

Caregiver Distress in Home Palliative Care

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Abstract

Aim: This study aims to determine the symptom burden of caregivers who were following their loved ones at home and factors associated with this burden. **Methods:** From a consecutive number of patients followed at home by a specialistic palliative care team, a sample of 46 couples of patients-caregivers was screened. Epidemiological data of both patients and caregivers were collected, also including some variables, such as the level of religiousness, education, economic conditions, and financial distress. The Edmonton Symptom Assessment System (ESAS) was measured in both patients and caregivers. Caregivers were asked to provide a comment in a semi-structured interview, about “what do you think of your loved one’s suffering?” They were also invited to release any further comment. **Results:** Caregivers’ symptom burden was relevant. Sleep disturbances were even more relevant in caregivers. Caregivers with a lower level of education and financial distress experienced more global symptom burden. Caregivers manifested a deep sense of injustice and gripes regarding previous hospitalizations. **Conclusion:** There is an association between patient-reported severity of symptoms and caregiver symptoms. These data suggest delivering support to those caregivers who express higher levels of symptoms. There is a need for further research to explore the possible interventions to mitigate caregivers’ symptom burden.

Keywords

advanced cancer, caregiver, distress, palliative care, symptoms

Introduction

Advanced cancer can lead to physical and psychological symptom burden that affects both patients and their relatives. Caregivers may be overwhelmed with the burden of caregiving, especially with very severely ill patients with cancer.¹ In some studies, caregivers have been reported to experience pain, fatigue, sleep disorders, poor appetite, financial burden, marital strain, and emotional distress.^{2–5} About 75% of caregivers developed physical problems before patients’ discharge from hospital and 50% continued to have such symptoms after discharge.⁶ Social and financial burden were also reported in caregivers of patients receiving anticancer therapies.⁷ The symptom burden may affect the caregivers’ ability to provide care to the patient.^{2,8} In fact, higher caregiver-reported objective burden was associated with higher care recipient depressive symptoms.⁹

Formal assessment of caregiver symptom burden is not routinely performed in palliative care. A regular evaluation of caregiver symptom burden would allow to have a basis for an early support from the palliative care staff. The Edmonton Symptom Assessment System (ESAS) is a common tool used for measuring patients’ physical and psychological

symptoms.¹⁰ Recently, ESAS was measured in caregivers to assess the physical and psychological burden. In an outpatient palliative care setting, a significant correlation was found between ESAS scores measured in caregivers and their time spent feeding and housekeeping. They also reported reduced activities and total sense of burden.¹¹

Information about the burden among caregivers who follow their loved ones at home is lacking. The aim of the present study was to determine the burden of caregivers in a home care setting and to assess factors associated with this burden.

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Moreover, caregivers were interviewed to assess how they lived with the condition of suffering of their loved one.

Methods

Patients who consecutively requested specialistic home care assistance for a period of 6 months were initially screened. Patients were included if they had a diagnosis of advanced cancer and had a primary caregiver and provided consent to participate. A caregiver was considered as a person who spent at least 4 hours/day with the patient.¹² Both patients and caregivers had to be ≥ 18 years old. Patients were excluded if they had impaired cognition or an expected survival of less than 2 weeks. *The first 46 patients who met the inclusion criteria were asked to participate, according to the necessary sample size.* Institutional Review Board approved the study, and patients and caregivers provided their informed consent to participate.

Data Collection

Epidemiological patients' data, including age, gender, cancer diagnosis, and Karnofsky level were recorded. Education, marital status, awareness of diagnosis and prognosis, religious belief relationship to patient, religion, level of religiosity, role of religion, frequency of prayer, familiar income/month (< 1000 euros, 1000-3000 euros, and > 3000 euros), and financial distress (measured from 0 to 10) were collected in both patients and caregivers.¹³

Edmonton Symptom Assessment System (ESAS) was also measured. The ESAS is a widely used 10-item scale measuring a variety of physical and psychosocial symptoms. Symptoms include pain, dyspnea, nausea, weakness, drowsiness, depression, anxiety, poor sleep, poor appetite, and poor well-being.¹⁰ The ESAS was found to be a feasible tool for identifying caregiver symptom burden. About 3/4 of caregivers reported that completing the ESAS was useful for expressing their symptom burden.¹¹ These data were collected by trained home social workers 7-10 days after starting home palliative care, when presumably a relationship had been established with the team.

Caregivers were approached by a social worker experienced in interviews with family members for different reasons linked to their activity. They were asked to provide a comment in a semi-structured interview on a voluntary basis. *The opening question was:* "what do you think of your loved one's suffering?" They were also invited to release any further comment on their distress.

