

A Support Intervention for Family Caregivers of Advanced Cancer Patients

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Abstract

Family caregivers are the primary providers of care. Education and support are needed to prepare them for the complex physical, psychological, social, and spiritual effects of cancer. This randomized clinical trial tested a palliative care intervention with 240 family caregivers, focusing on family caregivers who reported financial strain from cancer and treatment. A four-part educational program demonstrated improved outcomes in the intervention group in the measures of objective burden, caregiving preparation, and quality of life. The role of advanced practitioners in providing tailored psychoeducation and support to caregivers is important in order to meet the integral needs of patients with cancer as well as to enhance caregiver self-care.

Advanced practitioners (APs) in oncology spend significant time communicating with and supporting family caregivers. The family caregiver's role has become increasingly important as cancer care has shifted from inpatient to home-based care. Family caregivers are the primary providers of cancer care across the trajectory, from initial diagnosis through treatment, remission, recurrence, long-term survivorship, and end-of-life care.

In 2017, a review of literature on family caregiving in oncology published from 2010 to 2016 was conducted (Ferrell & Wittenberg, 2017). An analysis of 810 citations produced

results from 50 randomized trials that described the need to prepare family caregivers for the complex role they play in cancer care. Several studies demonstrated that interventions led to an improved quality of life and improved emotional support for family caregivers. Several studies also addressed communication and relational intimacy, which are key concerns. An additional focus was in the area of caregiving tasks and ways to diminish the burden of caregiving and preparedness for this role (Ferrell & Wittenberg, 2017). While all family caregivers experience challenges with the complexity of cancer caregiving, those with limited financial resources are of special concern

(Ferrell & Kravitz, 2017; Ferrell, Kravitz, Borneman, & Friedmann, 2018; Zafar, 2016).

Previous studies have documented aspects of family caregiving to include quality of life (QOL) dimensions of physical, psychological, social, and spiritual well-being. These studies cite the physical effects of caregiving, including fatigue, sleep disruption, and worsening of the caregiver's own health, which is of great importance given the aging patient and family caregiver population (Dionne-Odom et al., 2015; Given, Given, & Sherwood, 2012; Goren, Gilloteau, Lees, & da Costa DiBonaventura, 2014).

The psychological concerns of family caregiving, including anxiety, depression, fear, and living with uncertainty, are also well documented (Dionne-Odom et al., 2015; Given, Given, & Sherwood, 2012; Goren, Gilloteau, Lees, & da Costa DiBonaventura, 2014). These caregiver needs are also becoming even more important given the increase in the overall survival of cancer patients due to new targeted therapies and multiple treatment options (Hampton & Newcomb, 2018; Kent et al., 2016; Kershaw et al., 2015)

Providing care to a patient undergoing cancer treatment impacts multiple aspects of family members' lives and the family experience. The relationship between the patient and family members has been well described in previous literature. The social impact on quality of life includes changing roles and relationships, sexuality concerns, and the financial impact of illness (Kent et al., 2016; Kershaw et al., 2015; Longacre et al., 2018). The spiritual domain of QOL for family caregiving encompasses issues such as faith, existential concerns, and hope. However, the ability to provide care for a loved one with cancer can also be a very rewarding experience (Longacre et al., 2018; Tan, Molassiotis, Lloyd-Williams, & Yorke, 2018).

There is a growing body of evidence regarding the financial burden of cancer (Stilos et al., 2018; Tan et al., 2018; Ubel, Abernethy, & Zafar, 2013; Zafar, 2016; Zafar et al., 2013). Financial factors are numerous including, but not limited to, out-of-pocket expenses, lost work time, travel costs, medication co-payments, insurance deductibles, payment for over-the-counter medications, payment for services the patient or caregiver can no longer

do (child care, housekeeping, gardening), lab tests that are not covered by insurance, increased utility bills, the cost of special foods, the cost of insurance premiums, and a wide range of often unanticipated expenses. Clinicians recognize that these financial concerns have a direct impact on the patient's ability to complete treatment and on the family members providing care.

PURPOSE

The purpose of this study was to test a palliative care support intervention for oncology family caregivers.

CONCEPTUAL FRAMEWORK

The study was guided by a model of Family Caregiver Quality of Life developed by researchers at City of Hope Cancer Center and used extensively in family caregiver research (City of Hope Pain & Palliative Care Research Center, 2019; Sun et al., 2015a, 2015b). The model includes four dimensions of physical, psychological, social, and spiritual well-being. The model domains provided the basis for the intervention as well as the study outcomes.

Sample and Setting

A total of 240 caregivers were recruited for study participation. Eligibility criteria for study inclusion were:

1. Primary family caregivers of cancer patients with stage III or IV gastrointestinal, gynecologic, or genitourinary cancers. Caregivers of patients with these three groups of cancer diagnoses were targeted because these patient groups have high caregiver burden and symptom management needs
2. Primary family caregivers who self-identified as being financially strained by the illness or treatment
3. Primary family caregivers of cancer patients who had a prognosis greater than 6 months
4. Age 18 or older.

