participants stated feeling constrained, adding that she could not go out on a date or even think of marriage as a result of her caregiving role. To cope with their painful situation, the Lebanese caregivers in Doumit et al.'s study reported resorting to spirituality, adding that their faith in God helps them to accept their relatives' situation.

C. The Caregiving Conceptual Framework

Several models have been offered in the literature in order to identify the extensive number of factors associated to the caregiving experience (Pearlin, Mullan, Semple, &Skaff, 1990; Smith, 1994). Nijboer et al.'s (1998) conceptual framework of the caregiving process is one of these models that highlights several main dimensions which can adequately explain burden of care. The model stipulates that caregiver characteristics, patient characteristics, care characteristics, and social resources contribute to caregiver reactions and burden of care. The caregiver's characteristics include his/her age, gender, education, socioeconomic status, the relation to the patient (whether the caregiver is the patient's spouse, parent, child etc), the quality of the caregiver- patient relationship, and the caregiver's mental health prior to the onset of the patient's illness. The patient's characteristics refer to the stage of illness, the level of the patient's dependency on the caregiver, and the patient's psychological state. The care characteristics include the type of care provided, whether they are practical care tasks or emotional care tasks, as well as the duration of the caregiving role and its intensity, referring to the number of hours and days spent per week taking care of the patient (Nijboer et al., 1998). The caregiver's social resources include the strength of the caregiver's social support. In a later study, Nijboer, Tempelaar, Triemestra, ven den Bos, and Sanderman (2001) added the psychological resources to the model, which included personality traits such as mastery, extraversion, and neuroticism. This framework highlights the many factors that together affect caregiver reactions and the burden of care. While it would be important to assess all of these factors in order to gain a thorough and comprehensive understanding of the caregiver experience, examining all the factors is beyond the scope of this paper. The study examined the extent to which several factors, of Nijboer et al.'s (1998) conceptual framework, associated to the caregiver characteristics, care characteristics, and caregiver resources predicted burden of care among caregivers of patients with cancer.

Chapter II

PREDICTORS OF BURDEN OF CARE

A.Caregiver Characteristics

Research studies on caregiver characteristics have focused on the caregiver's age, gender, education, socioeconomic status, and the caregiving duration. Inconsistent findings have been reported regarding the association between socio-demographic variables and burden of care, psychological distress, or caregiving difficulty. Regarding the age of the caregiver, several research studies have found a relationship between the caregivers' age and increased levels of burden of care, whereby younger caregivers experienced higher levels of burden of care than older caregivers (Francis, Worthington, Kypriotakis, & Rose, 2010; Gaston-Johansson, Lachica, Fall-Dickson, & Kennedy, 2004; Goldstein et al., 2004; Payne, Smith, & Dean, 1999). Gaugler et al. (2005) reported that younger caregivers were more likely to feel exhausted and fatigued with care demands. Younger caregivers were also shown to have higher levels of psychological distress (Kim, Wellisch, Spillers, & Crammer, 2007), higher levels of caregiver difficulty (Schumacher, Stewart, &Archbold, 2007), and worse mental quality of life than their older counterparts (Kershaw, Northouse, Kritpracha, Schafenacker, & Mood, 2004). Nonetheless, other research studies have found no association between age and burden of care, indicating that burden of care remained the same across different age groups (Daly, Douglas, Lipson, & Foley, 2009; Garlo et al., 2010; Gunes et al. 2012; Papastavrou, Charalambous, &Tsangari, 2009).

Examining the impact of education on burden of care, Gunes et al. (2012) found that caregivers with low education have higher levels of burden of care. Kershaw et al. (2004) showed that caregivers with low education have a better mental quality of life, while other studies reported no significant relationship between education and quality of life or burden of care (Garlo et al., 2010; Tang, 2009). Regarding the relationship between socioeconomic status and psychological distress, surprisingly, Kim et al. (2007) found that caregivers with higher income were more likely to have increased levels of psychological distress, while the researchers did not comment on such an unusual finding. Yet, Garlo et al. (2010) revealed that income was not significantly associated with burden of care.

The duration of caregiving or time since diagnosis have also been examined in the literature with inconsistent findings. Goldstein et al. (2004) and Garlo et al. (2010) reported that the time spent in the caregiving role was not a significant predictor of burden. Similarly, Han, Cho, Kim, and Kim (2011) found that time since diagnosis was also not a significant predictor of psychological distress in caregivers. On the other hand, Gaugler et al.'s (2005) study showed that caregivers of patients who have been receiving treatment for a shorter period of time reported having stronger feelings of role captivity. Gaugler et al. explained that such a finding could be due to an adaptation effect, meaning that the emotional distress felt by caregivers would decline with time as a result of their habituation to the nature and high demands of their caregiving role. Blood, Simpson, Dineen, Kauffman, and Raimondi (1994) also revealed that as time since diagnosis was longer, burden of care decreased.

The relationship between burden of care and caregivers living in rural and urban communities was also examined in few research studies. Imaiso, Tsukasaki, and Okoshi (2012) revealed that caregivers of elderly individuals living in urban areas experienced more burden of care than those living in rural settings. Moreover, McKenzie, McLaughlin, Dobson, and Byles (2010) conducted a review study on the difference in burden of care between caregivers of elderly people living in urban and rural areas. McKenzie et al. (2010) revealed conflicting findings in the literature, as some research studies found no difference in burden of care between urban and rural caregivers, while others found that caregivers of patients with cognitive impairments who were living in urban areas experienced more burden of care than those living in rural areas. According to Imaiso et al., such differences between urban and rural caregivers could be due to variations in social norms, social support, geographical circumstances and population structure.

The patient's age, stage of cancer, and the caregiver's marital status have also been examined, but in very few research studies. The results of such research studies have also been conflicting. Studying the patient's age in relation to burden of care, Garlo et al. (2010) and Park et al. (2012) found no significant association between patient's age and burden of care. Regarding psychological distress, Dumont et al. (2006) revealed that caregivers experienced more psychological distress only when the patients were younger and completely bedridden. Nevertheless, in the earlier stages of cancer, the patient's age was non-significantly related to the caregiver's psychological distress.

Concerning the relationship between marital status and burden of care, Meyers and Gray (2001) as well as Goldstein et al. (2004) reported that the caregiver's marital status was not significantly correlated with burden of care. Examining quality of life as a dependent variable however, Sherman et al. (2006) revealed a significant association between the caregivers' marital status and their physical quality of life, whereby married caregivers of patients with cancer reported having better physical well-being compared to single caregivers.

Due to these mixed findings, the study explored the effects of the caregiver's age, socioeconomic status, education, and time since diagnosis on burden of care and also controlled for them. Moreover, the patient's age, stage of cancer, the caregivers' marital status, and geographical living location were only controlled for since they were found to have non-significant associations with burden of care in the majority of studies. Gender was not examined in the current study, since Dr. Hibah Osman, the medical director of the Lebanese Center for Palliative Care, revealed that caregivers in Lebanon are predominantly females (personal communication, October 19, 2012).

In addition to the socio-demographic variables, the current study examined three main variables, which are mutuality, social support, and spirituality. While spirituality was selected due to its significance in the Lebanese context, mutuality and social support were selected based on previous research findings in addition to Nijboer et al.'s (1998) caregiver characteristics and social resources domains of the conceptual framework.

B. Mutuality

Mutuality is defined as the quality of the relationship between the patient and the caregiver; it is the positive emotional interaction between the two, which includes a certain degree of closeness, shared activities, and a confiding in one another (Archbold et al., 1990; Schumacher et al., 2007). Interestingly, what differentiates mutuality from the other studied variables related to the topic, is that unlike spirituality and social support, mutuality is not solely restricted to the caregiver's external resources, or to his/her set of values; mutuality also involves the patient, since a positive relationship needs the efforts of both parties.

Several studies involving mutuality investigated the variable in relation to role strain. Archbold et al. (1990) conducted a research study to investigate the influence of mutuality on nine dimensions of role strain, which include strain from direct care, strain from lack of resources, strain from worry, strain from role conflict, strain from economic burden, strain from mismatched expectations, strain from increased tension, global strain, and feelings of being manipulated. The participants were both the patients and the caregivers. The findings of the study showed that mutuality was correlated with three facets of role strain. Increased levels of mutuality predicted a decrease of strain from direct care, from increased tension, and from global strain.

Another research study by Schumacher et al. (2008) also looked into the relationship between mutuality and caregiver strain. Schumacher et al.'s study found that mutuality was significantly associated with caregiver strain, indicating that as levels of mutuality increase, caregiver strain decreases. Nevertheless, the results of the study should be reported cautiously because several other dependent variables, such as depression, total mood disturbance, fatigue, tension, difficulty, anger, vigor and confusion were included and nine multiple regression analyses were carried out, increasing the probability of type I error.

Schumacher et al. (2007) revealed that high levels of mutuality were directly associated with lower caregiving difficulty. Furthermore, Schumacher et al. (2007) reported that the relationship between caregiving demand and caregiving difficulty was moderated by levels of mutuality, that is, having high levels of mutuality contributed among other variables in decreasing the positive association between caregiving demand and caregiving difficulty. Examining mutuality as a moderator is beyond the scope of the current study.

Williamson and Schulz (1995) studied the correlation between the caregiver-patient communal relationship, a construct similar to mutuality, before the onset of illness and burden of care after the diagnosis of cancer. Caregivers and patients having a communal relationship were identified by Williamson and Schulz as sharing a reciprocal concern and understanding of one another. Caregivers who reported having fewer communal behaviors with the patient before the onset of the disease, as opposed to those with more communal behaviors, stated feeling more burdened after the patient was diagnosed with cancer, which in turn increased their depression levels. While interesting to look at the caregiver-patient relationship before the onset of illness, the current study will only be looking at the current state of the relationship.

C. Social Support

Social support is an important external resource associated to the caregiving experience. Several research studies examined the effects of social support on burden of care (Chen et al., 2009; Daly et al., 2009; Garlo et al., 2010; Goldstein et al., 2004; Kim, Duberstein, Sorensen, & Larson, 2005; Park et al., 2012; Shieh et al., 2012). Social support is defined as a network of individuals that a person depends on to receive emotional and/or instrumental support that can help him/her cope with stressful situations (Wang & Dai, 2011). Similarly, perceived or subjective social support is the extent to which the individual is satisfied with the support he/she is receiving (Zimet, Dahlem, Zimet, & Farley, 1988).

Chen et al.'s (2009) study, which included both the caregivers and the patients with oral cancer, revealed that social support was the strongest predictor of burden of care; demonstrating that decreased levels of the caregivers' social support were related to higher levels of burden of care. Similarly, Kim et al. (2005) and Goldstein et al. (2004) revealed a direct negative relationship between social support and burden of care, demonstrating that spouses of cancer patients who had greater social support reported feeling less burdened. A study conducted by Garlo et al. (2010) showed that the strongest predictor of high levels of burden of care was the need for more aid with daily errands, an aspect of social support. Gaugler et al. (2005) also found that with lower levels of caregivers’ social support, caregivers’ emotional distress increased and intimacy between the caregiver and the patient decreased.

Shieh et al. (2012) conducted a study to assess the correlation between perceived social support and burden of care among caregivers of patients with colorectal cancer. The five subscales of burden of care that were used in the study were disrupted schedule, financial burden, physical burden, lack of family support, and self-esteem. Results showed that perceived social support was negatively correlated with all the burden of care subscales except for the self-esteem dimension, whereby no significant relationship was found between perceived social support and self-esteem. Additionally, perceived social support was significantly related to the total burden of care, indicating that the higher the perceived social support, the lower the burden of care.

Another study which looked at the influence of social support on burden of care was conducted by Daly et al. (2009). Caregivers of newly diagnosed adult cancer patients participated in the study, during which the five dimensions of burden of care were studied. The results suggested that caregivers with increased social support experienced a less disrupted schedule, more family support, and fewer health problems. Additionally, Park et al. (2012) reported that caregiver support, which was defined as having people to share the caregiving role with, had a significant negative correlation on four dimensions of burden of care: lack of family support, financial problems, disrupted schedule, and health problems.

D. Spirituality

Spirituality is defined as deriving meaning and purpose from life as well as seekingfeelings of peace from a higher power (Colgrove, Kim, & Thompson, 2007). While spirituality was not identified in Nijboer et al.'s (1998) conceptual framework of the caregiving experience, it was identified in the only qualitative study conducted in Lebanon on the caregiving experience as an important internal resource (Doumit et al., 2008). Studies have examined the relationship between spirituality and caregivers' psychological distress, positive aspects of caregiving, and quality of life, and have confirmed the buffering effect of spirituality (Colgrove et al., 2007; Kim et al., 2007; Tang, 2009).

Kim et al. (2007) revealed that caregiving stress was the strongest predictor of the caregiver's psychological distress, followed by spirituality and gender-specific cancers such as ovarian or breast. On the other hand, Colgrove et al. (2007) showed that the strongest predictor of the caregiver's mental health was spirituality. Such results indicated that high spirituality was associated with better mental health. Furthermore, both studies showed a significant interaction effect between caregiving stress and caregiver spirituality on psychological distress and mental health, demonstrating that high levels of caregiving stress resulted in greater psychological distress and mental health in caregivers with decreased spirituality. Similarly, Tang (2009) also found that higher levels of caregivers' spirituality were significantly correlated with a better quality of life in caregivers.

Chapter III

AIMS AND HYPOTHESES

The aim of the study was to investigate the relationships between socio-demographic variables, mutuality, social support, spirituality and burden of care. More specifically, the primary aim was to examine the extent to which mutuality, social support, and spirituality would predict a lower level of burden of care on caregivers of patients with cancer.