Statistical Analysis

A sample size of 46 couples of patients and caregivers yielding a statistical power of 80% with alpha type 1 error of .05 would allow the detection of a difference of 30% with an SD of ± 2 in symptom intensity score reduction between 2 groups.

Continuous variables are presented as mean (SD) or median with interquartile range (IQR), and categorical variables are expressed as number of patients (percentage). Chi-square

or Fisher's exact tests were used for categorical variables, as appropriate.

Related-samples Wilcoxon signed rank test was used to compare nonparametric continuous variables between patients and caregivers. Univariate analysis of variance (ANOVA) test was employed to identify variables associated with global ESAS in patients and caregivers.

The data were analyzed by the SPSS software, version 22 (SPSS Inc, Chicago, IL, USA). All statistical tests were two-tailed, and statistical significance was defined as $P \leq .05$.

Results

The characteristics of patients and their caregivers are listed in Table 1. The mean age was 75.1 years (SD, 12.5), the mean Karnofsky level was 34 (SD, 9), and 30 patients were males. Most of caregivers were better informed than patients about diagnosis and prognosis ($P < .0005$ in both cases). Religious issues and financial distress were similar, although the frequency of prayer was higher in caregivers. The mean financial distress was relevant (≥ 4).

The intensities of ESAS items in patients and caregivers are shown in Table 2. A total of 43 caregivers (86%) reported an intensity of ≥ 1 , and 41 caregivers (82%) reported an intensity of ≥ 4 for at least one symptom. The most frequently symptoms with an intensity ≥ 1 were weakness ($n = 43$, 86%), poor well-being ($n = 42$, 84%), depression ($n = 37$, 74%), and sleep disturbances (36, 72%). These were the same symptoms that were most frequently reported with an intensity ≥ 4 , and included weakness ($n = 41$, 82%), poor well-being ($n = 37$, 74%), sleep disturbances ($n = 27$, 54%), and depression ($n = 25$, 50%). High mean intensity levels of ESAS items were found in caregivers, unless for nausea, drowsiness, and dyspnea intensity, which were significantly higher in patients. Intensity of sleep disturbances was significantly higher in caregivers than in patients (Table 2).

Factors Associated With Physical and Psychological Distress (Total ESAS)

In patients, total ESAS was inversely associated with being believers practicing ($P = .007$; ANOVA test) and daily prayers ($P = .036$; ANOVA test). Total ESAS was higher in females ($P = .06$; ANOVA test), in divorced subjects compared with married subjects ($P = .045$; ANOVA test), and in those having psychological distress, including anxiety and depression ($P < .0005$; ANOVA test). In caregivers, total ESAS was inversely associated with the level of education ($P = .034$; ANOVA test).

Interviews

Fourteen per cent of caregivers agreed with the interview. The most frequent answers to the question "What do you think of your loved one's suffering?" were based on a deep sense of injustice: "I think he shouldn't have had these sufferings

Table 1. Characteristics of Patients and Caregivers.

	Patient	Caregiver	P
Education			
Primary	20	13	
Middle school	11	15	
Secondary school	13	10	
Degree	2	8	
Marital status			
Married	43	39	
Living together	1	1	
Separated/divorced	2	2	
Single	2	4	
Awareness of diagnosis			
Known	28	45	
Partially known	11	1	< .0005*
Unknown	7	0	
Awareness of prognosis			
Known	9	40	
Partially known	16	6	< .0005*
Unknown	21	0	
Religious belief			
Catholic	43	41	
Orthodox	1	0	.124*
Atheist	0	1	
Other	2	4	
Level of religiosity			
Believer practicing	13	18	
Believer	31	24	.057*
Non-believer	0	4	
Role of religion			
Fundamental	8	19	
Important	12	9	
Fairly important	24	15	.098*
Not very important	1	3	
Not important	1	4	
Frequency of prayer			
Daily	22	28	
Weekly	12	7	
Monthly	9	3	.047*
Yearly	1	0	
Never	2	8	
Familiar income/month			
Less than 1000 €	12		
1000–3000 €	24		
more than 3000 €	5		
Financial distress	4.6 (3.0)	5.4(2.9)	.868

*Pearson chi-square test. Related-samples Wilcoxon signed rank test.

because he didn't deserve them (...). He was always a good husband, a good father" "I think she didn't deserve my grandmother's suffering...." "I think my son is suffering unjustly (...), I hope that this suffering will not last long" "What did he do to deserve this suffering?"

They also added comments about hospitalization: "Many things could have been avoided if there had been more careful,

more accurate treatment in the hospital setting (...)." "I noticed much more attention and efficiency in this home service probably due to the patient's individuality" "... There are too many patients and few doctors to well manage a patient" «[Telling of hospitalization]: You will understand how I felt! (...). Now, I feel a little more serene ».