Participants were randomly assigned to standard/usual care (control) or to a Family Caregiver Palliative Care Intervention (FCPCI). Of 240 caregiver participants, 123 were in the control group and 117 were in the treatment group. At a 1-month evaluation post intervention, there were 183 caregivers remaining in the study (control, n = 97; intervention, n = 86).

DESIGN

To test the FCPCI intervention effects on caregiver outcomes, a randomized trial was designed and utilized. The study employed a 2 × 2 longitudinal design, in which the primary outcome variables (caregiver burden, psychological distress, caregiving preparedness, and caregiver QOL) were examined over two timepoints by group membership (control or intervention). Of particular interest in this study was the interaction between group and time. Data were collected using caregiver surveys at baseline and at 1 month. In addition to outcome measures, descriptive data collected at baseline included caregiver demographics, caregiver health and caregiving information, caregiver training, caregiving experiences, and caregiving's financial impact.

Family Caregiver Palliative Care Intervention

Based on extensive studies by the investigators, the intervention consisted of a four-part family caregiver educational intervention delivered by an advanced practice oncology nurse and a personalized self-care plan to promote caregiver well-being. Content was based on caregiver concerns identified through initial QOL studies. Findings were then augmented and validated against cancer caregiver literature.

The intervention included four teaching sessions organized by the four QOL domains, assessment of current self-care strategies, and the formulation of a tailored self-care plan. During the caregiver sessions, the intervention advanced practice registered nurse discussed relevant supportive care resources and made necessary referrals. A binder containing written materials and resources was provided. Sessions were combined if desired and delivered in-person or by phone over a 4-week period.

The control group received usual care consisting of usual nursing care and referral to support services as needed. Follow-up telephone calls clarified questions and teaching content, reviewed the caregiver self-care plan, and addressed caregiver concerns.

The sessions were tailored to the caregiver's needs and availability. Designed as face-to-face or telephone sessions, telephone sessions were most often requested, ranging from 15 to 90 minutes de-

pending upon caregiver needs and issues raised. Many of the caregiver issues arose from their emotional adjustment to their loved one's catastrophic illness and the responsibility to provide safe and effective patient care and support.

Referrals were made to assist the caregiver in meeting identified needs, the most frequent being referrals to clinical social work and financial counseling. Other referrals included support groups and community-based resources in the caregiver's home community.

Instruments

Outcomes were tested using well-established family caregiver instruments including the City of Hope QOL tool for family caregivers (City of Hope Pain & Palliative Care Research Center, 2019), Caregiver Burden Scale (Montgomery, Stull, & Borgatta, 1985), Preparedness Scale (Archbold, Stewart, Gereenlick, & Harvath, 1990), and the Psychological Distress Thermometer (National Comprehensive Cancer Network, 2019).

Statistical Analysis

A comparative analysis between control and intervention caregivers revealed there were no differences between groups in terms of caregiver sociodemographic characteristics, caregiver health status, caregiving information including patient characteristics, whether they received caregiver training, caregiving experiences, and the financial impact of caregiving. Calculations were performed using means and standard deviations for continuous variables and frequencies and percentages for categorical variables. Because the preliminary results indicated no differences between the control and intervention groups, there was no need to include covariates or control for caregiver characteristics in subsequent analyses.

This study's specific aims were to (1) Describe family caregivers' health status and caregiving information including patient characteristics, training received by the caregiver, caregiving experiences, and the financial impact of caregiving; (2) Test the effects of the FCPCI on family caregivers in the intervention group on caregiver burden and psychological distress compared to caregivers in the control group; and (3) Test the effects of the FCPCI on family caregivers in the

intervention group on caregiving skills preparedness and QOL compared to caregivers in the control group.

To achieve the first aim, a descriptive analysis (means, standard deviations, frequencies, and percentages) was conducted on caregivers' health status, caregiving information including patient characteristics, caregiver training, caregiving experiences, and the financial impact of caregiving. For the second and third aims, a series of 2×2 repeated measures analysis of variance (ANOVA) were used to evaluate the interaction between group assignment and primary outcome measures of caregiver burden, psychological distress, caregiving skills preparedness, and QOL over time.

RESULTS

Demographic Data

Table 1 summarizes the demographics of the study's subjects. Caregivers ranged in age, with a mean age of 55 years. Approximately 80% were female. Just under half (49%) of caregivers were white, not Hispanic. Hispanics/Latinos were the most prominent minority group (31%). The vast majority of caregivers (84%) were married or partnered. Almost two thirds had at least a college degree and a household income greater than \$50,000 (63% and 64%, respectively). Twenty-nine percent were employed full-time, with an additional 22% employed part-time. Just under one third indicated their employment status had changed since the patient's diagnosis, with 45% saying they had to quit working due to caregiving responsibilities.

Characteristics of Caregivers and Caregiving

Data collected from all caregivers at baseline included caregiver's health, caregiving information and patient characteristics, training received, caregiving experiences, and caregiving's financial impact. The descriptive analyses that follow address the first aim of this study.

Caregiver Health

As seen in Table 2, 86% of caregivers had a primary care doctor and 37% indicated they suffered from a chronic illness. The top five caregiver chronic illnesses were hypertension, high cholesterol, arthritis/rheumatism, diabetes, and asthma.