Despite the numerous studies conducted on the topic, spirituality has not been investigated in relation to burden of care specifically, while caregiver-patient mutuality was examined in relation to constructs similar to burden of care. In Lebanon, only one qualitative study was carried out in the country to describe the caregivers' experiences with cancer patients. Given the Lebanese context and the family's high involvement in caregiving for patients, the caregiving experience in Lebanon may be different from that of other cultures. Therefore, the study could be a major contribution to the literature by identifying whether the above variables are relevant in predicting a lower level of burden of care in the Lebanese community. The outcome of the study may also guide professionals to focus on specific aspects with caregivers to help them cope with their caregiving responsibilities, such as strengthening their social support system, attending to their spiritual beliefs, as well as enhancing their relationship with the patient. The following hypotheses were examined while controlling for time since diagnosis, stage of cancer, the caregiver's and patient's age, the caregiver's income, education, geographical living location, and marital status.

Mutuality was shown to predict lower levels of role strain, caregiver strain and caregiver difficulty (Archbold et al., 1990; Schumacher et al., 2007; Schumacher et al., 2008).

Hypothesis 1: Higher levels of caregiver-patient mutuality will predict lower levels of burden of care while controlling for time since diagnosis, stage of cancer, the caregiver's and patient's age, the caregiver's income, education, geographical living location , and marital status.

Social support was found to predict lower burden of care and emotional distress (Chen et al., 2009; Daly et al., 2009; Garlo et al., 2010; Gaugler et al., 2005; Goldstein et al.; 2004; Kim et al., 2005; Park et al., 2012; Shieh et al., 2012).

Hypothesis 2: Greater social support will predict lower levels of burden of care while controlling for time since diagnosis, stage of cancer, the caregiver's and patient's age, the caregiver's income, education, geographical living location, and marital status.

Spirituality was associated with reduced levels of stress, psychological distress, and a better quality of life (Colgrove et al., 2007; Kim et al., 2007; Tang, 2009).

Hypothesis 3: Higher levels of spirituality will predict lower levels of burden of care while controlling for time since diagnosis, stage of cancer, the caregiver's and patient's age, the caregiver's income, education, geographical living location, and marital status.

Exploratory Hypotheses

Due to the conflicting findings on the socio-demographic variables, exploratory analyses were conducted to both examine these variables in relation to burden of care and control for their effects since they might act as extraneous variables. Specifically, some of the studies revealed that age was a significant predictor of burden of care (Francis et al., 2010; Gaston-Johansson et al., 2004; Goldstein et al., 2004; Payne et al., 1999), while other research studies have found no association between age and burden of care (Daly et al., 2009; Garlo et al., 2010; Gunes et al. 2012; Papastavrou et al., 2009).

Conflicting findings have also been reported when studying education in relation to burden of care, as some studies found that caregivers with low education have higher levels of burden of care (Gunes et al., 2012), and others found that caregivers with a low education have a better mental quality of life (Kershaw et al., 2004). On the other hand, education was neither found to be associated with burden of care nor with quality of life (Garlo et al., 2010; Tang, 2009).

Regarding socioeconomic status, Garlo et al. (2010) reported that income was not associated with burden of care. In relation to psychological distress, some studies have found that caregivers with a higher income experienced more psychological distress (Kim et al., 2007).

Inconsistent findings on time since diagnosis have also been noticed, as some studies have found that time since diagnosis was not correlated with burden of care or psychological distress (Garlo et al., 2010; Goldstein et al., 2004; Han et al., 2011), while other studies such as Blood et al. (1994) revealed that when time since diagnosis was longer, the caregivers' burden of care decreased. Gaugler et al. (2005) also showed that caregivers of patients who have been receiving treatment for a shorter period of time reported having stronger feelings of role captivity. Despite having few studies reporting a significant relationship between time since diagnosis and burden of care, the variable will be explored to investigate whether a significant correlation will be found in the current study.

Chapter IV

METHODOLOGY

A.Research Design

The proposed study is considered to be correlational because it attempts to assess the extent to which mutuality, social support, spirituality, age of the caregiver, education, socioeconomic status, and time since diagnosis predicts burden of care, the dependent variable. Age, education, socioeconomic status, and time since diagnosis were also controlled for. The variables were tested through self-report questionnaires. A factor analysis was conducted to assess the reliability of the subscales and the scales as a whole, and then a hierarchal regression analysis was carried out, whereby the above predictors were entered into several blocks.

B. Translation of the Scales

The informed consent form (refer to appendix A) and the five questionnaires that were adopted in this studywere translated using the translation-back translation technique. First, the informed consent form and the questionnaires were translated to Arabic by an Arabic linguist who is also a professional translator. Then, the translated version was back-translated to English by another translator. No inconsistencies were detected between the translated and back-translated versions and thus no changes were made to the Arabic versions of the questionnaires.

C. Instruments

1. Socio-demographics Questionnaire. This questionnaire includes the following elements: age of the caregiver, age of the patient, gender of the caregiver, type of cancer, type of treatment, stage of cancer, time since diagnosis, time since caregiving, the caregiver's relationship to the patient, marital status, number of children, level of education, geographical living location, and socio-economic status (refer to appendix B).

2. Caregiver Reaction Assessment Scale (Given et al., 1992).Burden of care is the dependent variable of the study and was measured using the Caregiver Reaction Assessment Scale (refer to appendix C), which is a twenty-four- item instrument that assesses the caregivers' reactions to caregiving (including burden of care and self-esteem) and targets caregivers of patients who suffer from various health problems. The five-point Likert scale includes five dimensions, four of which are negative and those consist of five items measuring disrupted schedule, three items assessing financial problems, five items measuring lack of family support, four items looking at health problems; while one of the constructs is positive and consists of seven items measuring the caregivers' self-esteem or their positive feelings toward their caregiving role. High scores on the four negative constructs indicate high levels of burden of care, while a high score on the self-esteem construct indicates a better self-esteem (Harkness&Tranmer, 2007). In the current research study, the self-esteem subscale was reverse coded to have a total burden of care score, where the higher the total score, the more the burden of care. According to Persson, Wennman-Larsen, Sundin, and Gustavsson (2008), the internal reliabilities of the Caregiver Reaction Assessment dimensions were good, ranging between 0.76 and 0.86.

3*. *Mutual Psychological Development Questionnaire (Genero, Miller, & Surrey, 1992). To test for the quality of the relationship between caregivers and patients, the Mutual Psychological Development Questionnaire (refer to appendix D)was used. The six- point Likert scale is comprised of two forms, each including 11 items. The first form measures the caregiver's perspective of the relationship, while the second form assesses the caregivers' opinion of the other person's perspective. The Mutual Psychological Development Questionnaire contains the following six dimensions: empathy, engagement, authenticity, zest, diversity, and empowerment. The Cronbach's alpha coefficients of the measure range from 0.89 to 0.94, indicating a high level of internal consistency (Genero, Miller, Surrey, & Baldwin, 1992).

4. The Medical Outcomes Study Social Support Scale (Sherbourne& Stewart, 1991).Social support was measured using the Medical Outcomes Study Social Support Scale (refer to appendix E), which is a five-point Likert scale consisting of 19 items. According to Sherbourne and Stewart, the scale is divided into four dimensions which are tangible support, emotional/informational support, positive interaction support, and affection. Robitaille, Orpana, and McIntosh (2011) revealed excellent internal consistencies for the four subscales, as their Cronbach's alphas ranged from .93 to .97.

5. Functional Assessment of Chronic Illness Therapy- Spiritual Well-being Subscale (Peterman, Fitchett, Brady, Hernandez, &Cella, 2002). The last predictor, spirituality, was assessed by the non-illness version of the Functional Assessment of Chronic Illness Therapy- Spiritual well-being subscale (refer to Appendix F), since the illness version is rated by the patients and not the caregivers. As stated by Bredle, Salsman, Debb, Arnold, and Cella (2011), the five-point Likertinstrument is general and does not address any specific spiritual and religious beliefs; it consists of 12 items divided into three constructs which are peace, meaning and faith. The Functional Assessment of Chronic Illness Therapy- Spiritual well-being subscale is part of a larger scale that addresses physical well-being, family/social well-being, emotional well-being, and functional well-being. The Cronbach's alphas of the three constructs of the instrument ranged from 0.78 to 0.84, as reported by Canada, Murphy, Fitchett, Peterman, and Schover (2007), indicating good internal consistency.

D. Pilot Study

A pilot study was conducted to test the reliability of the questionnaires. Due to the difficulty of recruiting caregivers of cancer patients, only ten caregivers were recruited to participate in the study. As predicted the questionnaires took 15 to 30 minutes to be completed, depending on the pace of each participant. No changes were applied to the questionnaires because the pilot study indicated no modifications to them.

1. Statistical Assumptions.Due to the pilot study's small sample size, both the statistical assumptions of the factor analysis and the factor analysis itself will not be accurate. Thus, only the reliability analyses of the scales as a whole will be reported.

2. Caregiver Reaction Assessment Scale.The reliability analysis of the scale as a whole reached a Cronbach's alpha of .64, but increased to .71 when item 13 was deleted. These results revealed that the Caregiver Reaction Assessment scale has a good overall reliability if item 13 was deleted, and thus can be used in the main study. Since the internal consistency of the scale as a whole might improve with a larger sample size, we decided not to delete item 13 and wait for the results of the psychometric properties that will be conducted on the main sample.

3. Mutual Psychological Development Questionnaire.Results revealed that the reliability of the scale as a whole was weak (Cronbach's $\alpha = .44$). Nevertheless, if we decide to delete items 1, 14, and 19, the scale would score a good internal consistency (Cronbach's $\alpha = .70$). These results suggest that the scale can be used in the main analysis, since its internal consistency can improve in case the three items are dropped.

Nevertheless, since the internal consistency of the whole scale is prone to increase with a larger sample size, we decided not to delete the three items and wait for the results of the main study's psychometric properties instead.

4. The Medical Outcomes Study Social Support Scale.The reliability of the scale as a whole was excellent reaching a Cronbach's alpha of .90. The outcome of the reliability analysis suggests that the scale has a high reliability and can be used in the main study.

5. Functional Assessment of Chronic Illness Therapy- Spiritual Well-being Subscale. Testing for the reliability analysis of the scale as whole, results showed a good internal consistency of the scale (Cronbach's $\alpha = .71$). The outcome of the scale's reliability analysis revealed that the Functional Assessment of Chronic Illness Therapy- Spiritual Well-being Subscale can thus be used in the main study.

E. Main Study

1. Procedure. Approval from the Institutional Review Board for the study protocol was provided within two months. After receiving the approval from the Institutional Review Board, a formal approval to recruit participants was sought from the medical directors of the American University of Beirut Medical Center and Trad Hospital. The formal written approval from the American University of Beirut Medical Center to recruit participants from the Naef K. Basile Cancer Institute was obtained after one month, however, the request to recruit participants from the hospital through posters was rejected. Obtaining approval from Trad Hospital lasted four months, during which data collection was coming to its end at the Naef K. Basile Cancer Institute. Thus, the recruitment was only carried out at the Naef K. Basile Cancer Institute and posters were not used to recruit participants. Following the approval of the American University of Beirut Medical Center, formal written approvals were also obtained from all the oncologists working at the Naef K. Basile Cancer Institute. Data Collection lasted for around two months and a half, beginning during the first week of October and ending during middle of December.

The caregivers of cancer patients were approached one at a time by the research investigator in the waiting room of the Naef K. Basile Cancer Institute. The same approach was used with all participants, whereby the research investigator first asked whether the potential participant was a current caregiver of a cancer patient and whether he/she was the main caregiver. If the person approached did not turn out to be the main caregiver, he/she was excluded from the study. Then, the investigator briefly explained the purpose of the study and asked whether the caregiver would agree to participate in the study. In case of the caregiver's agreement, the research investigator accompanied the caregiver to a quiet empty room to ensure his/her privacy while filling out the questionnaires. Following this process, the research investigator asked which language the participants preferred to fill out the questionnaires in and handed them the oral informed consent form. The form briefly described the aims of the study, the anonymity of the participants, the confidentiality of the received data, the potential risks and benefits of participation, as well as the participants' right to refuse the participation in the study. To ensure their anonymity, the participants were not asked to provide their names. Once the participants provided their oral consent, the research investigator handed them a packet of five questionnaires to fill out. The measures required a maximum of 15 to 30 minutes to be completed, and were given to the participants in random order using counterbalancing to control for carryover effects. The sequences of the questionnaires were equal in number such that each questionnaire was placed before and after the other scales approximately the same number of times (Christensen, Johnson, & Turner, 2011).

Data collection was carried out daily from Monday through Friday, for an average of 4 hours per day. At the beginning of the recruitment process, the number of caregivers who were recruited each day ranged between five and seven. Nevertheless, by the middle to the end of the data collection process, recruitment became much more difficult, as an average of only two to three caregivers were recruited per day.

2. Sample characteristics.Based on Tabachnick and Fidell (2007), the formula that should be used to decide on the sample size for a regression analysis is 104+m, where m is the number of predictors. The current research study examined seven predictors, four of which were also controlled for. Thus, the study sampleincluded 111 participants, which is the minimum number of participants required. Time constraints and the difficulty in recruiting participants prevented the investigator from including a larger sample size in this study.

