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Family Caregivers' Distress Levels Related to Quality of Life, Burden, and Preparedness

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Abstract

Objective—Family caregivers (FCGs) caring for loved ones with lung cancer are at risk for psychological distress and impaired quality of life (QOL). This study explores the relationship between FCGs' distress, per the Distress Thermometer (DT), and FCGs' QOL, burden, and preparedness. The purpose is to identify types of problems unique to FCGs in cancer care.

Methods—FCGs of patients diagnosed with non-small cell lung cancer (NSCLC) were recruited from an adult outpatient setting at a comprehensive cancer center. Questionnaires included demographic information, City of Hope QOL Scale-Family Version, Caregiver Burden Scale, FCG Preparedness, and DT. Baseline data were utilized for this analysis.

Results—Of the FCGs (N=163), 68% were spouses, 64% female, and 34% worked full-time. FCG age ranged from 21 to 88 years with a mean of 57 years. FCGs cared for patients with NSCLC stage I-III (44%) and stage IV (56%). Psychological distress (DT mean = 4.40) was moderate. DT scores were highly correlated with seven of the eight explanatory variables. Secondary principal components analysis of the explanatory variables combined correlated variables into three constructs identified as Self Care Component, FCG Role Component, and

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FCG Stress Component. Simultaneous multiple regression of distress onto the three components showed they accounted for 49% of the variance in distress.

Conclusion —This exploration of FCGs' concerns associated with elevated distress scores, as measured by the DT, helped identify three component problem areas. These areas warrant further psychosocial assessment and intervention to support FCGs as they care for the patient with cancer.

Keywords

family caregivers; lung cancer; oncology; distress thermometer; quality of life; caregiver burden

Introduction

Family caregivers (FCGs) of patients diagnosed with non-small cell lung cancer (NSCLC) have been shown to experience high levels of distress related to their caregiving role with deterioration over time in psychological well-being and quality of life (QOL) [1]. The psychological distress and deterioration of QOL of the FCG often reflect the distress of the patient with cancer [2, 3]. Distress of the FCG may compound as the challenges of the caregiving role increase, negatively impacting the FCG's ability to provide optimal patient care [1, 4]. Early screening of distress and a related needs assessment should be a part of comprehensive care of families living with cancer.

In 2007, the Institute of Medicine (IOM) conducted a year-long study to identify barriers to psychological care in oncology practices. With a goal of improving psychological care, the IOM recommended integration of the psychosocial domain into routine cancer care for patients and their families [5]. The IOM framework for delivery of care included identification of psychosocial needs, connection of patients and families to services to meet those needs, support of patients and families who are managing illness, and follow up of effects of services provided. Use of a psychosocial screening instrument that accurately and efficiently detects health related psychosocial problems was recommended as the first step in this process [5].

Psychological distress has been recognized as an important area of assessment for cancer patients. In 1999 the National Comprehensive Cancer Network (NCCN) developed and introduced guidelines for distress management in patients with cancer, which includes recommendations on how to monitor the nature and level of distress throughout the cancer trajectory [6]. The guidelines have been updated regularly and define distress as a multidimensional, unpleasant emotional experience that may stem from physical, psychological, social and/or spiritual symptoms and may interfere with one's ability to cope with cancer. The extent to which distress is experienced may range from feelings of sadness, fear, and vulnerability to feelings of panic, depression and anxiety, and existential crisis [6]. The Distress Thermometer (DT) is recommended as a means of rapid assessment and screening for patients in distress [7]. The DT depicts a 10 point thermometer with 0 = no distress and 10 = extreme distress. This is accompanied by a Problem List of 36 specific items organized within Pratical Problems, Family Problems, Spiritual/Religious Concerns and Physical Problems [6]. The oncology clinician can then use the information from the screening tools to prompt further evaluation of psychosocial needs followed by referral to accessible psychosocial services [6].