Caregiving Information and Patient Characteristics

Table 2 provides a summary of caregiving information related to the patient for whom the caregiver was providing care. Seventy-five percent of caregivers lived with the patient and 64% indicated the patient was a spouse or partner. In over 90% of cases, the subject was the patient's primary caregiver. Nearly 60% said they were the only caregiver and an additional 25% said there was one other family member providing care. Thirty percent were caring for other family members in addition to the patient. When asked if they had a choice in assuming responsibility of providing care, approximately half indicated yes. On average, caregivers had been providing patient care for 4.4 years.

The patients of the caregivers belonged to one of three cancer diagnosis groups: gastrointestinal (27%), genitourinary (55%), and gynecologic (19%). Over 80% of patients were stage IV, and the remaining patients were stage III (Table 2).

Caregiver Training

When asked if they had received training by a health-care provider or other provider, caregivers most commonly replied they had received training on managing side effects or symptoms, helping the patient manage pain and nausea, and administering medicine. A little more than one fourth of caregivers (between 26%–29%) received training on all topics (see Table 3).

Caregiver Experience

On average, caregivers were providing care 7.53 hours a day, 5 days a week (Table 4). Employed caregivers worked on average 30.5 hours/week. When asked how difficult it was to balance work and caregiving demands and how often their paid work interfered with caregiving responsibilities, half of all caregivers (52%) indicated it was somewhat, very, or extremely difficult to maintain balance. Caregivers responded similarly when asked how often paid work interfered with caregiving responsibilities, as 48% said paid work interfered some, most, or all of the time (Table 4).

Caregiver Financial Burden

As to caregiving's financial burden, subjects were asked to rate on a scale of 0 (none) to 10 (extreme)

Table 1. Caregiver Demographics (N = 240)

Demographic	No. (%)
<i>Age^a</i>	
18-29	10 (4.2)
30-39	34 (14.2)
40-49	28 (11.7)
50-59	59 (24.6)
60-69	71 (29.6)
70-79	35 (14.6)
80+	3 (1.3)
<i>Gender</i>	
Female	194 (80.8)
Male	46 (19.2)
<i>Race/Ethnicity</i>	
American Indian or Alaska Native	1 (0.4)
Asian	17 (7.1)
Black or African American	13 (5.4)
Native Hawaiian or Other Pacific Islander	2 (0.8)
White (Hispanic/Latino)	75 (31.3)
White (not Hispanic/Latino)	117 (48.8)
More than one ethnicity	14 (5.8)
Unknown	1 (0.4)
<i>Marital status</i>	
Married/partnered	201 (83.8)
Not married	39 (16.3)
<i>Highest education level</i>	
Kindergarten to eighth grade	3 (1.3)
High school	86 (35.8)
College	81 (33.8)
Graduate/Professional school	70 (29.2)
<i>Annual household income (N = 237)</i>	
\$10,000 or less	18 (7.6)
\$10,001 to \$20,000	18 (7.6)
\$20,001 to \$30,000	20 (8.4)
\$30,001 to \$40,000	16 (6.8)
\$40,001 to \$50,000	14 (5.9)
Greater than \$50,000	151 (63.7)
<i>Current employment status</i>	
Full time	70 (29.2)
Part time	53 (22.1)
Unemployed	117 (48.8)
<i>Change in employment since patient's diagnosis</i>	
No	164 (68.3)
Yes	76 (31.7)
<i>If yes, how has employment changed? (N = 76)</i>	
Working more hours	5 (6.6)
Working fewer hours	37 (48.7)
Quit working	34 (44.7)

Note. ^aMean, 55.2; standard deviation, 14.19.

Table 2. Caregiver Health and Caregiving Information (N = 240)

Characteristic	No. (%)
<i>Primary care doctor</i>	
No	33 (13.8)
Yes	207 (86.3)
<i>Chronic illness</i>	
No	151 (62.9)
Yes	89 (37.1)
<i>If yes, what chronic illness do you have? (top 5, n > 10)</i>	
Hypertension	42
High cholesterol	29
Arthritis or rheumatism	22
Diabetes	19
Asthma	12
<i>Lives with patient</i>	
No	61 (25.4)
Yes	179 (74.6)
<i>Relationship to patient</i>	
Spouse/Partner	154 (64.2)
Daughter	41 (17.1)
Sister	13 (5.4)
Parent	8 (3.3)
Son	8 (3.3)
Friend	8 (3.3)
Other	8 (3.3)
<i>Primary caregiver</i>	
No	20 (8.3)
Yes	220 (91.7)
<i>Number of other family members providing patient care (N = 238)</i>	
0	141 (59.2)
1	60 (25.2)
2	25 (10.5)
3+	12 (5.1)
<i>Caring for other family members (in addition to patient)</i>	
No	168 (70.0)
Yes	72 (30.0)
<i>Choice in taking on responsibility of providing care</i>	
No	122 (50.8)
Yes	118 (49.2)
<i>Years of caregiving, mean ± SD</i>	
	4.4 ± 3.80
<i>Patient diagnosis</i>	
Gastrointestinal	61 (26.6)
Genitourinary	125 (54.6)
Gynecologic	43 (18.8)
<i>Stage</i>	
III	42 (18.3)
IV	187 (81.7)

Note. SD = standard deviation.