The sample included 56 males (50.5%) and 55 females (49.5%). The caregivers' age ranged from 18 to 65 (M= 39.77; SD= 11.19): 1.8% of the caregivers were between the ages of 18 and 19; 20.7% of the caregivers were between the ages of 21 and 29; 25.2% were between the ages of 30 and 38; 28.8% ranged in age between 40 and 49; 17.1% of them were between the ages of 50 and 59; and 5.4% ranged in age between 60 and 63. As can be noticed, the highest percentage of caregivers ranged in age between 40 and 49. The majority of these caregivers were married (69.4%), while only 30.6% of them were single.

Similarly, 69.4% of the caregivers lived in urban areas as opposed to 30.6% of them who lived in rural areas. Out of all the caregivers, 61.2% had children and 38.7% had no children. The highest percentage of caregivers in the sample consisted of the patients' daughters (27.3%), while 24.5% were the patients' sons. Sisters shared the same percentage as husbands in our sample, which was 12.7%, while the wives constituted 8.2% of the sample. Similarly, 8.2% of the caregivers were the patients' brothers. The rest of the caregivers were mothers (1.8%), nieces (1.8%), nephews (0.9%), fathers (0.9%), or fathers in law (0.9%). When asked about their educational background, 36% of the caregivers reported having an intermediate or high school education, 36% reported having a Bachelor's university degree, 20.7% reported having a graduate university degree (either Master's or Doctorate degree), 5.4% had a technical school degree, while only 1.8% had an elementary education. These findings show that the majority of the caregivers in our sample are highly educated, as 56.7% have a university education. Reports on the caregiver's family income revealed that 29.7% of the caregivers had a family income ranging between \$500 and \$1000; 27.7% had a family income ranging between \$1000 and \$2000; 18.8% had a family income ranging between \$2000 and \$3000; 16.8% had a family income above \$3000; and 6.9% had a family income between 0 and \$500.

Regarding the age of the patients, their ages ranged between 21 and 80 (M = 56.27, SD = 14.45): 5.4% of the patients ranged in age between 21 and 29; 8.1% were between the ages of 30 and 39; 17.1% of them ranged in age between 40 and 49; 27% were between the ages of 50 and 59; 25.2% of them were between the ages of 60 and 68; and 17.1% ranged in age between 70 and 80. Based on these results, the highest percentage of patients was between the ages of 50 and 59.

Concerning the type of cancer, the largest percentage of patients had breast cancer with a rate of 35.5%, followed by Leukemia with 7.4%, lymphoma cancer with

6.4%, and brain cancer with 5.5%. Other types of cancer ranged in percentage between 0.9% and 4.5%. There was also a discrepancy in percentages related to the type of treatment that the patients have undergone, whereby 36.9% of patients underwent chemotherapy, followed by 19.8% who had both chemotherapy and surgery, and 13.5% who had chemotherapy, radiation therapy, and surgery. Only 0.9% of patients underwent either hormonal therapy or radiation therapy. The length of time since the patient has been diagnosed with cancer ranged from 2 weeks to 18 years (M = 21(9.5 months), SD = 10.48). The highest percentages revealed that 14.2% have been diagnosed with cancer since 1 year while 9.4% of them have been diagnosed with cancer since 3 years. When asked about the stages of cancer, 27.7% of the caregivers reported that the patient was in stage IV of the disease. The rest of the percentages on the patients' stage of cancer were: 26.5% for stage I, 24.1% for stage III, and 21.7% for stage II. Table 1 contains demographic characteristics of the participants.

Table 1

Demographic Information of Participants

Demographics	Frequency	Valid Percent
Gender		
Male	56	50.5
Female	55	49.5
Age of Caregiver		
18-19	2	1.8
21-29	23	20.7
30-38	28	25.2
40-49	32	28.8
50-59	19	17.1
60-63	6	5.4
Age of Patient		
21-29	6	5.4
30-39	9	8.1
40-49	19	17.1
50-59	30	27

60-68	28	25.2
70-80	19	17.1
Family Income		
0-$500	7	6.9
$500-$1000	30	29.7
$1000-$2000	28	27.7
$2000-$3000	19	18.8
above $3000	17	16.8
Location		
Rural areas	34	30.6
Urban areas	77	69.4
Marital Status		
Single	34	30.6
Married	77	69.4
Relation to Patient		
Daughter	30	27.3
Son	27	24.5
Husband	14	12.7
Wife	9	8.2
Sister	14	12.7
Mother	2	1.8
Father	1	.9
Brother	9	8.2
Father in law	1	.9
Niece	2	1.8
Nephew	1	.9
Missing	1	
Time since Diagnosis		
2-3 weeks	2	1.8
1-5 months	28	26.4
6-10 months	19	17.9
1-3 years	37	35
4-6 years	11	10.4
7-11 years	6	5.6
12-18 years	3	2.7
Missing	5	

Cancer Stage		
Stage I	22	26.5
Stage II	18	21.7
Stage III	20	24.1
Stage IV	23	27.7
Missing	28	
Education		
Elementary school	2	1.8
High school	40	36.0
Technical school	6	5.4
Universitydegree (BA/BS)	40	36.0
Graduate university degree (MA/Phd)	23	20.7

Chapter IV

RESULTS

A. Preliminary Analyses

Preliminary analyses were conducted prior to the main data analysis. These included missing value analysis, normality testing, and analysis of univariate and multivariate outliers.

1. Missing Data Analysis. Missing data analysis revealed that the only two variables with missing values greater than 5% were cancer stage and family income (25.2% and 9% respectively). None of the participants left these two questions blank, however, they answered with “I don’t know.” The high percentage of missing values on the family income variable is common, since it is a sensitive question. As for the stage of cancer variable, some of the caregivers were unaware which stage of cancer the patient was in and thus answered with “I don’t know.” To make sure that the missing values were not missing at random, we checked the little MCAR test which was not significant $p > .05$. This indicates that the pattern of missing values in the dataset was missing completely at random. Nevertheless, the stage of cancer variable was excluded from further analysis due to the high percentage of its missing values. Additionally, since this variable is not one of the main predictors in the study, excluding it would not be problematic. As for the family income variable, the missing values were not replaced in order not to interfere with the integrity of the participants' answers.

2.Normality. Normality of the scales was first examined visually through histograms and then through Z-scores of skewness and kurtosis. Mutuality, social support, burden of care, family income, education, caregiver's age, patient's age, number of children, and time since diagnosis were all normally distributed, with Z-scores of skewness and kurtosis below 1.96. Gender was also normally distributed with Z-scores of skewness below 1.96, nevertheless, it was platykurtic. Despite normal kurtosis, spirituality was shown to be negatively skewed, which means that the assumption of normality for this variable was violated, while the marital status and location variables were both negatively skewed and platykurtic. Despite some of the normality violations, no transformations were performed because most of these variables are control variables and the multiple regression analysis is robust to minor violations of normality.

3. Univariate and Multivariate outliers. Univariate outliers were inspectedusing Z scores with a cut-off point of absolute value of 1.96 since the sample is not too large. Cases 2, 11, 43, 85, 91, and 111 appeared to be univariate outliers in the "burden of care" dependent variable. When the "social support" variable was inspected, cases 2, 48, 53, 90, and 92 appeared to be univariate outliers. In the "spirituality" variable, cases 1, 48, 50, 55, 81, and 90 were found to be univariate outliers. As for the "mutuality" variable, cases 8, 15, 23, 30, 48, 72, 88, 98, and 107 were found to be univariate outliers. Univariate outliers in "time since diagnosis" variable were found in cases 19, 25, 61, and 111. Two univariate outliers were also detected in the “age of caregiver” variable and those were cases 8 and 33. Concerning the rest of the studied variables no cases were found to be univariate outliers. On the other hand, multivariate outliers were tested using the Mahalanobis Distance through SPSS SYNTAX with $p < .05$ criterion. None of the cases were found to be multivariate outliers. Since none of the variables were found to be both univariate and multivariate outliers and due to the small sample size, all the cases were retained.

B. Psychometric Properties

1. Statistical Assumptions.The sample size of 111 participants falls below Tabachnick and Fidell’s (2007) criterion of a minimum of 300 participants for a factor analysis. Nevertheless, we carried out the factor analysis to test for the reliability of the scales. Bartlett’s test of sphericity (which indicates whether correlations between items are large enough for PCA) was adequate for burden of care, spirituality, social support, and mutuality ($X^2(276) = 847.06$, $p< .001$; $X^2(66) = 440.48$, $p< .001$; $X^2(171) = 1450.50$, $p< .001$; $X^2(231) = 553.13$, $p< .001$ respectively). The Kaiser-Meyer-Olkin value (which assesses the sampling adequacy for the analysis) for social support was well above the recommended .7 for social support (KMO= .91), while it reached .7 for burden of care (KMO=.70). Nevertheless, Kaiser-Meyer-Olkin value for spirituality and mutuality was slightly below the recommended .7 (KMO= .69, KMO= .63 respectively). These results suggest that the sample size for mutuality and spirituality might not be adequate for factor analysis. Testing for the determinants of the studied variables, it was found that the determinants for spirituality and mutuality were greater than .00001, while the determinants for burden of care and social support were less than .00001. To further assess whether there are multicollinearity problems, the correlations matrix was checked. No correlations above .8 were found between the items of burden of care and mutuality, however, a high correlation of .85 was found between items 9 and 10 of the spirituality scale as well as between items 7 and 8 of the social support scale with a correlation of .84. As for the measures of sampling adequacy (MSA) found on the anti-image correlation matrices, they reached .5 and above for all variables except for item 4 of the mutuality scale which reached .46. Since the sample size is too small to have accurate results of these assumptions, and since the violations of some of the assumptions were minor, no changes were made to the scales and none of the items were deleted. A factor analysis was then conducted on the 4 scales using a principal component extraction method (PCA) since the aim of the analysis is scale reduction and validation. Furthermore, a varimax rotation (orthogonal) was used because the items were assumed to be independent and not correlated.

2. Caregiver Reaction Assessment Scale. The factor analysis revealed the presence of 7 factors (that was different from the 5-factor hypothesized structure) (refer to appendix G) with eigenvalues exceeding 1, which is Kaiser's criterion of retaining factors. A total of 64.20% was explained by the 7 factors together. Four of these factors were similar to the constructs that were identified by the author of the scale and those are: disrupted schedule,

financial burden, lack of family support, and health problems. Nevertheless, the items which loaded on one dimension in the original analysis which was conducted by the authors of the scale (the self-esteem subscale), were divided in our factor analysis as follows: items 1, 4, 17, and 23 formed one construct; items 9 and 20 formed another construct; while factors 7 and 12 formed the last construct. The first two factors will be called self-esteem 1 and self-esteem 2, since we do not have an explanation as to why these items loaded on two separate dimensions. Nevertheless, the third factor will be called resentment, since caregivers could have associated between feeling resentment toward caregiving and feeling that one cannot do enough caregiving. Such an association could be because the caregivers derive a sense of guilt from not being able to do enough to repay the patient and yet feel resentful towards the patient. Only one item, which is item 21 had a double loading on the financial burden construct (factor 4) and one of the two self-esteem constructs (factor 5). Since item 21 had a higher loading on the financial burden factor, it was retained as a part of it. Three items were reverse coded because they had negative loading and those were items 3, 7, and 13. Reliability analysis showed that the following factors were reliable (disrupted schedule, Cronbach's $\alpha = .80$; family abandonment, $\alpha = .75$; self-esteem 1, $\alpha = .75$; self-esteem 2, $\alpha = .77$; health problems, $\alpha = .74$). However, the financial burden ($\alpha = .65$) and the resentment factors ($\alpha = .40$) had low internal consistencies. The scale as whole had good reliability reaching a Cronbach's alpha of .78.

3.Mutual Psychological Development Questionnaire. Eight factors exceeding eigenvalues of 1 emerged from the factor analysis of the Mutual Psychological Development Questionnaire (refer to appendix H). A total of 65.99% was explained by these 8 factors combined. The items loaded on different clusters than those identified by the authors of the scale, known as empathy, engagement, authenticity, zest, diversity, and empowerment. The first factor included items 12, 13, 14, and 18. The second factor included items 4 and 10. Items 16, 20, and 21 formed the third construct, while items 15 and 17 formed the fourth construct. The fifth factor consisted of items 1, 2, 7, and 11, while the sixth factor included items 3 and 9. Items 5, 6, and 8 loaded on the seventh factor, leaving items 19 and 22 to load on the eighth factor. Only one item, which is item 13, had a double loading on the first and second factor, and was retained under the first factor because it had a higher loading. Four items were reverse coded and those were items 2, 13, 19, and 21. Reliability analysis revealed low Cronbach's alphas for all the subscales of the questionnaires except for the first construct (factor 1, Cronbach's α: .70; factor 2, α: .49; factor 3, α: .56; factor 4, α: .55; factor 5, α: .53; factor 6, α: .41; factor 7, α: .50; factor 8, α: .42). However, the reliability of the scale as a whole was good reaching a Cronbach's alpha of .77. The contradiction between the low reliability of the subscales and the good reliability of the questionnaire as a whole suggests that the questionnaire in our Lebanese culture might be uni-dimensional.

4. The Medical Outcomes Study Social Support Scale. The factor analysis of this scale revealed the presence of four factors exceeding eigenvalues of 1 (refer to appendix I). These 4 factors explained 73.36% of the variance. The factor analysis confirmed the hypothesized structure of the scale and those were: factor 1: emotional/informational support, factor 2: affection, factor 3: positive interaction support, and factor 4: tangible support. Items 1, 2, 3, 5, 9, 15, 16, 17, and 18 had double loadings and were retained under the dimensions which they had a higher loading on. All the subscales of the questionnaire had very good to excellent reliabilities (emotional/informational support, Cronbach's α = .93; affection, α = .87; positive interaction support, α = .81; tangible support, α = .73). The reliability analysis of the scale as a whole also showed excellent internal consistency reaching a Cronbach's alpha of .95.

