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ORIGINAL ARTICLE

Who will care for the caregiver? Distress and depression among spousal caregivers of older patients undergoing treatment for cancer

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Abstract

Purpose Although it is accepted that in general spousal caregivers of patients with cancer are under high emotional and physical strain, little is known about the quality of life specifically among spousal caregivers of older cancer patients. The aim of the current study is to explore the emotional toll of spousal caregivers of cancer patients aged 65–85 years.

Methods This study surveyed 242 spousal caregivers of patients ≥ 65 years old, diagnosed with cancer, treated with curative or palliative intent, and within 6 months of treatment at enrollment. Standardized measures completed by the caregivers included depression measure (Geriatric Depression Scale); distress (Distress Thermometer); and social support (the Cancer Perceived Agents of Social Support). Logistic regression analyses were used in order to identify the predictor of clinical depression and distress. The analyses were adjusted for patient (sociodemographic, functional performance, and medical status) and caregiver (sociodemographic and social support) factors.

Results Among the caregivers, the frequencies of clinical depression and distress were 16.5% and 28% respectively. Increasing patient age and time from diagnosis were associated with reduced levels of caregiver depression. Higher levels of friends and spousal support (support from the patients) were associated with non-clinical levels of depression and distress.

Conclusion Increasing patient age and caregiver's perceived spousal support may both have a positive effect on caregivers' levels of depression. This can be utilized by clinicians in the process of empowering older patients and their spousal caregivers to confront the challenges of cancer treatment into advanced old age.

Keywords Cancer · Old age · Caregiver · Spouse · Distress · Depression

Introduction

Cancer caregivers are increasingly recognized as playing a fundamental role in supporting patients undergoing treatment, often at the expense of their own physical and emotional health [1, 2]. Spouses typically assume the majority of caregiving tasks and are involved directly in the provision of care [3].

Prior studies have quantified caregiver burden and stress [4, 5] and shown that both internal coping factors, such as self-efficacy and finding meaning in the act of caregiving, and external factors, such as social support, may be important factors which serve to moderate levels of distress among caregivers [6]. A meta-synthesis of qualitative studies focusing on the experience of informal cancer caregivers (age range 19–85) described a high prevalence of negative feelings such as loss of happiness, loneliness, and frustration, and feelings of being prisoners in their own homes [7]. Although a few described positive effects of caregiving, these were reported less often [7]. All of these studies relate to a very wide range of ages with specific reference to the age of the patients and/or caregivers.

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Little is known about the caregiving experience of older spousal caregivers and the available data is controversial. There is some evidence to support the idea that spousal caregivers of older patients (patient's age > 65) may experience lower levels of distress than their younger counterparts. Some researchers concluded that the experience of older caregivers may prepare them for the caregiver role and it is easier for older caregivers to find meaning (that functions as a protective factor) in the caregiving process, and that older caregivers may be better prepared for a scenario of a spouse facing death [8–11].

Other researchers found a lower quality of life among caregivers to older patients and attributed this to the significant and complex needs of older patients, comorbid conditions among caregivers, and increasing social isolation in old age [12–14].

The aim of the present study was to address this knowledge gap and to explore the emotional toll of caregiving among spousal caregivers for older patients with cancer, ranging in age from 65 to 85 years old. A secondary goal was to examine possible variables that may predict clinical levels of self-reported emotional distress and depression among caregivers of the oldest old patients. We hypothesized that identifying contributors to distress and depression will advance our understanding of the experience of spousal caregivers.

Materials and methods

Participants and inclusion and exclusion criteria

The study population was part of an ongoing cross-sectional Israeli study on distress, coping, and hope among patients diagnosed with cancer, age $\geq$ 65 years, and their spousal caregivers. The participants of this study were spousal caregivers (as designated by the patients) of patients $\geq$ 65 years old and diagnosed with cancer, living with the patient for at least 10 years. Patients were treated with curative or palliative intent and had concluded a course of treatment within 6 months of the date of enrollment and were receiving follow-up care at an outpatient clinic of the participating institutions. The caregivers were recruited through the patients.