Table 3. Caregiver Training

Did any health-care provider or other provider give you any training or show you how to...	Yes No. (%)	No No. (%)	Not needed No. (%)
Manage any other side effects or symptoms?	68 (28.5)	95 (39.7)	76 (31.8)
Help the patient manage pain?	67 (27.9)	88 (36.7)	85 (35.4)
Administer medicine to the patient?	66 (27.5)	82 (34.2)	92 (38.3)
Help the patient manage nausea?	63 (26.3)	83 (34.6)	94 (39.2)
Help the patient manage fatigue?	53 (22.1)	115 (47.9)	72 (30.0)
Change the patient's bandages?	45 (18.8)	72 (30.1)	122 (51.0)
Provide any other treatments?	38 (16.5)	98 (42.6)	94 (40.9)

their financial need before their loved one's diagnosis, at the current moment, and the foreseeable future. As seen in Table 4, before the patient's diagnosis, the average financial need was low (1.8); need had increased and is expected to increase further, with an average score of 3.9 and 4.7 at the current moment and in the future, respectively. A small percentage (16.7%) indicated they have a paid helper to assist with caregiving (Table 4).

Caregiver Intervention Outcomes

Results of the series of repeated measures ANOVA analyses on caregiver outcomes for the second and third aims indicate that statistically, the interaction between group (between subjects variable) and time (within subjects variable) was significant (at $p \leq .05$) for the primary outcome measures of (a) objective burden (a subscale of overall caregiver burden assessment), (b) caregiver preparedness, (c) the psychological well-being subscale for QOL, (d) the spiritual well-being subscale for QOL, and (e) the overall QOL score (Tables 5 and 6). For all repeated measures ANOVAs, only the 183 participants with both baseline and 1-month information were included in the analysis.

Caregiver Burden

Table 5 summarizes the mean scores on each item of the Caregiver Burden Scale, the score for each burden subscale, the overall burden scale score, and the mean psychological distress score for the control and intervention groups at baseline ($N = 240$) and 1 month ($N = 183$) for all participants. Results of the repeated measures ANOVA show there is significant interaction effect between group and time on the objective burden subscale ($F(1, 181) =$

$3.66, p = .05$). Post-hoc comparisons of the mean change in baseline to 1-month objective burden scores showed that for the control group, objective burden was significantly lower at 1 month (control baseline mean = 22.5 ± 5.46 , 1-month mean = 21.6 ± 5.41 ; mean difference = $-0.9, F(1, 181) = 4.39, p = .04$), but for the intervention group the change in objective burden was not statistically significant (intervention baseline mean = 21.5 ± 5.79 , 1-month mean = 21.8 ± 4.87 ; mean difference = $.3, F(1, 181) = .43, p = .51$). There were no significant interaction effects for the other burden subscales, overall burden, or psychological distress.

Psychological distress (Table 6) was measured using the Distress Thermometer based on a scale of 0 (no distress) to 10 (extreme distress; National Comprehensive Cancer Network, 2019). Baseline scores for distress were 4.5 for the control group and 4.9 for the intervention group, with postintervention scores showing no significant improvement in distress.

PREPARATION FOR CAREGIVING

Preparedness is a term used to describe the caregiver's sense that they have the necessary knowledge and skills to provide the care needed for the patient. Using the Preparedness scale (Archbold et al., 1990; 0 to 4), an overall score for preparedness was calculated and used as the outcome measure in a repeated measures ANOVA. Results indicate there was a statistically significant interaction effect between group and time on the preparation for caregiving scale ($F(1, 181) = 4.35, p = .03$). Control group participants had a mean preparedness score of $2.6 \pm .71$ at baseline and $2.5 \pm .78$ at 1 month; intervention group participants had a mean preparedness

Table 4. Caregiver Experiences and Financial Impact

Time spent providing care	No.	Mean	SD		
Days/week	240	4.9	2.87		
Hours/day	240	7.53	8.07		
Hours/week caregiver works for pay (employed caregivers)	123	30.5	14.65		
	Not at all difficult/None of the time	A little difficult/A little of the time	Somewhat difficult/Some of the time	Very difficult/Most of the time	Extremely difficult/All of the time
How difficult is it to balance work and caregiving demands? no. (%)	28 (22.8)	31 (25.2)	45 (36.6)	14 (11.4)	5 (4.1)
How often does paid work interfere with caregiving responsibilities? no. (%)	29 (23.6)	35 (28.5)	46 (37.4)	10 (8.1)	3 (2.4)
	No.	Mean	SD		
Financial need (0 to 10, with 10 being extreme financial need)					
Before loved one was diagnosed	239	1.8	2.53		
Now	238	3.9	3.47		
In the foreseeable future	238	4.7	3.49		
	No. (%)				
Paid helpers					
No	200 (83.3)				
Yes	40 (16.7)				

Note. SD = standard deviation.

score of $2.3 \pm .77$ at baseline and $2.4 \pm .73$ at 1 month. Between-group post-hoc comparisons show a significant difference between the control and intervention group at baseline ($F(1, 181) = 7.65, p = .006$). The trend in the change in mean scores indicates that the perceived level of preparedness of control group caregivers decreased over time, while intervention group caregivers had an increase in their perceptions of level of preparedness over time.