5. Functional Assessment of Chronic Illness Therapy- Spiritual Well-being Subscale. According to the scale's psychometric properties that were reported in the literature, the scale consisted of three dimensions. Nevertheless, the factor analysis of this study revealed the presence of 4 factors, which are: faith, meaning, peace, and the new construct which we labeled inner comfort and harmony (refer to appendix J). Two items had double loadings and those were items 3 and 8. Item 3 loaded on both the comfort and meaning dimensions but was retained under the meaning dimension because it had a higher loading on it. On the other hand, item 8 loaded on both the meaning and peace dimensions but was maintained under the peace dimension due to its higher loading on it. As for the reverse coding, item 1 had a negative loading and was thus reverse coded. Interestingly, items 6, 7, and 12 which were included under the peace dimension in the original factor analysis loaded on a new and separate dimension in our sample. This could be due to the reason that these three items did not directly address the term "peace," but were more related to feelings of comfort and a sense of harmony within oneself. For example, in our culture, "I am able to reach down deep into myself for comfort" and "I feel a sense of harmony within myself" could have been understood differently from having peace of mind. An unexpected finding was the inclusion of item 8 (my life lacks meaning and purpose) under the peace dimension instead of the meaning dimension. Another unexpected finding was the loading of item 12 (even during difficult times I know that things will be okay) on the new construct which we called inner comfort and harmony instead of the faith construct. This could be due to the fact that this item did not directly address faith and could have been understood by the participants as being related to having a sense of comfort and harmony within oneself. The questionnaires' subscales demonstrated good reliability except for the fourth subscale (faith, Cronbach's $\alpha = .87$; comfort, $\alpha = .71$; meaning, $\alpha = .76$; peace, $\alpha = .53$). Concerning the reliability of the scale as a whole, it was good reaching a Cronbach's alpha of .74. Table 2 includes reliability analyses of the scales as a whole.

Table 2

Reliability Analysis of the Scales

Scale	Cronbach’s α
Caregiver Reaction Assessment	.78
Mutual Psychological Development Questionnaire	.77
The Medical Outcomes Study Social Support Scale	.95
FACIT- Spiritual Well-being Subscale	.74

C. Scale Descriptives

The mean for burden of care was below the midpoint (M = 2.29, SD = 0.46) showing that on average the caregivers did not have high levels of burden of care. Nevertheless, the means of spirituality, social support and mutuality were above the midpoint (M = 2.85, SD = 0.54; M = 3.65, SD = 0.91; M= 4.57, SD = 0.56), indicating that, on average, participants had slightly high levels of spirituality and social support, while they had even higher levels of mutuality scores. The small standard deviations on all four variables show that the data are closely clustered around the mean, suggesting that there are no vast variations in the answers provided by the participants. Table 3 presents the means and standard deviations of the scales.

Table 3

Scale Descriptives

	Mean	Standard Deviation
Spirituality	2.85	.54
Mutuality	4.57	.56
Social support	3.65	.91
Burden	2.29	.46

Midpoints for Caregiver Reaction Assessment Scale and MOS Social Support Survey = 3
Midpoint for Mutual Psychological Development Questionnaire = 3.5
Midpoint for Functional Assessment of Chronic Illness Therapy- Spiritual Well-Being Subscale = 2

D. Correlations Matrix

The main predictors which were spirituality, mutuality, and social support had a significantly negative correlations with burden of care with medium effect sizes (r = -.37, r = -.28, and r = -.36 respectively, p < .001). These results imply that burden of care decreases with higher levels of spirituality, mutuality, and social support. Time since diagnosis had a significantly positive correlation with burden of care with a medium effect size (r = .34, p < .001), suggesting that the caregiver's burden of care increases when the patient has been diagnosed with cancer for a longer period of time. No significant correlations were found between the rest of the socio-demographic variables and burden of care. This indicates that burden of care does not change with the patient's and caregiver's age, the caregiver's educational level, the caregiver's living location, and family income.

Correlations among the independent variables revealed a significantly positive relationship between spirituality and mutuality with a medium effect size (r = .36, p < .001), while a positively low correlation was found between spirituality and social support (r = .18, p < .05), indicating that the higher the spirituality levels of the caregiver, the higher the caregiver's social support and the better the quality of relationship between the caregiver and the patient. Mutuality also had a significantly positive correlation with the caregiver’s age with a small to medium effect size (r= .24, p < .01), implying that the older the caregiver the stronger the caregiver-patient quality of relationship. On the other hand, a negative relationship with a small effect size was revealed between social support and caregiver’s age (r = -.17, p < .05), showing that older caregivers have lower social support. Another significant correlation was found between marital status and spirituality with a small effect size (r = .19, p < .05), indicating that married caregivers had stronger spirituality levels as opposed to their single counterparts. Moreover, spirituality was significantly associated with geographical living location , with a small effect size (r =.18, p < .05), whereby caregivers living in urban areas were found to have stronger spirituality levels than those living in rural areas. Regarding social support, it was shown to be negatively correlated with time since diagnosis, but the effect size was small (r = -.19, p < .05). This implies that the caregiver’s social support decreased as more time passed since the patient has been diagnosed with cancer. The correlations table also showed a significantly negative association with a medium effect size between caregiver’s age and education (r = -.30, p < .01), which suggests that younger caregivers in our sample had a higher education than older caregivers. Older caregivers were also found to have been mostly married in comparison to their younger counterparts who were mostly single, as shown by the significant and positive correlation with a large effect size between caregiver’s age and their marital status (r = .53, p < .001). Married caregivers were found to be less educated than single caregivers in our sample, as shown by the significant negative correlation with a small to medium effect size between education and marital status (r = -.24, p < .05). Education was also positively correlated with geographical living location and family income with medium effect sizes (r = .30, p < .05; r= .44, p < .05 respectively), whereby caregivers living in urban areas had a higher educational level compared to those living in rural areas, and caregivers with a higher educational level had a higher family income as opposed to those with lower educational levels. Table 4 displays the correlations table.

Table 4

Pearson's Correlations between variables

	Burden of Care	Age of Caregiver	Age of Patient	Marital Status	Location	Time since Diagnosis	Education	Family Income	Spirituality	Mutuality
Age of Caregiver	.08									
Age of Patient	-.09	.09								
Marital Status	-.02	.53**	.09							
Location	.05	-.01	.18*	.02						
Time since Diagnosis	.34**	.09	-.13	.01	-.02					
Education	-.15	-.30*	.11	-.24*	.30*	-.23*				
Family Income	-.16	-.08	.09	-.09	.09	-.16	.44*			
Spirituality	-.37**	.13	-.05	.19*	.18*	.00	-.04	.04		
Mutuality	-.28**	.24*	-.14	.13	.09	-.07	.05	-.06	.36**	
Social Support	-.36**	-.17*	.00	.11	.04	-.19*	.06	.04	.18*	.05

**Correlation is significant at p < .001
*Correlation is significant at p < .05

E. Main Analysis: Hierarchical Multiple Regression

To study the predictors of burden of care among caregivers of cancer patients while controlling for certain variables as suggested by our hypotheses, a hierarchical multiple regression was carried out. Two sets of independent variables were considered. The first set included the socio-demographic variables, while the second consisted of the three main predictors (social support, mutuality, and spirituality).

A two-step hierarchical multiple regression was conducted on burden of care, the study's dependent variable. Demographic variables including age of the caregiver, age of the patient, time since diagnosis, caregiver’s education level, family income, caregiver’s marital status, and caregiver’s living location were included in the first block of the regression using the enter method, since we wanted to control for these variables. The main predictors including social support, spirituality, and mutuality were included in the second block also using the enter method, since the hypotheses on these variables were directional and not exploratory.

1. Statistical assumptions.The first trial of the regression analysis revealed that the assumptions of independence of errors, linearity, multicollinearity, and homoscedasticity were met. Nevertheless, the normality assumption was violated. The casewise diagnostics table showed that four cases might be outliers and those were: cases 107, 57, 50, and 19. When these cases were deleted the normality assumption was met, thus, we conducted a second trial of regression analysis excluding the four cases. The correlations matrix, the VIF values, and the Tolerance values revealed no problems in multicollinearity or singularity; as the correlation between the independent variables were all below 0.8, all the VIF values were below 10, and all of the Tolerance values were above 0.2. The Durbin-Watson statistic was 1.66, which means that the assumption of independence of errors is met (Refer to appendix K for details on assumptions and figures).

2.Hierarchical multiple regression.In the first block of the model, where the demographic variables were force entered, none of the variables turned out to be significant predictors. Thus, the first model did not significantly explain the variance (F (7, 91) = 2.06, p > .05). Nevertheless, when the second block of variables which included social support, spirituality, and mutuality was added to the model the total variance explained was 39.4% (R2 = .39) with F(10, 91) = 5.27, p < .01. In the final model as well, the adjusted R2= .32, implying that 7% of power is lost when we move from the sample to the population. This percentage of shrinkage might have been lower if our sample size was larger. Table 5 includes R, R2, adjusted R2, standard error of the estimate, and R2 change for the two steps of the regression analysis.

Table 5

R, R^2, adjusted R^2, and R^2 change of the Regression Equation

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate	R Square Change
1	.38[a]	.15	.08	.43	.15
2	.63[b]	.39	.32	.37	.25

After controlling for the socio-demographic variables, regression coefficients showed that the strongest predictor of burden of care is spirituality with a medium effect size, $\beta = -.31$, $p < .001$, followed by social support, $\beta = - .25$, $p < .05$, and mutuality, $\beta = - .20$, $p < .05$ with small to medium effect sizes as well. The negative relationship between these predictors and burden of care indicates that the caregiver's burden of care decreased with high levels of spirituality, social support and a better caregiver-patient quality of relationship.

Among the socio-demographic variables, time since diagnosis was a significant predictor of burden of care with a small to medium effect size, $\beta = .24$, $p < 0.05$. The positive relationship between time since diagnosis and burden of care indicates that the longer the time since the patient has been diagnosed with cancer, the greater the caregiver's burden of care. This result disconfirms the theory that stipulates that individuals become accustomed to their caregiving role, which decreases their burden of care as time passes by. The rest of the socio-demographic variables were not found to be significant predictors of burden of care, implying that burden of care does not differ with the caregivers' and patients' age, the caregiver's education level, living location, family income, and marital status.

As a conclusion, the results of the hierarchical multiple regression confirmed the study's three main hypotheses. Higher levels of spirituality, social support, and mutuality predicted lower burden of care. As for the socio-demographic variables only one was found to be a significant predictor and this was time since diagnosis. Spirituality was revealed to be the strongest predictor. Table 6 includes the unstandardized regression coefficients (*B*), the standard error of (*B*), and the standardized coefficients (β).

Table 6

Regression Parameters

	Unstandardized Coefficients		Standardized Coefficients	
Model	B	Std. Error	Beta	T
(Constant)	4.018	.474		8.47*
Age of Caregiver	.003	.004	.07	.65
Age of Patient	-.004	.003	-.14	-1.49
Marital Status	.032	.104	.03	.31
Location	.180	.091	.19	1.98
Time since Diagnosis	.010	.004	**.24**	2.60*
Education	-.022	.041	-.06	-.53
Family Income	-.032	.037	-.08	-.86
Spirituality	-.268	.083	**-.31**	-3.22*
Mutuality	-.166	.081	**-.20**	-2.05*
Social Support	-.123	.047	**-.25**	-2.63*

*Correlation is significant at p < .05

Chapter IV

DISCUSSION

A. Dimensions of Burden of Care in Lebanon

The current study examined the burden of care construct as measured by the Caregiver Reaction Assessment scale in the Lebanese context, and a factor analysis revealed the presence of a greater number of factors than what were originally found in a US sample. The original factor analysis of the Caregiver Reaction Assessment scale revealed the presence of five constructs which were: disrupted schedule, health problems, family abandonment, financial burden, and self-esteem. Nevertheless, in our current study seven constructs were extracted from our factor analysis of the Caregiver Reaction Assessment Scale, whereby the items which constituted the original self-esteem construct loaded on three separate factors in our analysis. The original self-esteem factor included a mix of positive feelings (such as feeling privileged to care for the patient, wanting to care for the patient, and feeling good about caregiving for the patient) and negative feelings (such as resenting to care for the patient). Yet, in our sample, “I will never be able to do enough caregiving to repay the patient,” loaded on the same factor as “I resent caring for the patient,” which we labeled resentment. It could be argued that this new construct in our analysis is an indication of the prominence of the caregivers’ feelings of resentment in the Lebanese context. In the Western culture, “I will never be able to do enough caregiving to repay the patient” reflected a greater sense of gratitude towards the patient and a wish to help him/her, and thus, loaded on positive self-esteem. Nevertheless, in our sample, caregivers may take it as their natural duty and responsibility to care for their sick relatives and are prone to develop negative feelings in cases where they believe that they are not fulfilling their caregiving role to its maximum.

B. The Low Average of Burden of Care

Interestingly, the mean for burden of care in the current study's sample was below the midpoint, demonstrating that on average the caregivers did not have high levels of burden of care. On the other hand, the means of spirituality, social support and mutuality were above the midpoint, indicating that, on average, participants had high levels of spirituality and social support, while they had even higher levels of mutuality scores. The high means of spirituality, social support, and mutuality may help explain the low average of burden of care. Another explanation may be that participants found it difficult to admit to high levels of burden of care due to social desirability or their belief in their duty to care for the patients.