Caregivers were excluded if they themselves (1) had been diagnosed with a terminal illness, (2) had been treated for cancer, or (3) had serious cognitive impairment, judged by a global assessment by the study researcher. We also excluded caregivers of patients if the patients (1) resided in a long-term care facility, (2) were unable to walk without assistance and needed help with toileting and basic essentials of self-care, or (3) had serious cognitive impairment, as judged by a global assessment by the study researcher. Participants were enrolled as a convenience sample at the time of a scheduled outpatient visit.

Sample size and refusals

A total of 320 patients were asked for permission to approach their spousal caregiver. Thirty-four (10.6%) dyads declined to participate (patients ($n = 27$) or spouses ($n = 7$)). We excluded 44 (13.75%) caregivers of patients who were considered ineligible because they were no longer receiving active treatment. The time from diagnosis was measured from the initial diagnosis at first presentation. In the case of patients with relapse of cancer, the time from diagnosis was considered to be the time of the diagnosis of relapse and did not take into consideration the disease-free interval. The final sample consisted of 242 caregivers to patients from the outpatient clinics of two major cancer centers in Israel. The centers are partially public tertiary hospitals, which by law provide comprehensive medical care to all Israeli citizens through the National Health Insurance program.

Ethical approval and procedure

The study protocol was approved by the Medical Ethics Review Committees of Hadassah-Hebrew University Medical Center and of the Sheba Medical Center. After obtaining the permission of the attending physicians, patients and caregivers were approached during routine medical visits to the outpatient clinics. Caregivers were interviewed individually, and each participant signed an informed consent form. Data were collected between May 2013 and January 2018.

Measures

Background data Caregivers completed sociodemographic questionnaires. Data regarding the patients' diagnosis, treatment, cancer stage, Eastern Cooperative Oncology Group (ECOG) performance status [15], and Charlson Comorbidity Index (CCI) [16] were obtained from medical records**.**

Depression Caregivers' depression was measured using the five-item version of the Geriatric Depression Scale (5-item GDS) [17]. The scale is a shorter version of the 15-item Geriatric Scale and was found as effective as the longer version [17]. The scale consists of five binary items (i.e., "Are you basically satisfied with your life?","Do you feel pretty helpless the way you are now"), scoring range 0–5. Among the elderly population, the English version of the 5-item GDS has shown excellent sensitivity (94%) and specificity (81%) for the diagnosis of depression and high values of inter-rater reliability ($k = 0.88$) and test-retest reliability ($k = 0.84$) [18]. The longer Hebrew version was also found to be valid and reliable [19]. For the current study, we used the recommended cutoff scores ≥ 2 as the clinical cutoff for susceptibility to depression [17].

Distress Distress was measured using the distress thermometer, which consists of a one-item screening tool with an 11-point Likert-type scale for distress in cancer patients (e.g., “Please circle the number below (0-10) that best describes how much distress you’ve felt during the last two weeks?”). This tool has been validated among both cancer patients and caregivers. It is used extensively in the USA, Europe, and Israel [20] as both a criterion-referenced measure and a continuous measure [21]. An Israeli validation study suggested a score of ≥ 3 in the Hebrew version as a clinical cutoff for distress. However, since most validation studies point to a higher optimal cutoff score, we opted for a more conservative cutoff of ≥ 5 [21].

Social support The Cancer Perceived Agents of Social Support [22] is a 12-item questionnaire (i.e., “To what extent do you feel you receive helpful information from your spouse?”), scoring range 1–5. The scale combines two theoretical content facets of social support: agent of support and type of support. In the current research, we used the aggregated score of the agents (spouse, family, friends, beliefs), each based on the mean of three items (instrumental, cognitive, and emotional support). The scale in Hebrew version was found to be valid and reliable for patients and spouses in Israel [22]. Internal reliability of the Hebrew version (Cronbach’s alpha values) in the current research was as follows: Cronbach’s alpha = 0.82, 0.87, 0.87, and 0.97 (spouse, family, friends, beliefs, respectively).