Distress screening, primarily using the DT, has been conducted with FCGs. Whalen et al reported on the strong psychometric properties of the DT with FCGs of patients with cancer analyzing cut-off scores for sensitivity and specificity for both anxiety and depression, using HADS as the sole criterion measure [8]. Further study by this group evaluated DT scores in patient-caregiver dyads. They found that when at least one partner was distressed, the proportion of dyads where both partners reported distress was the greatest, concluding that distress of one partner relates to distress in the other [9]. In another study, Chambers et al collected information about distress levels, per the DT, of patients and FCGs in Australia who called cancer help-lines and found that the types of problems and unmet supportive care needs, per the Supportive Care Needs Assessment Tool, associated with reports of distress differed for the two groups [10]. While the patients' distress was associated with fears about the future and lack of control, the FCGs were concerned with being able to deal with the physical and emotional needs of the patient, making life decisions in light of an uncertain future, and balancing their own needs with those of the patient [10].

Problem areas which are identified in the literature as being strongly associated with distress in FCGs of patients with cancer include lack of social support and resources [10–12], lack of familial cohesiveness [13], relationship discord [14], and caregiver burden [15]. In 2007 Schumacher et al examined quality of FCG-patient relationship and preparedness for caregiving as potential moderators of FCG stress and found that a three way interaction between role demand, mutuality of relationship and preparedness explained variance in both difficulty of caregiving and mood disturbance [16]. In a qualitative study examining FCGs' challenges in lung cancer, factors described as strongly associated with distress included uncertainty about the future, difficulty understanding the potential for functional decline of the patient, difficulty managing the patient's emotional reaction to their diagnosis, and difficulty managing the practical aspects and medical care of the patient with lung cancer [17]. Other psychosocial characteristics that may predict higher levels of distress include mood disorder [18], avoidance-coping style [19], financial issues [20], and family discord [21]. FCG distress and assessment may need to be system focused examining family and social network relationships, FCG's perception of the caregiver role, and FCG's anticipated and realized demands of their role [10, 15].

Studies examining distress levels and QOL over time in patients and FCGs help to give perspective to the multidimensional nature of distress and how it relates to QOL. In a qualitative study, physical, psychological, social, and spiritual well being and distress were described by FCGs and patients with lung cancer over the disease trajectory [2]. At key points, including initial diagnosis, return home after treatment, recurrence, and terminal stage, FCGs described higher distress levels. The multidimensional distress of the FCG mirrored that experienced by the patient with lung cancer as they dealt with high symptom burden and poor prognosis [2]. Variability of both over time underscores the need for ongoing screening and assessment of the caregiver's distress level and associated problems. Distress screening in FCGs provides initial information valuable in further assessment of FCGs with unmet QOL concerns [1, 2].

The current analysis presents descriptive findings from the usual care phase of a National Cancer Institute (NCI)-funded Program Project Grant that aims to test the efficacy of an interdisciplinary palliative care intervention for patients and families living with NSCLC. The Lung Cancer Program Project Grant involves the synergistic implementation of three intervention projects (Early Stage Patients, Late Stage Patients, and FCGs) to integrate palliative care into comprehensive cancer care in NSCLC. This analysis focuses on distress screening as an approach to identify FCGs who are experiencing difficulties while carrying out their caregiver roles. The NCCN guidelines define distress and recommend the DT as a means to screen for distress through the cancer trajectory [6]. This multidimensional, multifactorial definition of distress along with the DT screening tool provides the conceptual framework for this analysis [6]. The aim of this study is to examine the relationship between distress scores using the DT and FCGs' multidimensional QOL, burden, and perceived caregiving preparedness. The rationale for this quantitative analysis is to identify those areas or combinations of areas most highly associated with distress in FCGs, exploring the types of problems unique to the FCG role which warrant further psychosocial assessment and intervention to alleviate distress. The current analysis adds to the literature about use of the DT with FCGs in cancer care by exploring the problem areas in QOL, demands of caregiving, and preparation for caregiving that are associated with higher distress scores.

Methods

Detailed design and methods for this study have been described elsewhere and are summarized below [1].

Sample and Setting

A total of 163 FCGs of patients with NSCLC were recruited from the medical oncology adult ambulatory care clinic at an NCI-designated comprehensive cancer center in the United States. To qualify for participation in the study, FCGs had to be caring for a patient with NSCLC accrued to the study, 18 years or older, English speaking, either family member or friend of the patient, and identified by the patient as the primary caregiver. Of the 217 patients on study, 178 FCGs consented to participate, and 163 FCGs completed baseline data. Baseline data was used for this analysis from which there was no missing data. FCGs were accrued over a 1-year period to assess them during the usual care phase of the Lung Cancer Program Project Grant.