The high means of the social support, spirituality, and mutuality can be interpreted as a reflection of the caregivers' strong reliance on these factors to derive comfort and release their distress. Thus, the high means of these predictors indicate their significance in the caregivers' daily lives. They also reaffirm the collectivist/relational nature of our culture, specifically when it comes to interpersonal relationships, family bonds, and social support. The results also show that caregivers still hold on to their faith and derive strength from their spiritual beliefs, despite the highly demanding and distressing role that they take on with the patients.

C. Socio-demographic Variables

Compared to the inconsistent findings in the literature regarding the relationship between socio-demographic variables and burden of care, the current study found that none of the socio-demographic variables, except for time since diagnosis, was significantly correlated with burden of care. Such an outcome was similar to that of some of the studies which showed that burden of care did not differ across the caregiver’s age, educational level, and socioeconomic status (Daly et al., 2009; Garlo et al., 2010; Gunes et al. 2012; Papastavrou et al., 2009; Tang, 2009).

The relationship between time since diagnosis and burden of care showed that the more time since the patient had been diagnosed with cancer, the greater was the burden of care. Such a finding suggests that despite being habituated to the caregiving role, caregivers still experience higher levels of burden of care as more time passes by since the patient’s diagnosis. This might be due to the increased financial expenses, the higher demands required of caregivers especially with the advancement of cancer, as well as the accumulation of the caregiver’s fatigue and stress over time. Such an outcome disconfirms the hypothesis that stipulates that burden of care decreases with habituation (Blood et al., 1995; Gaugler et al., 2005).

In the traditional Arab culture, females are expected to fulfill their role as caregivers as part of their duties toward their family members (Dwairy, 1997). Often, they are not offered an opportunity to have their own careers, and may even be expected to drop their careers in order to take the role of caregivers in their families. Yet, contrary to what has been assumed, males and females fulfilled the role of caregiving for patients with cancer despite the expected cultural role of females. In our study, percentages showed that 50.5% of the sample consisted of male caregivers, and 49.5% consisted of female caregivers. The high percentage of patients with breast cancer (35.5%) in our sample, who probably required that their husbands accompany them to the hospital for their treatment, could be one possible explanation to the high presence of male caregivers in the Naef K. Basile Cancer Institute.To identify whether any differences existed in burden of care between male and female caregivers, additional exploratory analyses were conducted in this study. The results revealed that gender was not a predictor of burden of care.

An interesting outcome of this study was the high percentage of participants (25.2%) who did not know the stage of cancer the patient was in. This could be an indication of the overwhelming and distressing nature of cancer, whereby caregivers would not pay attention to such medical details. Another explanation can be the educational level of the caregivers, as caregivers with a higher education are expected to inquire more about the details of the disease and how it progresses. This was particularly evident when the t-test was conducted as part of the missing value analysis between the caregiver's educational level and the patient's stage of cancer. Results showed that participants who did not know which stage of cancer the patient was in had an intermediate or high school education.

D. Spirituality as the Strongest Predictor

Spirituality was included as an independent variable in the current study after taking into consideration the difference between the Western and non-Western cultures; specifically, the significant role that spirituality plays in the Lebanese context (Adib&Hamadeh, 1999; Doumit et al., 2008). Despite the fact that spirituality has not been studied before in relation to burden of care, interestingly, it was found to be the strongest predictor in our study. Furthermore, the negative association between spirituality and burden of care revealed that spirituality can act as a protective factor of burden of care, since the more spiritual the caregivers reported themselves to be, the lower their burden of care. As mentioned above, this finding highlights the significance of spirituality in the caregivers’ lives, as it can act as an effective coping mechanism against their feelings of burden. It indicates that individuals with a strong sense of purpose, meaning, and faith in life and who feel at peace with themselves can handle their stressful caregiving role with reduced burden of care compared with individuals who have lower spirituality levels. Nevertheless, knowing that spirituality is the strongest predictor, it is important to note that the association between spirituality and burden of care did not exceed a medium effect size.

E. Social Support and Mutuality as other Predictors of Burden of Care

Similar to what have been reported in various studies, social support has been found to bea significant predictor of burden of care in our study. The results showed that burden of care decreases when caregivers of cancer patients are usually surrounded and supported by friends and family. This finding is not surprising, since caregivers who have friends and family to support them, would have more time to attend their jobs and to carry out different activities and errands that are not related to caregiving. This in turn, would make them feel less stressed, less abandoned, and would result in fewer health problems. In Lebanon, the presence of social support from family and friends in the caregivers’ lives may also provide financial support, which would in turn reduce the caregivers’ financial burden. Nevertheless, social support did not appear as strong as spirituality in predicting lower burden of care levels among caregivers of cancer patients, especially with its small to medium effect size. One possible explanation could be that the internal process which distinguishes spirituality from social support in addition to the inner peace and comfort that are derived from high spirituality levels can further protect caregivers from burden of care compared to social support.

Lastly, mutuality which is defined as the quality of the caregiver-patient relationship was also found to be a significant predictor of burden of care. Contrary to social support and spirituality, this variable involves both the caregiver's and the patient's role in reducing the burden of care that is experienced by the caregiver. More specifically, mutuality exclusively addresses the relationship between the caregiver and the patient. In this study, it was revealed that burden of care among caregivers of cancer patients lessens with a better quality of caregiver-patient relationship. Caregivers who have a good quality of relationship with the patients are those who have a mutually trusting relationship with their sick relatives, whereby not only do they understand the patients' concerns and listen to them but also get to share their thoughts, concerns, and feelings with the patients. This means that caregivers with a better quality of a relationship with their sick relatives could feel more attuned to them, have better communication with them, be more at ease with carrying out their caregiving role, and consider their caregiving role less of an obligation. As a result of all these positive aspects of a good quality of a caregiver-patient relationship, the caregiver may feel less burdened to care for the patient and may even enjoy the caregiving process more than those who have a bad relationship with their sick relatives. Similar to social support, mutuality also had a small to medium effect size in relation to burden of care. This suggests that relying on inner resources such as spirituality can be more effective than depending on social support and mutuality to better cope with the patient's disease.

As a conclusion, the current study showed that part of Nijboer et al.'s (1998) conceptual framework is applicable to Lebanon, as several of the variables that were included within its domains were significantly correlated to burden of care. More specifically, mutuality, which was incorporated in the caregiver's characteristics domain of the conceptual framework, time since diagnosis which was included under the care characteristics domain, and social support which constituted the social resources domain, were found to be significant predictors of burden of care. Nevertheless, the rest of the variables that were included under the caregiver characteristics domain of the conceptual framework, such as age, gender, education, and socio-economic status had no significant association with burden of care.

F. Clinical Implications

Caregivers of cancer patients pass through various difficulties and challenges during their caregiving process, such as accepting the patient's disease and coping with its chronic nature, accepting and coping with the high demands that their caregiving role entails, accepting and coping with the major changes that will occur in both their lives and the patient's, as well as dealing with the psychological distress and the physical fatigue that result from caring for the patient. Thus, the main concern to be addressed is how to aid caregivers of cancer patients to better handle such a big responsibility.

According to the outcome of the study, having high spirituality levels, good social support, and a strong quality of a relationship with the patient can help decrease the caregivers' burden of care.More specifically, spirituality was shown to be the strongest predictor of burden of care. This highlights the importance of having caregivers to depend on their inner resources to extract strength and comfort. It also suggests that interpersonal relationships are not the only means that aid caregivers in overcoming their difficult caregiving experiences, as they should also pass through a personal process to find their own inner sense of comfort and peace of mind.

Health care professionals can also play a role in aiding caregivers to handle their caregiving responsibilities with reduced feelings of burden. This can be accomplished by forming a social support group for caregivers, whereby caregivers can share their difficult caregiving experiences and assist with other caregivers who are passing through similar challenges. Thus, the social support group would aid caregivers in broadening their social support system, accepting their caregiving role, and preparing for their upcoming challenges through listening to other caregivers' experiences. Through the social support group as well, caregivers can discuss their strengths and their positive interactions with the patients, which may encourage caregivers to adopt new more adaptive approaches of dealing with the patients, which may in turn, improve the caregiver-patient mutuality. Furthermore, forming a social support group is particularly important, since the findings of this study showed that the caregivers' social support decreases as time passes by on the patient's diagnosis and that burden of care increases with time. This means that with time, caregivers can lose one of their main protective factors of burden of care. In such a case, the caregivers' need for support would increase and the social support group may compensate for these unmet needs.

On a similar level, psycho-educational sessions can be provided to the caregivers to help them strengthen their relationship with the patients. The caregivers' lack of knowledge regarding the details of the patients' disease may keep the caregivers uninformed of how they should deal with the critical psychological and health problems that the patients are suffering from. This may in turn, reflect badly on the caregiver-patient interaction, as many misconceptions, misunderstandings, and conflicts may arise, turning caregiving into an even more difficult process. Thus, it is important to educate caregivers on the various stages of cancer, how the patients react to their pain, and how their disease affects their psychological states as well as their interaction with people. Through the psycho-educational sessions, the caregivers can also learn new techniques to properly communicate with the patients, to properly deal with their fragile psychological states, and to engage in activities that are of interest to both the caregiver and the patient. Providing such valuable information to the caregivers would help them become more aware of the patients' general psychological and health states and thus, more understanding of the patients' reactions. It would also guide the caregivers on how to interact with their sick relatives, which would in turn enhance the quality of their relationship with the patients and help reduce their burden of care.

It is noteworthy to mention that services are already being provided by few non-governmental organizations in Lebanon to help caregivers of terminally ill patients to better adapt to their caregiving experience. The results of the current study further confirm the need for these services to be integrated into the medical centers in Lebanon to reach out to a greater number of caregivers. The Lebanese Center for Palliative Care, Balsam, is one of the few non-governmental organizations that aim to relieve patients from their suffering and enhance their quality of life. The organization offers emotional, psychological, and social support to the patients and their families during the illness period. It also aids the patients' families to better understand end of life concerns, family dynamics, and existential processes. Additionally, Balsam supports caregivers by teaching them methods to properly care for their sick relatives (http://www.balsam-lb.org/services.php). Such services demonstrate the importance of supporting caregivers, attending to their spiritual needs, and providing them with methods to enhance the quality of their relationship with their sick relatives.

G. Contribution to the Literature

Spirituality was neither examined in relation to burden of care in the literature nor incorporated in Nijboer et al.'s (1998) conceptual framework. Thus, the main contribution of the current study to the literature is its inclusion of spirituality as an independent variable in relation to burden of care. Moreover, the results of the current study, which revealed spirituality as the strongest predictor of burden of care, highlighted the important role of such an internal resource, an area which has not been focused on in the literature. Another contribution is the implementation of this study within the Lebanese context, especially with the absence of any quantitative studies in Lebanon on the topic.

H. Limitations

Despite the significant findings that have been revealed by this study, several limitationsshould be reported. A major limitation of the current study is the absence of a comparison group due to time constriction and the difficulty of recruitment. A comparison group would have helped in identifying whether differences in burden of care existed between caregivers of cancer patients and caregivers of patients of another disease.

In comparison to some studies in the literature which included both patients and caregivers in their sample (Chen et al., 2009), the current sample only consisted of caregivers. This can pose as a limitation to the study, since the inclusion of patients can provide a more comprehensive view of the caregiving experience. For example, it can highlight on the specific problems that are instigated between the caregivers and the patients. Moreover, it can give a clearer view on the demands of patients and how they influence burden of care among caregivers.

Another limitation is the nature of the questionnaires, which are self-report measures. Self-report measures are prone to response biases, especially when the sensitive nature of the topic and our culture are taken into consideration. In other words, despite the anonymity of the study, the caregivers may have felt uncomfortable with reporting high levels of burden of care, when they believe that it is their obligation to provide care to their sick relatives and thus there may be a social desirability confound or bias. It is also noteworthy to mention that we cannot infer causation from self-report questionnaires. Another limitation in the questionnaires was related to the low reliability coefficients of the Mutual Psychological Development Questionnaire subscales, despite the high reliability of the scale as whole.

Recruiting participants from the cancer center's waiting room, introduced another limitation. Some of the participants who were filling out the questionnaires had to stop in the middle of the questionnaire when they were called for to attend their doctor's appointment. In such cases, the participants completed filling the questionnaires after they finished their appointments. On another level, some participants asked more questions than others, while some asked that I remain seated next to them while reading the questions to them. My presence next to the participants while they were filling out the questionnaires could have influenced their responses. This also means that not all participants completed the measures under the same conditions, which could have introduced a bias to the study.

Finally, the participants who agreed to participate in the study could have different characteristics than those who refused to participate in the study, thus creating a potential voluntary response bias. For example, caregivers who accepted to fill out the questionnaires could have lower burden of care levels than those who refused. Such a possibility means that the study could have excluded caregivers who suffered from high levels of burden of care.

I. Future Recommendations

One of the main limitations of the current study was the absence of a comparison group. Thus, future research studies on the topic are recommended to include a comparison group. The comparison group can consist of caregivers of patients with kidney failure, who undergo dialysis for their treatment. What makes the comparison between these two groups reasonable is that caregivers of patients with kidney failure share certain common characteristics with caregivers of patients with cancer. First, both kidney failure and cancer are chronic diseases that require a long term treatment (http://www.kidneyfund.org/kidney-health/kidney-failure/). This infers that caregivers of patients with cancer and caregivers of patients with kidney failure invest a lot of time and resources to provide proper care for their sick relatives. Additionally, both caregivers of patients with cancer and caregivers of patients with kidney failure accompany the patients to the hospital and wait for them there to receive their treatment. Future studies are also recommended to include both patients and caregivers in their sample to get a more comprehensive view of the caregiving experience.