Quality of Life

Mean scores on all items measuring the caregivers' QOL on four dimensions (physical well-being, psychological well-being, social concerns, and spiritual well-being) by group (control and intervention) at baseline (N = 240) and at 1-month follow-up (N = 183) are detailed in Table 7. Quality of life was measured using the City of Hope Family Caregiver tool, a 34-item scale, with 0 as a negative outcome and 10 as a positive outcome (City of Hope Pain & Palliative Care Research Center, 2019). Table 7 includes the mean scores for each

QOL subscale and the overall QOL score, which were the outcomes used in the series of repeated measures ANOVA analyses to determine if there was a significant interaction between group and time for QOL measures. Results of the repeated measures analyses indicate there is a significant interaction between group and time on the psychological aspect of QOL ($F(1, 181) = 6.21, p = .01$), the spiritual component of QOL ($F(1, 181) = 4.96, p = .02$), and for QOL overall ($F(1, 181) = 5.97, p = .01$).

Post-hoc analysis of the group means on the psychological QOL scores at baseline and 1 month indicate that for the control group, mean scores significantly decreased over time (baseline mean = 73.7 ± 26.02 , 1-month mean = 70.5 ± 26.10 ; mean difference = $-3.2, F(1, 181) = 4.48, p = .036$). For the intervention group, the mean difference between baseline and 1 month was not statistically significant, but mean scores on psychological QOL increased over time (baseline mean = 68.7 ± 23.13 , 1-month mean = 71.0 ± 23.80 ; mean difference = $2.26, F(1, 181) = 2.04, p = .155$).

Table 5. Caregiver Burden Assessment

	Group	Baseline (control, n = 123; intervention, n = 117)		1 month (control, n = 97; intervention, n = 86)		F (df)	p value
		Mean	SD	Mean	SD		
Objective burden						3.66 (1,181)	.05 ^a
Time to yourself	Control	3.9	1.07	3.8	1.10		
	Intervention	3.7	1.16	3.8	0.95		
Personal privacy	Control	3.4	0.87	3.3	0.88		
	Intervention	3.4	0.99	3.4	0.87		
Time to spend on recreational activities	Control	3.9	1.10	3.8	1.10		
	Intervention	3.7	1.15	3.7	0.99		
Vacation activities and trips	Control	3.9	1.20	3.7	1.33		
	Intervention	3.6	1.37	3.8	1.25		
Time to do your own work and daily chores	Control	3.6	1.12	3.5	1.01		
	Intervention	3.5	1.10	3.5	0.90		
Time for friends and other relatives	Control	3.8	1.10	3.6	1.08		
	Intervention	3.7	1.13	3.7	1.03		
<i>Objective burden scale score</i>	Control	22.5	5.37	21.7	5.41		
	Intervention	21.6	5.92	21.8	4.87		
Subjective stress burden						.27 (1,181)	.60
Stress in your relationship with your relative	Control	3.6	0.93	3.5	0.94		
	Intervention	3.4	1.09	3.5	0.90		
Tension in your life	Control	4.1	0.91	3.9	0.97		
	Intervention	4.1	0.77	4.0	0.76		
Concerning your relationship with your relative	Control	3.7	0.97	3.5	0.86		
	Intervention	3.7	0.98	3.6	0.86		
Anxiety about things	Control	4.0	0.96	3.9	0.77		
	Intervention	4.0	0.87	3.8	0.81		
<i>Subjective stress burden scale score</i>	Control	15.3	2.98	14.8	2.76		
	Intervention	15.2	2.86	14.9	2.60		
Subjective demand burden						.04 (1,181)	.83
Attempts by your relative to manipulate you	Control	3.1	0.71	3.1	0.78		
	Intervention	3.0	0.92	3.2	0.88		
Unreasonable requests by your relative	Control	3.2	0.78	3.2	0.82		
	Intervention	3.1	0.87	3.0	0.77		
Feelings that you are being taken advantage of by your relative	Control	3.0	0.96	3.1	0.75		
	Intervention	2.9	0.93	3.0	0.85		
Demands that are over and above what s/he needs	Control	3.2	0.90	3.2	0.75		
	Intervention	3.1	0.87	2.9	0.82		
<i>Subjective demand burden scale score</i>	Control	12.5	2.73	12.5	2.44		
	Intervention	12.0	2.98	12.1	2.78		
Overall burden scale score	Control	50.3	8.07	49.0	7.48	.90 (1,181)	.34
	Intervention	48.9	8.26	48.8	7.82		

Note. SD = standard deviation.

^aStatistically significant at $p \leq .05$.