Procedures

The study was approved by the Institutional Review Board, and all participants provided informed consent. Eligible FCGs were approached by advanced practice nurses (APNs) during the patient's clinic visit for recruitment after the patient was accrued to the study. Following informed consent, baseline assessment questionnaires were completed either in clinic or at home and returned by mail.

Instruments

Demographics were obtained on the baseline questionnaire and included the FCG's age, race/ethnicity, gender, relationship to patient, marital status, household members, household annual income, employment status, education, along with self-reported co-morbidities [22], smoking history [23], and functional status [22].

The **Distress Thermometer** (DT) was used to screen for FCG distress, as experienced over the past week, with a single self-rated item ranging from 0 (no distress) and 10 (extreme distress). When the DT is compared with HADS, previous studies reported cut-off scores of greater than 4 for detecting distress [8, 24]. A score of greater than four is considered to be clinically important distress.

Multidimensional QOL was assessed using the **City of Hope-QOL Scale – Family Version**, a 37 item ordinal instrument that measures the QOL of a family member caring for a patient with cancer. The ordinal scale ranges from 0 to 10, with lower scores meaning worse QOL. Four QOL subscales, calculated as mean scores of the items in each, include physical, psychological, social, and spiritual well-being. The revised instrument was tested from 1994 to 1998, with the test-retest reliability of r=.68 and internal consistency of alpha r=.89. Factor analysis confirmed the four QOL domains as subscales for the instrument [25–27]. Coefficient alpha levels for the subscales of QOL were computed as Physical QOL r=.76, Psychological QOL r=.90, Social QOL r=.80, Spiritual QOL r=.76.

The impact of caregiving was assessed using the **Caregiver Burden Scale**. The 14-item survey measures FCG burden on three dimensions: objective demand, subjective demand, and subjective stress. Six items are utilized to measure Objective Demand Burden, which is defined as perceived infringement or disruption of tangible aspects of the FCG's life [28–30]. Four items measure Subjective Demand Burden, which is defined as the extent to which the FCG perceives care responsibilities to be overly demanding [28]. Four items measure Subjective Stress Burden, which is defined as the emotional impact of caregiving on the FCG [28, 29]. The ordinal scale has 5 points and ranges from "a lot less" to "a lot more." Internal consistency for the three dimensions ranges from 0.82 to 0.88 [30]. Cut-off scores were established for each of the burden dimensions, with objective demand burden scores of greater than 23, subjective demand burden scores of greater than 15, and subjective stress burden scores of greater than 13.5 indicating significant levels of burden [30].

The **Preparedness for Caregiving Scale**, an eight-item scale of the Family Care Inventory, was used to assess caregiver skills preparedness [31]. Preparedness is defined as the perceived readiness for multiple domains of the caregiving role, such as providing emotional support, setting up in-home support services, providing physical care, and dealing with the stress of caregiving. Items address FCG's preparation and comfort in caring for patient needs and are scored from 0 (not at all prepared) to 4 (very well prepared). The higher the score (4 maximum), the more prepared the FCG feels about caregiving. Internal consistency ranges from 0.88 to 0.93 [16, 31].

Data Analysis

The questionnaires were scanned, audited for accuracy, and read into an SPSS system file. Frequencies and measures of central tendency (as appropriate) were computed for FCGs personal characteristics including age, gender, education, chronic illness, race, culture, relationship to patient, marital status, income, caregiver smoking history, and patient's lung cancer stage and time since diagnosis. FCGs responded to a checklist of co-morbidities, and the number of co-morbidities for each FCG was summed, ranging from 0–8 (no co-morbidities to as many as eight). Descriptive statistics were computed for all items and subscales of the three primary scales (City of Hope –QOL Scale-Family Version, Caregiver Burden Scale, and the Preparednesss for Caregiving Scale). Next, a correlation matrix of the subscales of QOL, Preparedness for Caregiving, the subscales of Caregiver Burden, and DT scores in relationship to one another was computed for examination of possible multicollinearity. Due to moderate to high correlations between explanatory variables, a secondary principal components analysis with varimax rotation was conducted to identify underlying constructs. Two underlying constructs were identified. Subjective Stress Burden double loaded on these components and was included separately in the subsequent regression analysis. Factor scores were computed by the regression method, were standardized with a mean of 0 and a standard deviation of 1, and are orthogonal to one another. Finally, a simultaneous multiple regression analysis regressing DT scores onto the two component scores and Subjective Stress Burden subscale was conducted.