Spirituality, social support, and mutuality were found to be significant predictors in our study, however, their effect sizes in relation to burden of care ranged between small to medium. Thus, further research should be conducted to investigate whether variables other than the ones we have studied would have a stronger effect size in their relation to burden of care. Since the current study did not examine all the variables within Nijboer et al.'s (1998) conceptual framework, future research studies are recommended to examine the rest of the variables that were excluded from this study to test whether or not they contribute to changes in burden of care. Such variables can include the level of the patient's dependency on the caregiver, the duration of the caregiving role and its intensity.

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Appendix A

American University of Beirut
P.O. Box 11-0236
Riad El Solh, 1107 2020
Beirut, Lebanon

ORALCONSENT TO SERVE AS A PARTICIPANT IN A RESEARCH PROJECT

Project Title: *Protective Factors of Burden of Care among Caregivers of Patients with Cancer*

Project Director and Research Investigator: *Fatima El- Jamil, Ph.D.*
Graduate Program Coordinator, Department of Psychology, AUB
fa25@aub.edu.lb
01-350000 Ext. 4372

Research Collaborator (Co-investigator): *Hala R. Naffah, Graduate Student of Psychology, Department of Psychology, AUB*
hrn04@aub.edu.lb

Nature and Purpose of the Project:

The purpose of this study is to identify the factors that protect caregivers of cancer patients from high levels of burden of care, which will help professionals in strengthening the caregivers' adaptation to the caregiving situation.

Explanation of Procedures:

As a research participant, you will have to read this oral consent form and consider carefully your participation. You will then receive a packet of questionnaires from the research collaborator regarding predictors of burden of care. You will have the option to choose the language you are most comfortable with (English or Arabic). The questions asked will help determine the factors that may reduce burden of care. You are only urged to answer in a <u>*truthful*</u> *and* <u>*honest*</u> *manner. To ensure your privacy, you will be asked to fill out the questionnaires at a distance from other people in your surroundings. You can also ask for the co-investigator's phone number to assign another date for participating in the study. The data will be collected from both the American University of Beirut Medical Center and Trad Hospital. This will be done through direct approaching in the waiting rooms and through posters that will be hung in the abovementioned hospitals and other public places. This informed consent is only applicable to those sites only.*
Your name will <u>*not be asked*</u>*. Only the project director and the co-investigator will have access to the data. All results will be kept in a locked cabinet in the office of the project director for a period of seven years after which the data will be discarded.*

It is expected that your participation in this survey will last no more than 15 to 30 minutes.

Potential Risks and/or Benefits

There are no more than minimal risks associated with participation in this survey, although the possibility of some unforeseeable risks exists. Some of the questions may cause you distress. In case this happens, you are kindly asked to inform the co-investigator collecting the data. The potential benefit is that you will participate in a study that will contribute to the field of Psychology. The results of this study, which will be based on approximately 150 caregivers, will help determine which factors help caregivers to cope more adaptively with their caregiving role.

Costs/Reimbursements:

Your participation in this survey incurs no costs and there are no monetary incentives.

Alternative Procedures:

Should you decide not to give oral consent to participate in this survey, no alternative procedures will be offered. You may, however, contact the project director or co-investigator to learn more about the study conducted.

Alternatives to Participation:

There are no alternatives to participation if you were to decide not to participate in this survey.

Termination of Participation:

Should you decide to give oral consent to participate in this survey, the project director and co-investigator might disregard your answers if the results show that you have not abided by the instructions given at the top of each set of questions or if the answers appear not to be truthful. You may choose to terminate your participation at any point by contacting the project director or co-investigator.

Confidentiality:

The results of your participation will be kept confidential to the fullest extent possible. This means that only the project director and co-investigator will have access to the data, which will be anonymous, as no identifying information would be linked to the data you provided. Only information that cannot be traced to you will be used in reports or manuscripts published or presented by the director or investigator. Raw data on data-recording systems will be kept in a locked cabinet in the office of the project director for a period of seven years following the termination of the study. After the seven years have elapsed, the raw data will be discarded.

Withdrawal from the Project:

Your participation in this survey is completely voluntary. You may withdraw your consent to participate in this research at any point without any explanation and without any penalty. You are also free to stop filling the questionnaires at any point in time without any explanation.

Who to Call if You Have Any Questions:

The approval stamp on this consent form indicates that this project has been reviewed and approved for the period indicated by the American University of Beirut (AUB) Institutional Review Board for the Protection of Human Participants in Research and Research Related Activities.

If you have any questions about your rights as a research participant, or to report a research related injury, you may call:IRB, AUB: 01-350000 Ext. 5445

If you have any concerns or questions about the conduct of this research project, you may contact:HalaNaffah: hrn04@aub.edu.lb, 03-085363

Debriefing:

If you are interested in learning about the outcome of the study, you may contact HalaNaffah. After data analysis would be completed, a summary of the results can be emailed to you upon request.

Oral Consent to Participate in this Research Project:

Your oral consent is needed. By consenting you agree to participate in this research project. The purpose, procedures, and the potential risks and benefits of your participation have been explained to you in detail. You can refuse to participate or withdraw your participation in this study at any time without penalty. You will be given a copy of this consent form.

____

Printed Name of Research Director   Today's Date

___________________________________   _____________

Signature of Research Director   Time

INSTITUTIONAL REVIEW BOARD APPROVAL STAMP:

==

أعباء مقدمي الرعاية لمرضى السرطان

الجامعة الأميركية في بيروت
ص.ب. 0236-11
رياض الصلح، 11072020
بيروت، لبنان

موافقة شفهية للخدمة كمشارك في مشروع بحث

عنوان المشروع: عوامل الحماية من أعباء العناية بين مقدّمي الرعاية لمرضى السرطان

مديرة المشروع والباحثة: د. فاطمة الجميل
منسقة برنامج الدراسات العليا، دائرة علم النفس، الجامعة الأميركية في بيروت
البريد الإلكتروني: fa25@aub.edu.lb
هاتف: 01-350000 تحويل داخلي 4372

الباحثة المشاركة: هالة نقّاع، طالبة دراسات عليا في علم النفس
دائرة علم النفس، الجامعة الأميركية في بيروت
البريد الإلكتروني: hrn04@aub.edu.lb

طبيعة المشروع وغايته:

الهدف من هذه الدراسة هو تحديد العوامل التي تحمي مقدمّي الرعاية لمرضى السرطان من أعباء العناية الثقيلة الوطأة، مما يساعد المختصين على تعزيز قدرة مقدمي الرعاية على التكيّف مع أوضاع العناية وظروفها.

شرح الإجراءات:

بصفتك مشاركاً في البحث، عليك أن تقرأ بعناية هذه الاستمارة للموافقة الشفهية وتفكّر جيداً في موضوع مشاركتك. ثم ستسلمك الباحثة المشاركة مجموعة من الاستبيانات حول مؤشرات أعباء الرعاية. يمكنك

اختيار اللغة التي تفضل الإجابة بها (العربية أو الإنكليزية). تساهم الأسئلة المطروحة في التوصل الى معرفة العوامل التي يمكن أن تخفف الأعباء عن مقدّمي الرعاية، لذا يُرجى أن تكون إجاباتك **صادقة** **وصريحة**. للمحافظة على خصوصيّتك كمشارك في هذا البحث، سيتم الطلب منك ملء الإستمارة بعيداً عن الأفراد الموجودين في محيطك. يمكنك أيضاً طلب رقم هاتف الباحثة المشاركة للإتفاق على موعد آخر للمشاركة في هذا البحث. سوف يُجرى هذا البحث في المركز الطبّي للجامعة الأميركية في بيروت ومستشفى طراد. وستُجمع المعلومات عبر التوجّه المباشر الى مقدّمي الرعاية في غرف الإنتظار وعبر الملصقات التي سيتم تعليقها في المستشفيات المذكورة أعلاه وفي أماكن عامّة أخرى. هذه الإستمارة قابلة للإستخدام في هذه المواقع المذكورة فقط.

لن يُطلب منك إعطاء اسمك، ولن يطّلع على المعلومات المعطاة سوى مديرة المشروع والباحثة المشاركة. فجميع الإجابات تُحفظ في خزانة مقفلة في مكتب مديرة المشروع لمدة سبع سنوات، ثم تُهمل البيانات الواردة فيها.

من المُقدّر أن تستغرق مشاركتك في هذا الاستقصاء من 15 الى 30 دقيقة على الأكثر.

الفوائد و/أو المخاطر المحتملة

ليست المخاطر المرتبطة بالمشاركة في هذا الاستقصاء سوى مخاطر ضئيلة جداً، مع احتمالات بروز بعض المخاطر غير المتوقعة. إنّ بعضاً من الأسئلة قد يسبّب لك بالإنزعاج. في حال حصل ذلك، يُرجى إعلام الباحثة المشاركة. أما الفوائد المحتملة فهي أنك ستُسهم في دراسة ذات نتائج بنّاءة في مجال علم النفس. فاستنتاجات هذه الدراسة، التي ستُبنى على إجابات حوالي 150 من مقدّمي الرعاية، من شأنها أن تساعد على معرفة العوامل التي تدعم قدرة مقدّمي الرعاية على التكيّف مع متطلبات مهمتهم كمقدّمي رعاية.

التكاليف/المدفوعات

لا تترتب على مشاركتك في هذا الاستبيان أي كلفة، ولا تُعطى في مقابل ذلك أي حوافز مالية.

الإجراءات البديلة

في حال قررت عدم إعطاء موافقة شفهية على المشاركة في هذا الاستقصاء فليس ثمّة إجراءات بديلة. لكن يمكنك، إذا شئت، الاتصال بمديرة المشروع أو بالباحثة المشاركة للاستعلام عن هذه الدراسة.

بدائل المشاركة

ليس هناك بدائل للمشاركة – إذا قررت **عدم** المشاركة في هذا الاستقصاء.

انتهاء المشاركة

إذا قررت إعطاء موافقة شفهية على المشاركة في هذا الاستقصاء فيجوز لمديرة المشروع وللباحثة المشاركة إهمال إجاباتك إذا أظهرت النتائج أنك لم تلتزم بالتعليمات المنصوص عليها قبل كل مجموعة أسئلة أو إذا بدا أن إجاباتك غير صادقة. وبإمكانك أن تقرّر إنهاء مشاركتك في أي وقت، وذلك بالاتصال بمديرة المشروع أو الباحثة المشاركة للإبلاغ عن قرارك.

السرية

تتم المحافظة على سرّية نتائج مشاركتك الى أقصى درجة ممكنة. أي أن مديرة المشروع والباحثة المشاركة هما الوحيدتان اللتان يمكنهما الاطلاع على البيانات التي تظلّ مجهولة المصدر إذ لا تُربط بالبيانات التي تزوّدنا بها أي معلومات تُعرّف بصاحبها. ولن تستخدم في التقارير أو المخطوطات التي تنشرها أو تقدمها المديرة أو الباحثة سوى المعلومات التي لا يمكن نسبتها إليك. كما إن البيانات الأولية الموجودة على أنظمة تسجيل البيانات ستحفظ في خزانة مقفلة في مكتب مديرةالمشروعمدة سبع سنوات تلي انتهاء الدراسة. وبعد انقضاء هذه المدة يتمّ إهمال تلك البيانات الأولية.

الانسحاب من المشروع

إن اشتراكك في هذا الاستقصاء هو اختياري محض. لذا يمكنك سحب موافقتك على الاشتراك في هذا البحث في أي وقت تشاء ومن دون تقديم أي تفسير ومن دون أن يترتب عليك أي عقوبة. وكذلك، لك ملء الحرية في أن تتوقف عن ملء صفحات الاستبيان في أي وقت تساء ومن دون تقديم مبررات.

الاتصال في حال كان لديك أي استفهام

يشير ختم الموافقة المطبوع على هذه الاستمارة الى أن هذا المشروع قد راجعته ووافقت على إجرائه في المدة المحددة هيئة المراجعة المؤسسية لحماية الأفراد المشاركين في الأبحاث والأنشطة المتعلقة بها التابعة للجامعة الأميركية في بيروت.

إذا كان لديك أي سؤال حول حقوقك كمشارك في البحث، أو أردت الإبلاغ عن ضرر مرتبط بهذا البحث، فيمكنك الاتصال بـ:

هيئة المراجعة المؤسسية، الجامعة الأميركية في بيروت، هاتف 350000-01 تحويل داخلي: 5445.

وإذا كان لديك أي استعلام أو سؤال حول إجراء مشروع البحث هذا، فيمكنك الاتصال بـ:

هالة نقّاع hrn04@aub.edu.lb 085363-03.

الاطلاع على النتائج

إذا كنت ترغب في معرفة نتائج الدراسة، فيمكنك الاتصال بالآنسة هالة نقّاع لهذه الغاية، وبالإمكان، بعد إنجاز تحليل البيانات، إرسال ملخص بالنتائج، بواسطة البريد الإلكتروني، بناءً على طلبك.