Statistical analyses

The distributions of both depression and distress were left-skewed (skewed towards lower levels of distress and depression) (depression: median = 0, mean = 0.76, SD = 1.15, Kolmogorov-Smirnov test for normal distribution: $Z = 45.13$, $p < 0.0001$, 55% of the caregivers had a score of zero; distress: median = 2, mean = 2.95, SD = 2.63, Kolmogorov-Smirnov test for normal distribution: $Z = 2.48$, $p < 0.0001$, 71.9% of the caregivers had a score of < 5). Based on these findings, we decided to treat both depression and distress as discrete and not continuous variables. We used the recommended cutoff score of ≥ 2 for the depression and a conservative cutoff of ≥ 5 for distress.

We performed a hierarchical binary logistic regression procedure to estimate the incremental contribution of background, medical, and psychological variables to predict clinical distress and depression (above cutoff levels) over all other variables. We used the binary division of clinical vs. non-clinical levels of depression and distress as the predicted variables in the logistic regression model. Covariates in the model did not include the cancer diagnosis, since there were too many categories with relatively small differences between age groups (the category “other cancers” consisted of about 30.9% of the sample and included > 10 cancer types with frequencies < 5% each).

Treatment data were excluded from the list of covariates due to missing data (22.2% of patients). Disease status was also excluded since almost all patients (92.1%) had recently undergone disease-modifying therapy (i.e., had an indication for receipt of regional and systemic therapy). Otherwise, we used a conservative approach and controlled for all possible confounders, even if they were not found to be significantly related to depression or distress. All analyses were conducted using the computer program SPSS version 21.0 [23].

Results

Table 1 presents the characteristics of caregivers and patients. The mean age of caregivers was 74 and 37% were males. Caregivers reported very high mean scores of spousal and family support (means of 4.01 and 4.07 respectively on a scale of 1–5). Among patients, the common cancer types were lung (21.1%) and prostate (14.5%) and 63% were diagnosed with stage 4 and were undergoing some form of disease-modifying therapy.

Levels of depression and distress among caregivers 16.5% of the caregivers were found to be above the cutoff for clinical depression (high depression level, 95% confidence interval 12%–21%). Twenty-eight percent of the caregivers presented distress levels above the clinical cutoff (high distress levels, 95% confidence interval 22%–34%).

We used a hierarchical logistic regression analysis to examine the relationship between background variables and the predicted clinical scores of distress and depression. We calculated two models of logistic regression, one for depression and one for distress. The predictors (independent variables) included patients’ medical and sociodemographic data (age, stage, comorbidities, performance status, and time from diagnosis); caregiver sociodemographic data (age, sex, and having formal help); and perceived social support by the caregiver. Results are presented in Table 2.

Depression The total regression model was found to be significant ($\chi2(12) = 73.47$, $p < 0.0001$; Cox & Snell R square = 0.265). The overall correct classification of participants to the high and low depression groups was 88.3%. Table 2 presents the predictors in the final regression model. Decreasing patients’ age and time from diagnosis were associated with clinical levels of caregiver depression (younger patients with less time from diagnosis were associated with clinical levels of depression among caregivers). Lower levels of friends and spousal support (support from the patients) were associated with clinical depression. Higher levels of support from family (positive beta value, when included with all other variables)

Table 1 Caregivers and patients characteristics

Caregivers	Age (years) mean ± SD	73.69 ± 9.44
	Range	47–94
	Sex (male) *n* (%)	89 (36.9%)
	Formal (paid) help *n* (%)	69 (28.5%)
	Perceived social support	
	Spouse mean ± SD	4.01 ± 1.09
	Family mean ± SD	4.07 ± 0.95
	Friends mean ± SD	3.27 ± 1.26
	Faith mean ± SD	2.51 ± 1.57
Patients	Age (years) mean ± SD	77.53 ± 9.29
	Range	65–97
	ECOG *n* (%)	
	0–1	122 (50.4%)
	2–3	120 (49/6%)
	Cancer type *n* (%)	
	Breast	31 (12.8%)
	Colorectal	30 (12.4%)
	Lung	51 (21.1%)
	Melanoma	21 (8.7%)
	Prostate	35 (14.5%)
	Other	74 (30.6%)
	Treatment *n* (%)	
	No treatment	33 (17.5%)
	Hormonal	17 (9.0%)
	Chemo/radio	139 (73.5%)
	Cancer stage *n* (%)	
	1–3	108 (36.9%)
	4	185(63.1%)
	CCI mean ± SD	1.13 ± 1.23
	Time from diagnosis mean ± SD (months)	36.91 ± 49.40