Results

FCG demographic characteristics are presented in Table 1. Age of the FCGs ranged from 21 to 88 years with a mean age of 57 years. One hundred two FCGs had one or more chronic illnesses with a mean of 1.36 illnesses per FCG. Approximately 64% of FCGs were female and the predominant relationship to the patient was spouse/partner, 68%. Nearly 56% were caring for those with stage IV NSCLC, 23% with stage III, and 21% with stage I and II. Nearly 13% lived with children who were 18 years old or younger. Almost 35% of the FCGs were working full-time and 32% were retired.

Table 2 presents descriptive findings from baseline questionnaires including DT scores, QOL subscales, Caregiver Burden subscales, and Caregiver Preparedness. The mean DT score was 4.40, with 85 FCGs (52%) scoring above the cutoff score of 4.0 for high distress [8, 24]. Scores for the four QOL subscales were moderate (4 to 6) to high (7 to 10) with the psychological QOL subscale having the lowest mean of 5.32. For Caregiver Burden, FCGs experienced substantial Subjective Stress Burden with a mean score of 14.23, with 95 FCGs (58%) scoring above the 13.5 cut-off score for high burden. The mean score for the Objective Demand Burden subscale was 21.82, with 53 FCGs (32%) scoring above the cut-off score of 23 for elevated burden [30]. Caregiver Preparedness was rated high at 3.73 (maximum 4).

Table 3 displays the bivariate correlations among DT scores and QOL subscale scores, Caregiver Burden subscales and Caregiver Preparedness for FCGs (N=163). Seven of eight variables (Physical QOL, Psychological QOL, Social QOL, Spiritual QOL, Objective Demand Burden, Subjective Stress Burden, and Caregiver Preparedness) were significantly correlated with DT scores (p<.05 or less). There were also moderate to high correlations between some of the explanatory variables.

Table 4a shows the results of the secondary principal components analysis on the explanatory variables. The first component consists of QOL subscales and Objective

Demand Burden. Henceforth identified as the Self Care Component, this construct reflects both FCGs' perception of QOL (such as the FCG experiencing increased fatigue) and disruption in the FCG's ability to maintain QOL (such as not being able to participate in usual social activities). The second component consists of Caregiver Preparedness and Subjective Demand Burden and can be thought of as the FCG Role Component. This construct reflects the FCG's perceived demands of the role (such as demands by FCG's loved one that are over and above what is needed) and preparedness for the role (such as not feeling prepared to handle physical care of the FCG's loved one). As shown in Table 4b, both components are negatively and significantly correlated with DT scores such that the higher the distress, the poorer the QOL and the less prepared/more demand the FCG perceives. Subjective Stress Burden double loaded onto both components and was included as a separate component in the secondary bivariate correlation matrix with DT scores. Subjective Stress Burden positively correlates with DT scores such that high perceived stress caused by the FCG role is associated with high DT scores. This third component will be referred to as FCG Stress Component, as it reflects the perceived emotional distress caused by the FCG role (such as more tension in life related to the FCG role).

Although there were a few moderate correlations between explanatory variables, the condition index for this simultaneous multiple linear regression did not exceed 15 for any of the variables [32]. Forty-nine percent ($p<.001$) of the variance in DT scores was accounted for by the three component scores (see Table 5). Significant explanatory components included the Self Care Component and the FCG Stress Component. The Beta weights (standardized regression coefficients) show that inadequate self care was associated with higher distress, while FCG stress was directly associated with distress.