الموافقة الشفهية على المشاركة في مشروع البحث:

موافقتك الشفهية أمر ضروري. وموافقتك تعني قبولك المشاركة في مشروع البحث هذا. وقد قُدّمت لك شروح مفصّلة عن غاية المشروع وإجراءاته والفوائد والمخاطر المحتملة من جراء مشاركتك. يجوز لك رفض المشاركة في هذه الدراسة وكذلك سحب مشاركتك في أي وقت، من دون أن تترتب عليك أي عقوبة. سيتم تزويدك بنسخة من استمارة الموافقة هذه.

____

مديرة المشروع التاريخ

____________ _______________

التوقيع الوقت

ختم موافقة هيئة المراجعة المؤسسية:

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Appendix B

Socio-demographic Questionnaire

Please answer all questions honestly; you will not be judged based on your responses. Please feel free to ask if you need any of the questions explained to you.

1. Age of caregiver ______

2. Age of patient ______

3. Gender: Male ______ or Female ______

4. Type of Cancer: ___________________

5. Type of treatment:

______ Chemotherapy

______ Radiation Therapy

______ Hormonal Therapy

______ Surgery

______ Other If other, please specify: ___________________

6. Stage of cancer:

______ Stage I

______ Stage II

______ Stage III

______ Stage IV

______ I don't know

7. What is your relationship to the patient? ___________________

8. What is your marital status? Single______ or Married ______

9. How many children do you have? ______

10. Where do you live? Rural areas ______ or Urban areas ______

11. Since how long (weeks/months/years) has the patient been diagnosed with cancer? ______

12. How long have you been caring for the patient since his/her diagnosis? ______

13. What is the highest level of education you have completed?

Elementary school______

High school graduate ______

College/ Technical school training ______

University degree (BA/BS) ______

Graduate university degree (Master's or Doctorate degree) ______

14. Please provide an estimate of your family income by marking one of the below categories.

_______0-$500

_______$500-$1000

_______$1000-$2000

_______$2000-$3000

_______Above $3000

_______ I don't know

استبيان اجتماعي – ديموغرافي

يرجى الإجابة عن جميع الأسئلة بصراحة، لن تؤثر إجاباتك في تكوين أي نظرة خاصة أو رأي خاص بشأنك. لا تتردد في طرح أي استفهام بشأن أي سؤال بحاجة الى شرح.

1- عمر مقدّم الرعاية: ______

2- عمر المريض: ______

3- الجنس: ذكر _________ أنثى _________

4- نوع السرطان: ____________

5- نوع العلاج:

________________ العلاج الكيميائي

________________ العلاج بالأشعة

________________ العلاج بالهرمونات

________________ الجراحة

________________ علاج آخر. في هذه الحالة، يرجى التحديد

____

6- مرحلة السرطان

__________ المرحلة الأولى

__________ المرحلة الثانية

__________ المرحلة الثالثة

__________ المرحلة الرابعة

__________ لا أعلم

7- ما هي علاقتك بالمريض؟__________

8- ما هو وضعك العائلي؟ أعزب/عزباء ___________ أو متزوج/متزوجة

____

9- كم عدد أولادك؟ ___________

10- مكان السكن؟ منطقة ريفية ___________ أو مدينة ___________

11- منذ متى (أسابيع/أشهر /سنوات) شخّص السرطان لدى المريض؟

____

12- منذ متى تقدّم/تقدّمين الرعاية للمريض بعد تشخيصه؟ ___________

13- ما هو أعلى مستوى تحصيل علمي وصلت إليه؟

الابتدائية ___________

التخرج من المدرسة الثانوية ___________

كلية/ مدرسة تدريب تقني ___________

شهادة جامعية (بكالوريوس آداب/علوم) ___________

شهادة جامعية عليا (ماجستير أو دكتوراه) ___________

13- الرجاء إعطاء تقدير لمدخول عائلتك بوضع إشارة على الفئة المناسبة أدناه:

_______ 0-500$

_______ 500-1000$

_______ 1000-2000$

_______ 2000-3000$

_______ أكثر من 3000$

_______ لا أعلم

Appendix C

Caregiver Reaction Assessment Scale

Instructions: We are trying to understand how providing care for your family member has affected you, your family, and your daily routine in the past week. In the statements below, please circle the response that represents how you feel about each statement.

A blank in a sentence refers to the person you are caring for, but do not write any name to keep this confidential.

	Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
1- I feel privileged to care for ------.	1	2	3	4	5
2- Others have dumped caring for ------ onto me.	1	2	3	4	5
3- My financial resources are adequate to pay for things that are required for caregiving.	1	2	3	4	5
4- My activities are centered around the care for --------.	1	2	3	4	5
5- Since caring for ------ it seems like I am tired all the time.	1	2	3	4	5
6- It is very difficult to get help from my family in taking care of ----.	1	2	3	4	5
7- I resent having to take care of -------.	1	2	3	4	5
8- I have to stop in the middle of work to care for ------.	1	2	3	4	5

	Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
9- I really want to care for -------.	1	2	3	4	5
10- My health has gotten worse since I have been caring for ------.	1	2	3	4	5
11- I visit family and friends less since I have been caring for --------.	1	2	3	4	5
12- I will never be able to do enough caregiving to repay -------.	1	2	3	4	5
13- My family works together to care for -------.	1	2	3	4	5
14- I have eliminated things from my schedule since caring for -------.	1	2	3	4	5
15- I have enough physical strength to care for -------.	1	2	3	4	5
16- Since caring for ------ I feel my family has abandoned me.	1	2	3	4	5
17- Caring for -------- makes me feel good.	1	2	3	4	5
18- The constant interruptions make it difficult to find time for relaxation.	1	2	3	4	5
19- I am healthy enough to care for ------.	1	2	3	4	5
20- Caring for ------ is important to me.	1	2	3	4	5

	Strongly Disagree	Disagree	Neither Agree Nor Disagree	Agree	Strongly Agree
21- Caring for ------- has put a financial strain on the family.	1	2	3	4	5
22- My family (brothers, sisters, children) left me alone to care for ---	1	2	3	4	5
23- I enjoy caring for ------.	1	2	3	4	5
24- It is difficult to pay for -------'s health needs and services.	1	2	3	4	5

مقياس تفاعل مقدّمي الرعاية

تعليمات: ما نحاول معرفته هو كيف أثّر تقديمك الرعاية لفرد من أسرتك عليك وعلى الأسرة وعلى حياتك اليومية العادية خلال الأسبوع الفائت. في مقابل العبارات الواردة أدناه، الرجاء رسم دائرة حول الإجابة التي تمثّل شعورك بالنسبة لكل عبارة.

الفراغ في الجمل هو مكان اسم الشخص الذي تقدّم له الرعاية. لكن يُرجى عدم كتابة أي اسم، للمحافظة على السرية.

	أعارض بشدة	أعارض	لا أوافق ولا أعارض	أوافق	أوافق بشدة
1- أشعر بالفخر لرعاية	1	2	3	4	5
2- لقد رمى الآخرون عبء العناية بـ......... عليّ	1	2	3	4	5
3- مواردي المالية كافية لدفع تكاليف الأشياء المطلوبة لتقديم الرعاية.	1	2	3	4	5
4- تتركّز أنشطتي حول توفير الرعاية لـ	1	2	3	4	5
5- منذ أن أخذت أعتني بـ .... يبدو أنني أشعر بالتعب دائماً.	1	2	3	4	5
6- من الصعب جداً الحصول على مساعدة أفراد عائلتي في تقديم الرعاية لـ	1	2	3	4	5
7- أنا مستاء لاضطراري الى رعاية	1	2	3	4	5
8- أضطر أن أتوقف أثناء تأدية أعمالي من أجل الاهتمام بـ	1	2	3	4	5
9- إنني فعلاً أريد أن أقدم الرعاية لـ.........	1	2	3	4	5
10- لقد ساءت صحتي منذ أن بدأت أقدم الرعاية لـ	1	2	3	4	5

	أعارض بشدة	**أعارض**	**لا أوافق ولا أعارض**	**أوافق**	**أوافق بشدة**
11- لقد أصبحت أزور أفراد عائلتي وأصدقائي بشكل أقل منذ أن بدأت أقدم الرعاية لـ........	1	2	3	4	5
12- لا يمكن، مهما قدمت من رعاية لـ .... أن أوفيه حقه عليّ.	1	2	3	4	5
13- يتعاون أفراد أسرتي معاً من أجل العناية بـ	1	2	3	4	5
14- لقد حذفت أشياء من برنامجي منذ أن بدأت أعتني بـ	1	2	3	4	5
15- لديّ القوة البدنية الكافية للعناية بـ	1	2	3	4	5
16- منذ أن بدأت العناية بـ .... أحسّ أن أفراد عائلتي قد تخلّوا عني	1	2	3	4	5
17- تقديم الرعاية لـ .... يجعلني أشعر بالراحة	1	2	3	4	5
18- التدخلات المستمرة تجعل من الصعب إيجاد الوقت للراحة	1	2	3	4	5
19- صحتي جيدة بدرجة كافية للعناية بـ	1	2	3	4	5
20- الإهتمام بـ.......... هو أمر هام بالنسبة إليّ	1	2	3	4	5
21- الاهتمام بـ ..... قد رتّب على العائلة أعباء مالية	1	2	3	4	5

	أعارض بشدة	**أعارض**	**لا أوافق ولا أعارض**	**أوافق**	**أوافق بشدة**
22- أفراد أسرتي (أخوة، أخوات، أبناء) تركوني وحدي لتقديم الرعاية لـ	1	2	3	4	5
23- إنني أستمتع بتقديم الرعاية لـ	1	2	3	4	5
24- من الصعب تأمين تكاليف الاحتياجات والخدمات الصحية لـ	1	2	3	4	5

Appendix D

Mutual Psychological Development Questionnaire

Instructions: We would like to explore certain aspects of your relationship with the patient. Using the scale below, feel tell us your best estimate of how often you and the patient experience each the following:

1	2	3	4	5	6
Never	Rarely	Occasionally	More often than not	Most of the time	All the time

When we talk about things that matter to the patient, I am likely to...

be receptive	1	2	3	4	5	6
get impatient	1	2	3	4	5	6
try to understand	1	2	3	4	5	6
get bored	1	2	3	4	5	6
feel moved	1	2	3	4	5	6
avoid being honest	1	2	3	4	5	6
be open-minded	1	2	3	4	5	6
get discouraged	1	2	3	4	5	6
get involved	1	2	3	4	5	6
have difficulty listening	1	2	3	4	5	6
feel energized by our conversation	1	2	3	4	5	6

When we talk about things that matter to me, the patient is likely to...

pick up on my feelings	1	2	3	4	5	6

1	2	3	4	5	6
Never	Rarely	Occasionally	More often than not	Most of the time	All the time

feel like we are not getting anywhere	1	2	3	4	5	6
show an interest	1	2	3	4	5	6
get frustrated	1	2	3	4	5	6
share similar experiences	1	2	3	4	5	6
keep feelings inside	1	2	3	4	5	6
respect my point of view	1	2	3	4	5	6
change the subject	1	2	3	4	5	6
see the humor in things	1	2	3	4	5	6
feel down	1	2	3	4	5	6
express an opinion clearly	1	2	3	4	5	6

استبيان التطوّر النفسي المتبادل

تعليمات: نريد أن نستكشف بعض جوانب علاقتك بالمريض. يرجى أن تحدّد، في الجدول أدناه، أفضل تقديراتك حول مدى مواجهتك أنت والمريض لكلّ من الأحوال التالية:

1 **ولا مرة**	**2** **نادراً**	**3** **أحياناً**	**4** **في الغالب**	**5** **في معظم الأحيان**	**6** **دائماً**

حين نتحدث عن الأشياء التي تهم المريض، فإنني في معظم الأحيان:

أكون متفهماً	1	2	3	4	5	6
أفقد الصبر	1	2	3	4	5	6
أحاول الفهم	1	2	3	4	5	6
أحسّ بالملل	1	2	3	4	5	6
أشعر بالتأثر	1	2	3	4	5	6
أتجنب الصراحة	1	2	3	4	5	6
أكون منفتح الذهن	1	2	3	4	5	6
أشعر بالخيبة	1	2	3	4	5	6
أرتبط وأشارك	1	2	3	4	5	6
أجد صعوبة في الإصغاء	1	2	3	4	5	6
استمد القوة من حديثنا	1	2	3	4	5	6

حين نتحدّث عن الأشياء التي تهمني، فإن المريض في معظم الأحيان:

يتفهّم مشاعري	1	2	3	4	5	6
يشعر أننا لا نتفاهم	1	2	3	4	5	6
يُظهر الاهتمام	1	2	3	4	5	6
يشعر بالاستياء	1	2	3	4	5	6
يشاركني بتجارب مشابهة	1	2	3	4	5	6
يكتم مشاعره	1	2	3	4	5	6
يحترم وجهة نظري	1	2	3	4	5	6
يغيّر الموضوع	1	2	3	4	5	6
يرى الجانب المرح في الأشياء	1	2	3	4	5	6
يشعر بالإحباط	1	2	3	4	5	6
يعبرّ عن رأيه بوضوح	1	2	3	4	5	6

Appendix E

The MOS Social Support Survey

Instructions: Sometimes people look to others for companionship, assistance, or other types of support. How often are each of the following kinds of support is available to you if you need it?

