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Cancer Caregiver Fatigue: A High Level of Symptom Burden

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Abstract

Fatigue is the problematic symptom identified by cancer patients. However, fatigue has not been widely examined for caregivers of cancer patients. In this project, 131 caregivers of patients diagnosed with advanced stage cancer and actively receiving radiotherapy reported experiencing the most difficulties with fatigue (mean 46.9; on a 0 to 100 scale, with a 10-point difference having clinical meaning) at baseline and at a six-month follow-up (mean 48.3). This is in sharp contrast to other domains of quality of life and functioning being rated in the 60s, 70s and 80s by the cancer caregivers. Given the level of fatigue reported by the cancer caregivers, if confirmed by other investigators in larger and more diverse samples, interventions targeting caregiver fatigue should be explored.

Keywords

fatigue; cancer; caregivers; quality of life; symptom burden; burnout

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Introduction

Advanced cancer impacts the quality of life (QOL) of the cancer patient and of their loved ones; especially when loved ones are also in the caregiver role throughout the patient's disease trajectory.^{1–3} Many domains of QOL such as psychosocial and physical domains are impacted as a result of caregiving.⁴ Multiple studies performed during varying stages of cancer patients' disease trajectory report that caregivers experience significant detrimental impact to their burden,^{5–7} well-being,^{7–10} and quality of life.^{8–12} Mental health,^{12,13} anxiety,¹⁴ depression,¹⁵ physical health,¹⁶ and a wide range of psychosocial factors such as employment and income^{11,17} are also adversely affected. Unfortunately, family caregivers receive limited guidance regarding their caregiving role and they subsequently experience significant burden.¹⁸

Fatigue is one of the most prevalent and challenging symptoms experienced by cancer patients.^{19–25} The impact of cancer-related fatigue on a patient's ability to function is considerable, and cancer-related fatigue has been reported as the most distressing symptom experienced by cancer patients.²³ Undergoing radiotherapy and chemotherapy, physical symptom burden, and inpatient status are associated with worse fatigue.^{25,26} Cancer-related fatigue is linked with significant adverse health outcomes, including impairments in QOL, functional ability, depression, anxiety, reduced time to recurrence, and overall survival.^{23–25,27–32}

However, much less is known about the fatigue experienced by the caregivers of cancer patients. Family, friends, and other caregivers provide extensive care to loved ones with cancer. The responsibilities that patient care places on caregivers continue to increase in this country. Interestingly, concordance of symptoms between caregiver and patient is highest for fatigue.³³ Higher caregiver fatigue scores have been associated with increased depression,³⁴ anxiety,³⁵ and sleep disturbance.^{34,36} There are many sources of fatigue for caregivers. Fatigue related to physical exhaustion, emotional and psychological exhaustion, spiritual exhaustion, and compassion fatigue have all been identified as sources of fatigue in caregivers.

In summary while the prevalence and burden of fatigue has been well established for the cancer patient, much less is known about cancer caregiver fatigue. Therefore, the purpose of this secondary analysis was to examine the level of fatigue associated with caregiving for a loved one with advanced stage cancer who was receiving cancer care and to compare caregiver fatigue level to other symptom burdens.

Methods

Participants were recruited for a randomized, two-group, controlled clinical trial designed to compare the efficacy of a six-session, structured, multidisciplinary intervention, which included the caregivers (in four of the sessions), in maintaining QOL in patients with advanced cancer undergoing radiotherapy.³⁷ Eligibility criteria included an age of 18 years, an initial diagnosis of cancer in the past 12 months, intermediate to poor prognosis (0%–50% expected 5-year survival rate as judged by the primary radiation oncologist

enrolling the participant), and a caregiver who was willing to participate. The intervention was effective in maintaining patient QOL during radiotherapy but had no effect on long-term patient QOL or any effect at any time point on cancer caregiver QOL.³⁷

Participants

One hundred thirty-one caregivers participated in this project. Sixty-five caregivers participated in the intervention and sixty-six caregivers were in the control condition. There were no differences between conditions for caregiver demographics or symptom burden scores at any time point; therefore, the caregiver data is reported as a whole. Caregiver was identified by the patient as a family member or friend who was their primary caregiver. The majority of the caregivers were the patient's significant other (79%) and were employed (62%; see Table 1).

Measures

The Caregiver Quality of Life Index-Cancer Scale (CQOLI-CS) is a 35-item, 5-point Likert-type scale² that assesses the physical, social, financial, psychological, caregiver burden, and family dimensions of QOL. Individual items are rated as 0 (none at all) to 4 (very much). Internal consistency and test-retest reliability are both high; validity in cancer caregivers has been established.^{37,38}

Caregivers were also asked seven single-item symptom burden and QOL questions described here. On a scale of 0 to 10 with 0 (as bad as it can be) to 10 (as good as it can be), how would you describe your (1) overall quality of life? (2) overall mental (intellectual) well-being? (3) overall physical well-being? (4) overall emotional well-being? (5) level of support from friends and family? (6) overall spiritual well-being? and (7) average level of fatigue (fatigue level from 0 as no fatigue, to 10 representing constant tiredness). These items have been used with employees joining a wellness center,³⁹ cancer patients,⁴⁰ depressed psychiatrically hospitalized patients,⁴¹ geriatric cancer patients,^{24,42} stress-reduction participants,⁴³ and long-term lung cancer survivors.⁴⁴ These items have been shown to be valid and clinically relevant with a score of 0, 1, 2, or 3 being reflective of significant burden and a score of 7, 8, 9, or 10 indicative of positive functioning;³⁹ a change of 10 points has been shown to be clinically meaningful.^{45,46}

Statistical Considerations

Data for this analysis were collected during the randomized trial and included caregiver demographics as well as the caregiver completed assessments. All assessments were scored using the appropriate scoring algorithms and converted to 0–100 point scales where a score of 100 indicates best QOL or best functioning. Summary statistics were calculated for demographics and caregiver assessment scores.