Table 6. Psychological Distress Scale

Group	Baseline (control, n = 123; intervention, n = 117)		1 month (control, n = 97; intervention, n = 86)		F (df)	p value
	Mean	SD	Mean	SD		
Control	4.5	2.85	4.5	3.00	.53 (1,181)	.47
Intervention	4.9	2.84	4.8	2.76		

Note. * = statistically significant.

Post-hoc analyses for mean scores on spiritual QOL and overall QOL reveal a similar pattern. Control group mean scores significantly decreased from baseline to 1 month, while the mean scores for the intervention group, although not statistically significant, increased from baseline to 1 month. In the spiritual QOL dimension, control group participants had a mean spiritual QOL score of 50.6 ± 14.65 at baseline and 48.4 ± 15.17 at 1 month (mean difference = -2.2, $F(1, 181) = 5.23$, $p = .023$). Intervention participants had a mean spiritual QOL score of 48.4 ± 14.11 at baseline and 49.3 ± 13.04 at 1 month (mean difference = 0.9, $F(1, 181) = .82$, $p = .365$). On overall QOL, control group participants' mean scores at baseline were 209.3 ± 65.01 and at 1 month were 200.9 ± 65.80 (mean difference = -8.4, $F(1, 181) = 5.84$, $p = .017$). Intervention group participants' mean scores at baseline were 199.1 ± 57.70 and at 1 month were 203.1 ± 58.41 (mean difference = 4.0, $F(1, 181) = 1.17$, $p = .282$).

IMPLICATIONS FOR ADVANCED PRACTITIONERS

This randomized trial targeted the vulnerable population of family members who are caring for patients with advanced disease. This intervention can be applied in clinical settings to provide the support needed to prepare and support family members for the important caregiving role. The study findings support the need to assess family caregiver needs, including their own QOL concerns, financial strain, and use of resources to support their role as care providers. This intervention can be replicated by other APs in oncology. Our caregiver educational materials are made available so that others can initiate similar processes (City of Hope Pain & Palliative Care Research Center, 2019).

The study identified many aspects of caregiver preparation and caregiver burden assessed in oncology. The study data indicate that family members provide care over many months or years and that this care entails a broad range of patient needs, including physical, psychological, social, and spiritual needs. The study findings also reinforce the need for close collaboration with interdisciplinary colleagues, including social workers, chaplains, and financial counselors. The identification of patient and family caregiver needs begins with a comprehensive assessment and addressing financial burdens early in the course of disease.

CONCLUSION

The role of family caregiver in cancer care will continue to increase with oncology's evolution to a largely outpatient and home-care environment. This shift to family-delivered care comes at a time of an aging patient population and a family caregiver population facing their own health challenges and burdens of caregiving. Although it can be burdensome, family caregiving can also be rewarding. Oncology APs can provide the support for these family caregivers to enhance QOL for both patient and family. ●

Disclosure

The authors have no conflicts of interest to disclose.

References

Archbold, P. G., Stewart, B. J., Greenlick, M., & Harvath, T. (1990). Mutuality and preparedness as predictors of caregiver role strain. *Research in Nursing and Health*, 13(6), 375-384. Retrieved from <https://www.ncbi.nlm.nih.gov/pubmed/2270302>

City of Hope Pain & Palliative Care Research Center. (2019). Research instruments/resources: Quality of life instruments. Retrieved from https://prc.coh.org/res_inst_new.asp

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Table 7. Caregiver Quality of Life (QOL)

	Group	Baseline (control, n = 123; intervention, n = 117)		1 month (control, n = 97; intervention, n = 86)		F (df)	p value
		Mean	SD	Mean	SD		
QOL: Physical well-being						1.58 (1,181)	.21
Concerns of overall health	Control	5.2	2.98	5.7	2.88		
	Intervention	5.6	3.16	5.6	2.66		
Fatigue	Control	5.4	2.92	5.7	2.96		
	Intervention	5.4	2.93	5.9	2.69		
Appetite changes	Control	7.1	3.02	7.5	2.80		
	Intervention	7.2	2.98	7.4	2.71		
Pain or aches	Control	6.6	2.92	6.5	3.08		
	Intervention	6.5	2.94	6.6	2.78		
Sleep changes	Control	5.8	3.25	6.5	2.93		
	Intervention	5.1	3.05	5.9	2.99		
<i>QOL: physical well-being scale score</i>	Control	30.1	11.99	31.4	12.05		
	Intervention	29.8	11.66	31.4	10.63		
QOL: Psychological well-being						6.21 (1,181)	.01*
Difficulty coping as a result of family member's disease and treatment	Control	5.4	2.64	5.6	2.84		
	Intervention	5.2	2.74	5.5	2.78		
Overall quality of life	Control	6.2	2.55	6.1	2.38		
	Intervention	6.5	2.48	6.3	2.35		
How unhappy	Control	5.9	2.79	5.9	2.58		
	Intervention	6.0	2.40	6.0	2.48		
Feel like have lost control	Control	6.0	3.21	6.0	3.03		
	Intervention	6.2	2.85	6.5	2.57		
How unsatisfying is life	Control	6.5	2.57	6.3	2.56		
	Intervention	6.7	2.59	6.5	2.39		
Present ability to concentrate or remember things	Control	6.1	2.88	6.2	2.80		
	Intervention	6.1	2.73	6.1	2.54		
Feelings of uselessness	Control	7.4	2.71	7.2	2.66		
	Intervention	7.2	2.74	7.0	2.63		
How distressing was family member's initial diagnosis	Control	1.4	2.20	1.6	2.46		
	Intervention	1.4	2.22	1.7	2.48		
How distressing were family member's cancer treatments	Control	3.2	2.90	3.6	2.79		
	Intervention	3.1	2.79	3.3	2.45		
How much anxiety	Control	4.8	2.93	5.3	2.87		
	Intervention	4.9	2.76	5.2	2.56		
How much depression	Control	6.6	3.02	6.5	2.93		
	Intervention	6.4	2.75	6.6	2.65		
Fearful of the spreading of family member's cancer	Control	3.1	3.77	3.2	3.59		
	Intervention	2.9	3.48	3.1	3.39		
Concerns about overall psychological well being	Control	7.1	2.88	7.1	3.03		
	Intervention	6.9	2.67	7.1	2.59		
<i>QOL: psychological well-being scale score</i>	Control	69.7	25.81	70.5	26.10		
	Intervention	69.4	23.06	71.0	23.80		