1	2	3	4	5
None of the time	A little of the time	Some of the time	Most of the time	All of the time

1. Someone to help you if you were confined to bed	1	2	3	4	5
2. Someone you can count on to listen to you when you need to talk	1	2	3	4	5
3. Someone to give you good advice about a crisis	1	2	3	4	5
4. Someone to take you to the doctor if you needed it	1	2	3	4	5
5. Someone who shows you love and affection	1	2	3	4	5
6. Someone to a have a good time with	1	2	3	4	5
7. Someone to give you information to help you understand your problems	1	2	3	4	5
8. Someone to confide in or talk to about yourself or your problems	1	2	3	4	5
9. Someone who hugs you	1	2	3	4	5
10. Someone to get together for relaxation	1	2	3	4	5
11. Someone to prepare your meals if you were unable to do it yourself	1	2	3	4	5

1	2	3	4	5
None of the time	A little of the time	Some of the time	Most of the time	All of the time

12. Someone whose advice you really want	1	2	3	4	5
13. Someone to do things with to help you get your mind off things	1	2	3	4	5
14. Someone to help with daily chores if you were sick	1	2	3	4	5
15. Someone to share your most private worries or fears with	1	2	3	4	5
16. Someone to turn to for suggestions about how to deal with a personal problem	1	2	3	4	5
17. Someone to do something enjoyable with	1	2	3	4	5
18. Someone who understands your problems	1	2	3	4	5
19. Someone to love and make you feel wanted	1	2	3	4	5

استقصاء الدعم الاجتماعي (دراسة النتائج الطبية)

تعليمات: يتطلّع بعض الناس أحياناً الى الآخرين من أجل الرفقة أو المساعدة أو أنواع الدعم الأخرى.

فما هو مدى توافر كل من أنواع الدعم التالية إذا ما احتجت إليه؟

1	**2**	**3**	**4**	**5**
ولا مرة	**أحياناً قليلة**	**في بعض الأحيان**	**معظم الأحيان**	**دائماً**

1- شخص يساعدك إذا كنت ملازماً الفراش	1	2	3	4	5
2- شخص يمكنك الاعتماد عليه للإصغاء إليك عندما تحتاج الى الكلام	1	2	3	4	5
3- شخص يسدي إليك النصيحة الجيدة حول أزمةٍ ما	1	2	3	4	5
4- شخص يأخذك عند الطبيب إذا احتجت لذلك	1	2	3	4	5
5- شخص يُبدي لك الحب والعطف	1	2	3	4	5
6- شخص تتمتع بقضاء الوقت معه	1	2	3	4	5
7- شخص يعطيك معلومات تساعدك على فهم مشاكلك	1	2	3	4	5
8- شخص تثق به أو تتحدث معه عنك أو عن مشاكلك	1	2	3	4	5
9- شخص يضمّك	1	2	3	4	5
10- شخص ترتاح لوجودك معه	1	2	3	4	5
11- شخص يحضّر وجبات طعامك إذا كنت غير قادر على القيام بذلك بنفسك	1	2	3	4	5
12- شخص تحتاج فعلاً الى نصيحته	1	2	3	4	5
13- شخص تقوم بالأشياء بمشاركته لترتاح من بعض الهموم	1	2	3	4	5
14- شخص يهتم بالأعمال اليومية إذا كنت مريضاً	1	2	3	4	5

1 **ولا مرة**	**2** **أحياناً قليلة**	**3** **في بعض الأحيان**	**4** **معظم الأحيان**	**5** **دائماً**

15- شخص يشاركك همومك ومخاوفك الشخصية جداً	1	2	3	4	5
16- شخص تلجأ إليه طالباً رأيه حول كيفية التعامل مع مشكلة شخصية	1	2	3	4	5
17- شخص يمكن القيام بشيء ممتع معه	1	2	3	4	5
18- شخص يفهم مشاكلك	1	2	3	4	5
19- شخص تحبه ويجعلك تشعر بأنك إنسان مرغوب فيه	1	2	3	4	5

Appendix F

Functional Assessment of Chronic Illness Therapy- Spiritual Well-being Subscale

Instructions: Below is a list of statements that other people have said are important. Please circle or mark one number per line to indicate your response as it applies to the past 7 days.

	Not at all	A little bit	Some-what	Quite a bit	Very much
I feel peaceful	0	1	2	3	4
I have a reason for living	0	1	2	3	4
My life has been productive	0	1	2	3	4
I have trouble feeling peace of mind	0	1	2	3	4
I feel a sense of purpose in my life	0	1	2	3	4
I am able to reach down deep into myself for comfort	0	1	2	3	4
I feel a sense of harmony within myself	0	1	2	3	4
My life lacks meaning and purpose	0	1	2	3	4
I find comfort in my faith or spiritual beliefs	0	1	2	3	4
I find strength in my faith or spiritual beliefs	0	1	2	3	4
Difficult times have strengthened my faith or spiritual beliefs	0	1	2	3	4
Even during difficult times I know that things will be okay	0	1	2	3	4

تقييم وظيفي لعلاج المرض المزمن – مقياس فرعي للعافية الروحية

تعليمات: فيما يلي لائحة بعبارات قال عنها آخرون إنها هامة. الرجاء وضع علامة على أو دائرة حول رقم واحد مقابل كل عبارة للتعبير عن رأيك كما ينطبق على الأيام السبعة الماضية.

	لا، بتاتاً	**قليلاً**	**نوعاً ما**	**كثيراً**	**كثيراً جداً**
أشعر أني مطمئن	0	1	2	3	4
لديّ سبب للعيش	0	1	2	3	4
لقد كانت حياتي مثمرة	0	1	2	3	4
لديّ مشكلة في الإحساس براحة البال	0	1	2	3	4
أشعر أن لحياتي غاية	0	1	2	3	4
أستطيع الوصول الى أعماق نفسي للشعور بالراحة	0	1	2	3	4
أشعر بحسّ الانسجام مع نفسي	0	1	2	3	4
حياتي تفتقر الى المعنى والغاية	0	1	2	3	4
أجد الراحة في إيماني أو معتقداتي الروحية	0	1	2	3	4
أجد القوة في إيماني أو معتقداتي الروحية	0	1	2	3	4
لقد عزّزت الأوقات الصعبة إيماني أو معتقداتي الروحية	0	1	2	3	4
حتى في الأوقات الصعبة فإني أعلم أن الأمور ستكون على ما يرام	0	1	2	3	4

Appendix G

Rotated Factor Structure of Caregiver Reaction Assessment Scale

Rotated Component Matrix

	Component						
	1	2	3	4	5	6	7
CBq11	.822						
CBq14	.813						
CBq10	.756						
CBq18	.662						
CBq5	.620						
CBq8	.426						
CBq13		-.812					
CBq22		.744					
CBq6		.671					
CBq16		.622					
CBq2		.574					
CBq17			.805				
CBq23			.781				
CBq1			.646				
CBq4			.577				
CBq24				.797			
CBq3				-.786			
CBq21				.472	.449		
CBq9					.748		
CBq20					.735		
CBq15						.838	
CBq19						.753	
CBq12							.690
CBq7							-.579

Extraction Method: Principal Component Analysis.
Rotation Method: Varimax with Kaiser Normalization.
a. Rotation converged in 7 iterations.

Appendix H

Rotated Structure Factor of the Mutual Psychological Development Questionnaire

Rotated Component Matrix

	Component							
	1	2	3	4	5	6	7	8
MPDq12	.788							
MPDq14	.619							
MPDq18	.605							
MPDq13	-.472	.434						
MPDq4		.773						
MPDq10		.697						
MPDq20			.767					
MPDq21			-.684					
MPDq16			.626					
MPDq17				.793				
MPDq15	-.407			.648				
MPDq11					.681			
MPDq1					.539			
MPDq7	.465				.498			
MPDq2		.437			-.497			
MPDq9						.820		
MPDq3						.603		
MPDq6							.791	
MPDq8					-.444		.662	
MPDq5				.434			.506	
MPDq22								.838
MPDq19				.441				-.539

Extraction Method: Principal Component Analysis.
Rotation Method: Varimax with Kaiser Normalization.
a. Rotation converged in 14 iterations.

Appendix I

Rotated Factor Structure of the MOS Social Support Survey

Rotated Component Matrix

	Component			
	1	2	3	4
SSq8	.842			
SSq7	.833			
SSq12	.825			
SSq3	.698		.405	
SSq16	.669	.418		
SSq13	.613			
SSq18	.601	.569		
SSq2	.592		.531	
SSq19		.792		
SSq17	.406	.685		
SSq10		.671		
SSq9		.583	.451	
SSq15		.576		.463
SSq4			.739	
SSq6			.694	
SSq1			.655	.510
SSq5		.463	.644	
SSq11				.844
SSq14				.826

Extraction Method: Principal Component Analysis.
Rotation Method: Varimax with Kaiser Normalization.
a. Rotation converged in 7 iterations.

Appendix J

Rotated Factor Structure of Functional Assessment of Chronic Illness Therapy- Spiritual Well-being Subscale

Rotated Component Matrix

	Component			
	1	2	3	4
SWSq10	.938			
SWSq9	.906			
SWSq11	.783			
SWSq6		.777		
SWSq7		.748		
SWSq12		.675		
SWSq5			.830	
SWSq2			.805	
SWSq3		.450	.636	
SWSq4				.763
SWSq8			-.426	.692
SWSq1				-.647

Extraction Method: Principal Component Analysis.
Rotation Method: Varimax with Kaiser Normalization.
a. Rotation converged in 6 iterations.

Appendix K

The assumption of the ratio of cases to independent variables was met because the minimum required sample size is 111 (104+7 predictors) (Tabachnick&Fidell, 2007).

Figures 1, 2, and 3 display the histograms of normality, p-plots, and scatterplots for burden of care among caregivers of cancer patients. The histogram and the p-plot showed that the assumption of normality has been met, while the residual scatterplot indicated that the assumptions of linearity and homoscedasticity have been met (Tabachnick&Fidell, 2007).

To test for multicollinearity, the correlation matrix, VIF, and tolerance values were checked (Field, 2009). The correlation matrix indicated that none of the variables were correlated above .80. Furthermore, all the VIF values were below 10 with Tolerance values all above 0.2. These results indicated that there are no multicollinearity or singularity problems between the independent variables (Field, 2009).

The assumption of independence of errors was tested using the Durbin-Watson statistic. The value of the statistic should be close to 2 to indicate that the assumption has been has been met. The Durbin-Watson statistic of the regression analysis was 1.66, suggesting that the assumption of independence of errors has been met.

Figure 1. Histogram with Normal Curve (Burden of Care)

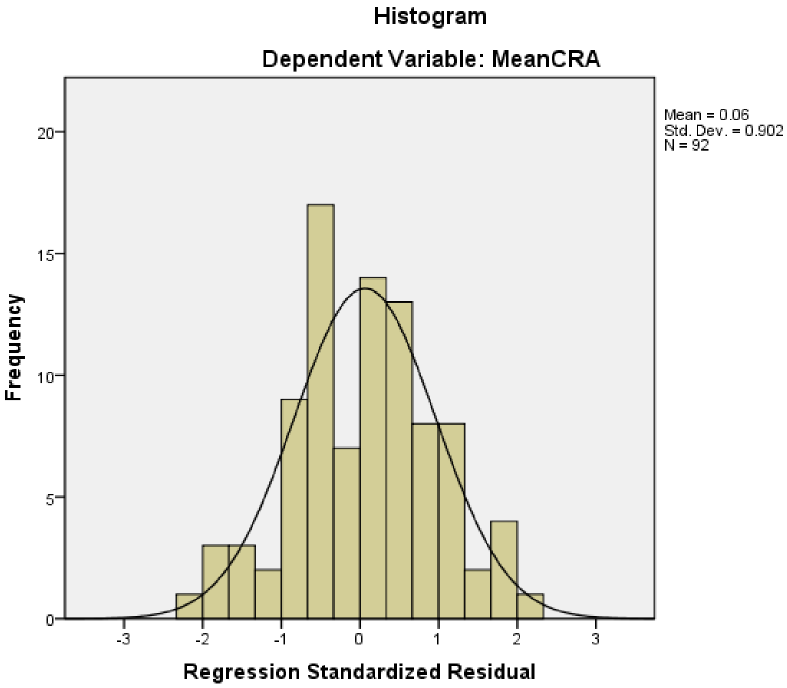

Figure 2. P-P Plot (Burden of Care)

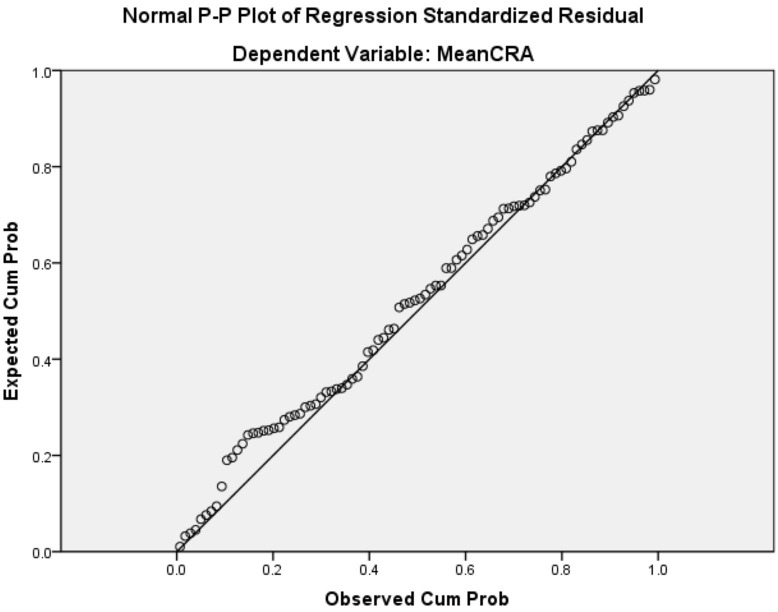

Figure 3. Scatterplot (Burden of Care)