Results

A total of 131 caregivers were enrolled in the study (see Table 1). All but one caregiver had at least a high school education or its equivalent; the majority were employed (62%), married (88%), practiced private prayer or meditation (92%), and attended religious services (87%).

The primary objective in this secondary analysis was to explore the burden experienced by cancer caregivers and to characterize caregiver fatigue. Fatigue scores were strikingly low in this cancer caregiver population (see Table 2). At baseline, fatigue scores were well below normal, with an average fatigue score of 46.9, and fatigue scores at week 4 were only slightly higher at 48.3. In contrast, other scores were in the 60's, 70's, and 80's, which are similar to mean scores on these items in previous studies.^{26,37,39,40,44,45}

Discussion

In this project, caregivers of patients with advanced stage cancer undergoing radiotherapy reported experiencing significant difficulties with fatigue. This finding supports the growing literature that both cancer patients and cancer caregivers face significant fatigue burden.^{23,47} Fatigue is a broad-based term, and includes both the physical exhaustion from providing physical care to the cancer patient, but also the mental stress of seeing a loved one undergo cancer treatment and concerns about the outcome. Given the burdens caregivers of cancer patients carry, it is not surprising they report experiencing significant difficulties with fatigue. The difficulties endorsed by cancer caregivers in other domains, such as overall quality of life, spiritual well-being, emotional well-being, or support from friends and family, were not as pronounced as level of fatigue, either at baseline or at the six-month follow-up. A 10-point difference on these items has been shown to be clinically meaningful, and fatigue scores were more than 20 points lower than any other domain. This further highlights how problematic fatigue is for the cancer caregiver and the importance of addressing caregiver fatigue.

One of the main philosophies of palliative and hospice care is taking care of the patient and family as a single unit, and addressing the needs of both parties in order to globally address their overall well-being and quality of life as a family unit. Whereas fatigue is an unavoidable—but treatable—symptom in cancer *patients*, fatigue in cancer *caregivers* is also common but is not as well understood; therefore, less is known about its effective management. As the patient's cancer advances into the terminal phase, this brings about new challenges for caregivers. This, in turn, increases the strain on them and adversely affects them emotionally, physically, psychosocially, and spiritually. Demands on the caregivers increase as the patient enters the dying phase and becomes more ill, more functionally impaired, and more dependent on the caregiver, leading to more emotional distress for the caregivers.⁴⁸ A study that investigated caregiver fatigue demonstrated a relationship to the caregiver's schedule: when the burden is higher, the fatigue is greater.⁴⁹ When the demands on a caregiver exceeded the caregiver's ability to cope, this led to burnout, which was frequently manifested as fatigue. Palliative care and hospice services are well known to improve caregiver well-being and satisfaction, especially at the end of life. Future interventions for caregiver fatigue should incorporate not just a physical approach, but a truly multidisciplinary approach that is consistent with the palliative and hospice principle of treating the family unit.

This study had several limitations. The population was primarily Caucasian and from the Midwest; therefore, these results may not apply to underserved or more diverse populations. Additionally a single-item question was used to assess fatigue, and the use of a standardized

validated fatigue questionnaire may have yielded more robust findings. Clearly, future investigators should examine more diverse populations using a range of validated fatigue assessments.

Conclusions

Cancer caregivers in this project reported experiencing the greatest symptom burden from fatigue, fatigue remained consistently problematic overtime, and fatigue was distinctly lower than other QOL or other symptom burden domains. As our treatments for cancer continue to improve, the numbers of cancer survivors and their caregivers will continue to increase. Therefore, identifying tailored strategies to help cancer caregivers manage fatigue will become increasingly important. If other investigators confirm these findings, perhaps designing interventions to reduce both patient and caregiver fatigue will prove to be efficacious.

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Table 1

Caregiver Demographics

Marital Status	Value (N)	Percentage (%)
Divorced	7	5
Married	115	88
Single	6	5
Widowed	3	2
Currently Employed		
Yes	81	62
No	50	38
Education Level		
High School or Less	30	23
Some College	36	28
4 Year College or More	50	38
Other	15	11
Religious Affiliation		
Catholic	46	35
Jewish	2	2
None	6	5
Protestant	73	55
Other	4	3
Significant Other	104	79

Table 2

Cancer Caregiver QOL and Symptom Burden Scores

	Baseline		Six Month Follow-Up	
	Mean	SD	Mean	SD
CQOLI-CS	68.1	12.5	69.3	14.3
Overall QOL	74.0	19.8	74.7	20.5
Mental Well-Being	74.5	19.9	73.9	21.5
Physical Well-Being	72.9	18.9	70.7	19.1
Emotional Well-Being	69.6	22.8	70.8	21.3
Level of Support from Friends and Family	85.0	17.9	77.0	23.3
Spiritual Well-Being	77.8	19.7	73.4	22.0
Level of Fatigue	46.9	25.8	48.3	26.2

CQOLI-CS, Caregiver Quality of Life Index-Cancer Scale

QOL, quality of life

All scores converted to a 0–100 scale with high being favorable.