 Table continued on the following page

Table 7. Caregiver Quality of Life (QOL) (cont.)

	Group	Baseline (control, n = 123; intervention, n = 117)		1 month (control, n = 97; intervention, n = 86)		F (df)	p value
		Mean	SD	Mean	SD		
QOL: Social concerns						1.61 (1,181)	.20
How distressing has family member's illness been for your family	Control	2.9	2.78	3.2	2.71		
	Intervention	3.0	2.66	3.5	2.66		
Amount of support has been sufficient	Control	6.3	3.30	5.8	3.19		
	Intervention	6.6	2.88	6.4	2.73		
Degree which family member's illness has interfered with personal relationships	Control	6.5	3.42	6.0	3.36		
	Intervention	6.2	3.33	5.8	3.09		
Degree to which family members illness has interfered with sexuality	Control	5.2	4.13	4.9	4.15		
	Intervention	4.7	4.27	4.2	3.80		
Degree to which family member's illness has interfered with employment	Control	6.5	3.81	6.3	3.89		
	Intervention	6.6	3.71	6.8	3.50		
Degree to which family member's illness interfered with activities at home	Control	5.5	3.06	5.8	2.98		
	Intervention	5.6	3.17	5.6	3.06		
Isolation caused by family member's illness	Control	6.4	3.19	6.3	3.34		
	Intervention	6.6	3.16	6.5	3.05		
Financial burden from family member's illness	Control	6.2	3.44	5.8	3.70		
	Intervention	5.5	3.29	5.8	3.45		
Overall social well-being	Control	6.3	2.85	6.5	2.69		
	Intervention	6.5	2.68	6.7	2.44		
<i>QOL: social concerns scale score</i>	Control	51.8	20.71	50.5	20.22		
	Intervention	51.4	18.95	51.4	19.82		
QOL: Spiritual well-being						4.96 (1,181)	.02*
Support from religious activities is sufficient	Control	7.4	3.33	7.4	3.14		
	Intervention	7.5	3.33	7.3	3.23		
Support from personal spiritual activities is sufficient	Control	7.8	2.97	7.8	2.81		
	Intervention	7.6	3.08	7.9	2.53		
Uncertainty felt about family member's future	Control	3.8	3.46	3.8	3.36		
	Intervention	4.1	3.32	4.2	3.33		
Family member's illness has had negative changes in your life	Control	5.9	3.43	5.8	3.56		
	Intervention	5.7	3.10	5.9	3.05		
Feel purpose/mission in life	Control	8.5	2.34	8.4	2.32		
	Intervention	8.6	2.30	8.6	1.93		
Feel hopeless	Control	7.8	2.63	7.7	2.61		
	Intervention	7.7	2.71	7.5	2.70		
Overall spiritual well-being	Control	7.9	2.47	7.5	2.75		
	Intervention	8.0	2.53	8.0	2.19		
<i>QOL: spiritual well-being scale score</i>	Control	49.0	14.49	48.4	15.17		
	Intervention	49.2	13.86	49.3	13.04		
Overall QOL score						5.97 (1, 181)	.01*
	Control	200.6	64.17	200.9	65.80		
	Intervention	199.8	57.77	203.1	58.41		

Note. * = statistically significant.