Discussion

In order to support and maximize health and well being of the individual coping with cancer, the NCCN guidelines recommend screening for distress with the DT as a first step to identify those who would benefit from further assessment of needs [6]. The findings from this study add to our understanding of the unique problems that FCGs in cancer care experience associated with elevated distress, as indicated with the DT. While the DT has been studied extensively for use with patients diagnosed with various cancer types [33–38], DT screening of FCGs has limited focus in the literature particularly in relationship to the types of caregiver problems associated with elevated DT scores [8–10]. The results from this study of FCGs in NSCLC show that higher DT levels in FCGs were associated with multiple problem areas as indicated in QOL subscales (Physical QOL, Psychological QOL, Social QOL, and Spiritual QOL), Caregiver Burden subscales (Objective Demand Burden, Subjective Demand Burden, and Subjective Stress Burden), and Caregiver Preparedness. These problem areas, however, are moderately correlated with each other. In order to condense the problem areas into component areas in which the problems are related, a factor analysis was conducted. Identification of three components resulted. The Self Care Component contains problems related to FCG self care and maintenance of QOL. The second component addresses FCG perceptions of the caregiving role in terms of the demands of the role and preparedness to manage the role, and has been named the FCG Role Component. The third component reflects the FCG emotional response to the caregiving role and is referred to as the FCG Stress Component. These components reflect problems identified as associated with increased emotional distress in previous studies of FCGs, but also add constructs of highly related problems not previously reported. These constructs add to our understanding and focus in assessment of FCGs' challenges experienced with increased distress.

Research with FCGs of patients with lung cancer indicates that between 10% to 50% experience high levels of psychological distress [1, 11, 39]. This is confirmed in our results which identify that the mean distress score in the population was greater than 4 which is above the cut-off score for clinically significant distress when using the DT to screen FCGs [8].

Several studies which examined deficits in QOL related to increased distress levels parallel our results with factors that make up the FCG Self Care Component. One study evaluated caregiver distress as indicated with the DT related to QOL measures both before and after palliative surgery in cancer and showed that subscales most highly correlated with greater distress levels included psychological and social well-being [39]. A strong correlation between psychological and social well being is supported in the literature which shows that social support is both beneficial and essential for the cancer caregiver's psychological well-being [12, 18]. Additional problems related to QOL and Objective Demand Burden, which make up the Self Care Component, have been shown in the literature to be highly related to elevated distress levels in FCGs. Results from one study showed that greater than 50% of the variance in distress of FCGs was accounted for by lifestyle interference, such as limits in ability to participate in valued activities and interests [40]. Mosher et al described social and economic changes of distressed FCGs of patients with lung cancer and found that 56% experienced significant loss of involvement in regular social and leisure activities [20]. When elevated distress levels are indicated by FCGs on the DT, problems with self care and the FCG's ability to maintain QOL should be assessed. If deficits in this area are indicated, the healthcare team may suggest respite to give FCG time to attend to self care and provide support for the FCG with encouragement to attend to their own well being.

The FCG Role Component, which consists of problems related to perceived demands of the FCG role as well as perceived preparedness for the role, in combination with the other components in this analysis, was shown to be a determinant of elevated DT levels in FCGs of patients with lung cancer. Research which has supported these factors as determinants of elevated distress in FCGs include a study by Schumacher et al, which looked at mutuality of relationship, preparedness for caregiving and demands of caregiving [16]. The FCG who experienced high mutuality and high preparedness was less distressed when experiencing high demands of the role [16]. Preparedness for caregiving with perceived demands of the role may be crucial areas of assessment when looking for the problems that a caregiver is experiencing associated with elevated DT levels. The clinician is in an ideal position to help the FCG increase his perception of preparedness for the role by offering resources and education to assist with the current and anticipated needs of the patient.

The third construct called the FCG Stress Component, reflects FCG stress specifically related to the caregiver role. Increased distress level as indicated on the DT may have multiple causes. Distress may relate to the stress of the caregiver role (such as being anxious about an uncertain future with the patient with cancer) as well as to stressors unrelated to the caregiver role. The FCG Stress Component refers specifically to stress related to the role. This may be another key area of assessment when determining the types of problems the FCG is experiencing with elevated DT levels. When FCGs identify the emotional response to the FCG role as being distressing, interventions should be identified that provide emotional support for the FCG. Counseling, psychological support, and respite provisions are just a few of the resources that can be brought to bear in these situations.

In summary, the identification of the three components associated with high distress scores, as indicated on the DT, includes the FCG's perception of self care, perception of the FCG role, and emotional response to the FCG role. Implementation of the DT as a screening tool to identify FCGs at risk, followed by an assessment related to the FCG's ability to maintain self care, the FCG's perceptions of the caregiving role, and the FCG's emotional response to the caregiving role can provide clinicians with valuable information to use in planning appropriate teaching, coaching, and interventions for FCGs.