Perceived social support from spouse = the social support of the patient to the caregiver as perceived by the caregivers. *ECOG*, the Eastern Cooperative Oncology Group performance status (0 = fully active; 1 = symptomatic but completely ambulatory; 2 = symptomatic, < 50% in bed during the day; 3 = symptomatic, capable of only limited self-care); *CCI*, Charlson Comorbidity Index

were associated with clinical levels of depression among caregivers.

Distress The regression model was found to be significant ($\chi 2(12) = 42.53$, $p < 0.0001$; Cox & Snell R square = 0.163). The overall correct classification of participants to the high and low distress groups was 77.0%. Table 2 presents the predictors in the final regression model. Decreasing patient age, higher levels of functioning in patients (as indicated by lower ECOG or lower levels of symptoms), and lower level of perceived spousal support (less perceived support from the patients) were associated with clinical levels of caregiver distress. More formal (paid) help at home was also associated with clinical levels of caregiver distress.

Discussion

In this study of older patients with advanced cancer and spousal caregivers, we found less depression and distress in caregivers than expected. Older age was associated with reduced levels (non-clinical) of caregiver distress and depression. Interestingly, higher perceived spousal support (i.e., support provided by the patient to the caregiver) was associated with a reduced level of caregiver's self-reported levels of distress and depression.

The total prevalence of participants in the clinical range of depression identified in this study is lower than that reported by other investigators [5, 24, 25]. This may be partly explained by the fact that patients and spouses in our study (mean age of 78 for both) were older than those reported in prior research [24, 26]. We posit that age may have prepared caregivers of older patients through protracted experiences of coping with life crises and past difficulties and that this may have enhanced their natural acceptance of caregiving roles [21]. Caregivers may find meaning in caregiving in the context of longstanding relationships, having "survived" other crises in life.

The reduced level of caregiver's self-reported levels of distress and depression may also be a result of contextual sociocultural factors of the Israeli society. Israel has a highly developed healthcare system and a comprehensive social security system, almost all of the medical treatment expenses are covered by national health care plans and there is significant financial and instrumental support to patients and their families by the Israeli social security system [27, 28]. Also, While Israel is considered a Western country, family structure and cultural values follow a more traditional Middle-Eastern paradigm that emphasizes social and familial support [29, 30]. The combination of less "out of pocket" expenses and higher levels and higher cultural value of social support may result in a lower burden on caregivers and hence lower levels of self-reported depression and distress.

The provision of social support from patient to caregiver was significantly associated with decreased depression and distress among caregivers. This is not surprising and may be a consequence of the fact that in many cases the focus of older couples is shifted inwards to the relation with the partner, as social networks in late life decrease due to the deaths of friends and relatives. Similarly, measures of functional status, physical performance, social engagement, and psychological wellbeing may be more accurate predictors of health and survival among older individuals than traditional risk factors extrapolated from middle-aged individuals [21].

Our findings support the concept that spousal caregivers' perception of the support they receive from their spouses (i.e., the patient) has impacts on their level of emotional wellbeing. Spousal support was highly predictive and was the only variable, other than age, that was associated with both distress

Table 2 Multivariate binary logistic regression for predicting depression and distress incidence—final block