- Tosteson, T., Li, Z.,...Bakitas, M. A. (2015). Benefits of early versus delayed palliative care to informal family caregivers of patients with advanced cancer: Outcomes from the ENABLE III randomized controlled trial. *Journal of Clinical Oncology*, *33*(13), 1446–1452. <https://doi.org/10.1200/JCO.2014.58.7824>
- Ferrell, B., & Wittenberg, E. (2017). A review of family caregiving intervention trials in oncology. *CA: A Cancer Journal for Clinicians*, *67*(4), 318–325. <https://doi.org/10.3322/caac.21396>
- Ferrell, B. R., & Kravitz, K. (2017). Cancer care: Supporting underserved and financially burdened family caregivers. *Journal of the Advanced Practitioner in Oncology*, *8*(5), 494–500. <https://doi.org/10.6004/jadpro.2017.8.5.5>
- Ferrell, B. R., Kravitz, K., Borneman, T., & Friedmann, E. (2018). Family caregivers: A qualitative study to better understand the quality-of-life concerns and needs of this population. *Clinical Journal of Oncology Nursing*, *22*(3), 286–294. <https://doi.org/10.1188/18.CJON.286-294>
- Given, B. A., Given, C. W., & Sherwood, P. (2012). The challenge of quality cancer care for family caregivers. *Seminars in Oncology Nursing*, *28*(4), 205–212. <https://doi.org/10.1016/j.soncn.2012.09.002>
- Goren, A., Gilloteau, I., Lees, M., & daCosta DiBonaventura, M. (2014). Quantifying the burden of informal caregiving for patients with cancer in Europe. *Supportive Care in Cancer*, *22*(6), 1637–1646. <https://doi.org/10.1007/s00520-014-2122-6>
- Hampton, M. M., & Newcomb, P. (2018). Self-efficacy and stress among informal caregivers of individuals at end of life. *Journal of Hospice & Palliative Nursing*, *20*(5), 471–477. <https://doi.org/10.1097/NJH.0000000000000464>
- Kent, E. E., Rowland, J. H., Northouse, L., Litzelman, K., Chou, W. Y., Shelburne, N.,...Huss, K. (2016). Caring for caregivers and patients: Research and clinical priorities for informal cancer caregiving. *Cancer*, *122*(13), 1987–1995. <https://doi.org/10.1002/cncr.29939>
- Kershaw, T., Ellis, K. R., Yoon, H., Schafenacker, A., Kata-podi, M., & Northouse, L. (2015). The interdependence of advanced cancer patients' and their family caregivers' mental health, physical health, and self-efficacy over time. *Annals of Behavioral Medicine*, *49*(6), 901–911. <https://doi.org/10.1007/s12160-015-9743-y>
- Longacre, M. L., Applebaum, A. J., Buzaglo, J. S., Miller, M. F., Golant, M., Rowland, J. H.,...Northouse, L. (2018). Reducing informal caregiver burden in cancer: Evidence-based programs in practice. *Translational Behavioral Medicine*, *8*(2), 145–155. <https://doi.org/10.1093/tbm/ibx028>
- Montgomery, R. V., Stull, D. E., & Borgatta, E. F. (1985). Measurement and the analysis of burden. *Research on Aging*, *7*(1), 137–152. <https://doi.org/10.1177/0164027585007001007>
- National Comprehensive Cancer Network. (2019). NCCN Clinical Practice Guidelines in Oncology: Distress management. V3. Retrieved from https://www.nccn.org/professionals/physician_gls/pdf/distress.pdf
- Stilos, K., Fitch, M., Nolen, A. E., DasGupta, T., Sapsford, M., McAndrew, A., & Moura, S. (2018). Exploration of families' experiences caring for loved ones with advanced ovarian cancer. *Journal of Hospice & Palliative Nursing*, *20*(5), 464–470. <https://doi.org/10.1097/NJH.0000000000000463>
- Sun, V., Grant, M., Koczywas, M., Freeman, B., Zachariah, F., Fujinami, R.,...Ferrell, B. (2015a). Effectiveness of an interdisciplinary palliative care intervention for family caregivers in lung cancer. *Cancer*, *121*(20), 3737–3745. <https://doi.org/10.1002/cncr.29567>
- Sun, V., Kim, J., Irish, T., Borneman, T., Sidhu, R., Klein, L., & Ferrell, B. (2015b). Palliative care and spiritual well-being in lung cancer patients and family caregivers. *Psycho-Oncology*, *25*(12), 1448–1455. <https://doi.org/10.1002/pon.3987>
- Tan, J.-Y., Molassiotis, A., Lloyd-Williams, M., & Yorke, J. (2018). Burden, emotional distress and quality of life among informal caregivers of lung cancer patients: An exploratory study. *European Journal of Cancer Care (English Language Edition)*, *27*(1), e12691. <https://doi.org/10.1111/ecc.12691>
- Ubel, P. A., Abernethy, A. P., & Zafar, S. Y. (2013). Full disclosure—Out-of-pocket costs as side effects. *New England Journal of Medicine*, *369*(16), 1484–1486. <https://doi.org/10.1056/NEJMp1306826>
- Zafar, S. Y. (2016). Financial toxicity of cancer care: It's time to intervene. *Journal of the National Cancer Institute*, *108*(5), djv370. <https://doi.org/10.1093/jnci/djv370>
- Zafar, S. Y., Peppercorn, J. M., Schrag, D., Taylor, D. H., Goetzinger, A. M., Zhong, X., & Abernethy, A. P. (2013). The financial toxicity of cancer treatment: A pilot study assessing out-of-pocket expenses and the insured cancer patient's experience. *Oncologist*, *18*(4), 381–390. <https://doi.org/10.1634/theoncologist.2012-0279>