Limitations of this analysis and possible directions for future research warrant discussion. This analysis explored distress levels in FCGs at one time point, baseline assessment. At baseline assessment, time since patient diagnosis varied from newly diagnosed to 171 months since diagnosis. Future research and analysis of DT scores over time along with associated caregiver issues may be helpful to see how distress and caregiver challenges vary across the disease trajectory. Distress scores of FCGs in relationship to patient treatments received, test results pending, or specific changes in disease trajectory would be valuable to assess in future research. Another limitation of the research presented involves variation in how the questionnaires were administered, which may have impacted our results. Additional limitations that are worth considering for future research are the homogeneity of this sample, as all subjects were FCGs of patients with lung cancer, and use of self-reported comorbidities and functional status of FCGs. Future research may focus on FCGs of patients with other cancer diagnoses or with non-cancer diagnoses, and report FCGs' comorbidities determined or confirmed with medical documentation. Future research that examines the addition of a problems list to the DT that is specific to FCGs may be of value. When high levels of distress are identified with the DT, the healthcare team's obligation of care includes a more in-depth assessment of needs followed by interventions to address identified needs. Determining which resources, support, and additional information are seen by the FCG as helpful warrants further investigation. While the DT may be useful in identifying those experiencing psychological distress, completing a more in-depth assessment and finding interventions and resources that caregivers will utilize to alleviate distress are essential.

In conclusion, this exploration of FCGs' concerns associated with elevated distress scores per the DT was successful in identifying three component problem areas: FCG self care, perceptions of the FCG role, and the emotional response to the FCG role. Comprehensive quality care in cancer, per NCCN guidelines, includes use of the DT as a point of initial screening for psychological distress in psychosocial assessment of the patient. This same focus and care is essential for the FCG to address psychosocial challenges of the role, to support the FCG's QOL, and to support the FCG's ability to provide quality health care to the patient throughout the disease trajectory.

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Table 1

Family caregiver characteristics (N=163)

	Mean	Standard Deviation
Age (years) Range 21–88 years	57.23	13.16
Number of Chronic Illnesses Range 0–8	1.36	1.56
Number of Years Caregiver Smoked Range=1.5–50.0	19.7	11.98
Pack Years Caregiver Smoked[1] Range .15–112.5	26.04	26.05
Months Since Patient Diagnosis Newly diagnosed to 171 Months	16.12	24.32
	N	**%**
Race		
White (includes Latino)	131	80.4
Asian	19	11.7
Black/African American	8	4.9
Native Hawaiian, Other Pacific Islander	2	1.2
American Indian/ Alaska Native	1	0.6
More Than One Race	2	1.2
Hispanic/Latino		
No	152	93.3
Yes	11	6.7
Gender		
Female	105	64.4
Male	58	35.6
Education		
Elementary School	2	1.2
Secondary/High School	61	37.4
College	100	61.3
Relationship		
Spouse/Partner	111	68.1
Daughter	26	16.0
Son	7	4.3
Parent	4	2.4
Other	15	9.2
Marital Status		
Married	126	77.3
Single	16	9.8
Divorced	11	6.7
Partnered	8	4.9
Separated	1	0.6
Widowed	1	0.6
Income		

	Mean	Standard Deviation
>$50000	92	56.4
$30001 to $50000	20	12.3
$10001 to $30000	13	8.0
<$10000	6	3.7
Prefer not to answer	32	19.6
Smoking Status		
Current Smoker	14	8.5
Former Smoker	63	38.7
Non-Smoker	86	52.8
Patient Stage		
Stage I	21	13.2
Stage II	13	8.2
Stage III	38	23.3
Stage IV	91	55.8
*Caregiver Lives With:		
Spouse/Partner	135	82.8
Children under 18	21	12.9
Children 19 and above	19	11.7
Parent(s)/Parent(s)-In-Law	12	7.4
Other Relative	10	6.1
Live Alone	6	3.7
Other	2	1.2
*Caregiver Employment		
Employed >32 hrs/wk	56	34.4
Retired	52	31.9
Employed <32 hrs/wk	17	10.4
Unemployed	17	10.4
Homemaker	14	8.6
Disabled	5	3.1
Other	15	9.2
***Caregiver Comorbidities (N=102)**		
Cardiovascular (Hypertension, heart disease)	62	60.8
Endocrine (Diabetes, Hypothyroidism)	30	29.4
Psychological (Anxiety, Depression)	30	29.4
Arthritis	23	22.5
Pulmonary (i.e. COPD, Asthma)	15	14.8
Stomach or Gastrointestinal Disorders	14	13.7
Osteoporosis	11	10.8
Cancer	9	8.8