	Depression					Distress				
Predictors	B	SE	Wald χ^2	95% CI for odds ratio	$p <$	B	SE	Wald χ^2	95% CI for odds ratio	$p <$
Patient's age	− 1.41	0.052	7.42	0.79–0.96	0.006**	− 0.07	0.03	4.89	0.87–0.99	.027*
Stage of cancer (0 = I-III, 1 = IV)	1.12	0.67	2.84	0.6–3.21	0.092 N.S.	0.56	0.43	1.67	0.75–4.05	.196 N.S.
ECOG performance status (0 = 0–1, 1 = 2–3)	0.25	0.46	0.28	0.915–1.89	0.139 N.S.	− 0.84	0.36	5.51	0.21–0.87	.019*
Charlson Comorbidity Index	0.27	0.19	2.19	0.515–3.18	0.595 N.S.	0.02	0.15	0.03	0.77–1.36	.866 N.S
Time from diagnosis	− 0.01	0.005	4.14	0.98–1.00	0.042*	− 0.01	0.00	2.27	0.99–1.00	.132 N.S
Caregiver's age	0.055	0.048	1.35	0.96–1.16	0.246 N.S	0.04	0.03	1.38	0.98–1.10	.241 N.S
Caregiver's sex (0 = male, 1 = female)	0.86	0.63	1.91	0.7–8.07	0.167 N.S.	0.72	0.43	2.85	0.89–4.77	.091 N.S.
Formal help (0 = no, 1 = yes)	0.98	0.57	2.96	0.87–8.16	0.086 N.S.	1.10	0.43	6.50	1.29–7.04	.011*
Spouse support	− 1.18	0.26	19.89	0.18–0.52	0.0001**	− 0.43	0.18	5.43	0.46–0.93	.020*
Family support	0.72	0.31	5.33	1.12–3.81	0.021*	0.11	0.22	0.24	0.73–1.70	.625
Friends support	− 0.53	0.22	5.96	0.38–0.9	0.015*	− 0.28	0.16	3.19	0.55–1.03	.074
Faith support	0.11	0.14	0.65	0.85–1.47	0.421 N.S.	− 0.01	0.10	0.02	0.80–1.21	.900

*$p < 0.05$; **$p < 0.01$

and depression among the study population in the multivariate analysis.

The marital relationship may well be the most important source of social support among older people diagnosed with cancer [31]. After years of cohabitation, one may infer that couples adapt and adjust to a mutual style of communication, expression of feelings, and negotiation of support according to each other's needs. An interesting finding is the association between perceived family support and depression, with more family support being associated with higher distress levels (controlling for all other variables). A plausible cautious hypothesis may be that increasing perceived family support diminishes the subjective appraisal of the spouse's role.

Our study has several limitations. The cross-sectional nature of the study does not allow inferences about causality. Caregivers were recruited through the patients and although refusal rates were small, we had no data concerning the characteristics of the patients who did not allow us to contact their caregivers or caregivers who refused to participate. Exclusion of patients with poor performance status also limits the generalizability of the study. It is possible and indeed likely that caring for patients with complex physical needs and disabilities adds another dimension to the caregiving role and may be a significant contributor to caregiver burden. We acknowledge that there may be alternative explanations to the age effect observed, such as contextual or socio-cultural factors; nevertheless, we consider the results of our study to be generalizable to other countries with similar health and social indicators.

Conclusion

Our findings highlight the need to understand and acknowledge the importance of both patients and caregiver age in defining burdens as well as rewards of caregiving in the context of advanced cancer.

In summary, the study contributes to our understanding of the lived experience and emotional health of spousal caregivers of older patients undergoing treatment for cancer. As the number of older cancer patients continues to rise, our finding that increasing patient age is significantly associated with decreasing levels of both depression and distress among spousal caregivers is of clinical importance. Age may be a protective factor for the caregiver, especially when the caregiver feels supported by their spouse. The knowledge that increasing patient age provides some degree of caregiver benefit, as well as the positive effect of the caregiver's perceived spousal support, may both serve as important elements in the process of empowering older patients and their spousal caregivers to confront the challenges of cancer treatment into advanced old age. The clinical implications of these findings support the need for enhancing support from cancer clinicians to both patients and caregivers during the continuum of cancer care.

Any such intervention should take into account the specific socio-cultural context of the patients and their caregivers.

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Compliance with ethical standards

Conflict of interest The authors declare that they have no conflict of interest.

Ethical approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed consent Informed consent was obtained from all individual participants included in the study.

Data control The authors have full control of all primary data and they agree to allow the journal to review the data if requested.

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