	Mean	Standard Deviation
Obesity	6	5.9
Other	21	20.[illegible]

[*] Participants could choose more than one response.

Table 2

Baseline family caregiver descriptive statistics (N=163)

		Mean	Standard Deviation
City of Hope Quality of Life Family Version	Physical QOL[*]	7.29	1.87
	Psychological QOL[*]	5.32	1.68
	Social QOL[*]	6.55	1.78
	Spiritual QOL[*]	6.39	1.96
Caregiver Burden Scale	Objective Demand Burden (score greater than 23=higher burden)	21.82	4.28
	Subjective Demand Burden (score greater than 15=higher burden)	10.78	3.59
	Subjective Stress Burden (score greater than 13.5=higher burden)	14.23	3.21
Preparedness for Caregiving Scale	Preparation for Caregiving Scored from 0(not at all prepared) to 4 (very well prepared)	3.73	.77
Distress Thermometer	Distress in the past week including today[**]	4.40	2.81

[*] Scores range on a scale from 0–10 with higher scores indicating better quality of life.

[**] Scores range on a scale from 0–10, with 0 = no distress and 10 = extreme distress.

Table 3

Bivariate correlations between family caregiver distress scores and QOL subscales, burden subscales, and preparedness (N=163)

	Physical QOL	Psychological QOL	Social QOL	Spiritual QOL	Objective Demand Burden	Subjective Demand Burden	Subjective Stress Burden	Prep. for Caregiving
Psychological QOL	.550***							
Social QOL	.391***	.637***						
Spiritual QOL	.136	.530***	.445***					
Objective Demand Burden	−.185*	−.384***	−.566***	−.363***				
Subjective Demand Burden	−.150	−.084	−.180*	−.170*	.207***			
Subjective Stress Burden	−.405***	−.556***	−.572***	−.414***	.465***	.487***		
Preparation for Caregiving	.136	.236***	.309***	.319***	−.195*	−.273***	−.319***	
Distress in the past week per DT	−.470***	−.632***	−.568***	−.325***	.472***	.141	.554***	−.287***

* P=.05

** P=.01

*** P=≤.001

Table 4

a. Secondary Factor Analysis of QOL, Burden, and Preparedness Scores: Rotated Component Matrix[1]

Variables	**Component Loading**	
	Self-Care Component[2]	**FCG Role Component[3]**
Psychological QOL	.889	
Social QOL	.798	
Physical QOL	.681	
Spiritual QOL	.567	
Objective Demand Burden	−.561	
Subjective Demand Burden		−.[illegible]
Caregiver Preparedness		.700

b. Bivariate correlations between family caregiver distress scores, component scores, and subjective stress burden (N=163)

	Self-Care Component	**FCG Role Component**	**Subjective Stress Burden**
FCG Role Component	.000		
Subjective Stress Burden	$-.553^{***}$	$-.454^{***}$	
Distress in the past week	−.[illegible]73***	−.17[illegible]*	$.554^{***}$

[*] p=.05

[**] p=.01

[***] p</=.001

[1] Subjective Stress Burden double loaded on the two components and was not shown in the factor analysis

[2] Eigenvalue=2.57; 36.7% of variance

[3] Eigenvalue=1.48; 21.2% of variance

Table 5

Distress in family caregivers: a simultaneous linear multiple regression with explanatory variables (N=163)

Model	Standardized Coefficients	t	p Value	(Adj. R^2)[1]
	Beta			
Self-Care Component	−.562	−7.[illegible]2	<.001	.492
FCG Stress Component (Subjective Stress Burden)	.201	2.49	.01[illegible]	
FCG Role Component	.082	1.22	.224	

[1] F=52.76, p<.001