Discussion

This study showed that in the home care setting the caregivers' burden, *assessed by ESAS*, is relevant and comparable to patients' burden for most symptoms, both physical and psychological ones. Of interest, sleep disturbances were even more relevant in caregivers than in patients. A second point of interest was that caregivers with a lower level of education and financial distress experienced more global symptom burden.

A significant number of caregiver instruments for assessing their burden have been used,¹⁴ although very few of them have been incorporated into regular clinical practice. In this study, we used the ESAS. Patients and caregivers filled in the chart with minimal training by the social workers, who were familiar with such an instrument. In a previous study, ESAS was found to be feasible (100% completed most items) and useful (73%) by caregivers to report their symptom burden. Most caregivers reported that completing the ESAS was useful for expressing their symptom burden.¹¹ Seventy-six per cent of caregivers had symptom distress scores ≥ 4 on at least one symptom. Fatigue, depression, anxiety, sleep, well-being, and total ESAS score of patients and caregivers were found to be significantly correlated. Financial distress and spiritual pain scores, which were not included in the ESAS of the present study, were also correlated. There was also a significant association between caregiver ESAS and time spent feeding and housekeeping and total time on combined caregiver activities, as well as total ZBI-12 scores, which is a widely used caregiver burden instrument.¹⁵ These correlations confirm previous observations.^{16,17} The median caregiver ESAS scores found in this study suggest a significant symptom burden. Higher scores were identified for some symptoms, such as weakness, anxiety, sleep disturbances, and poor well-being, which were similar to those found in patients. Similar levels of depression were found, although with lower intensity (less than 4/10 on average). These findings confirm data from a previous study.¹¹ Such symptoms may be explained by the burden required for assisting their loved one, differently from other symptoms, such as pain, nausea, drowsiness, or dyspnea, which are typically present in a severely ill patient. Some data also suggest that believers, females, divorced people, or those with low level of education may have more psychological distress. These aspects are interesting and deserve further investigation. For instance, financial distress¹¹ and the level of religiosity have been found to be associated with a higher symptom burden.¹⁸

Table 2. Edmonton Symptom Assessment System in Patients and Caregivers; Medians (interquartile range). Related-samples Wilcoxon signed rank test.

	Patient	Caregiver	P
Pain	5.0 (2.6–6.4)	2.0 (0–5)	.086
Dyspnea	2.0 (0–5)	0.0 (0–0)	< .0005*
Anxiety	5.0 (3–7)	6.0 (5–7.4)	.354
Depression	3.5 (2–6)	3.5 (2–5)	.842
Sleep disturbances	3.0 (0–4.8)	4.5 (2–6.4)	.019
Drowsiness	4.0 (1.8–6)	0 (0–4.8)	.037
Nausea	2.0 (0–3)	0 (0–0)	.002
Poor appetite	3.0 (0–5)	2.5 (0–5)	.747
Weakness	4.0 (1.8–6)	7.0 (6–8)	.437
Poor well-being	7.0 (5–8)	6.5 (5–8)	.322
Total Edmonton Symptom Assessment System	45.0 (30–56)	39.0 (27–48)	.167

Existing data in the literature are sparse. Caregivers of palliative care inpatients have been found to suffer from relevant depressive and anxiety symptoms, indicating the high need of psychological support. Gender, low socio-economic status, prior patient care other than home-based care, exhaustion, sleep disturbances, and worse palliative care outcome ratings were associated with higher depressive symptom levels.¹⁹

Most studies assessing caregiver burden have been performed in outpatient or inpatient settings. Patients and caregivers in a home care setting might have different levels of distress, particularly because patients are presumably more debilitated and caregivers would be more involved in the last weeks of life of their loved ones. The mean survival in home palliative care in Italy, in fact, is about 2 months.²⁰ In this study performed in home care setting, the pattern of symptom intensity of caregivers was superimposable to that reported by patients, unless for some specific symptoms of the advanced stage of disease, such as nausea and dyspnea. Indeed, the intensity of sleep disorders was higher in caregivers. It is likely that patients and caregivers followed at home experience different conditions and patients have more needs, requiring more caregiver activities. This finding may have a tremendous impact on the capacity to deliver caregiving and should be a trigger for more social support. Unless in a pioneer study, in which more than 50% of caregivers at home reported fatigue,²¹ no further data about caregivers' symptom burden are available in home care.

From the interviews with caregivers, one can argue that caregivers cultivate a sense of injustice for their loved ones and perhaps also a feeling of dissatisfaction and unhappiness for the inadequacy of the hospital setting for this type of patient. This aspect recalls the need to offer an early path of palliative care also within hospitals.¹² An intervention aimed to accelerate transition from oncological treatment to home-

based specialized palliative care, significantly attenuated caregivers' symptoms of anxiety and depression.²²

There are some limitations of this study. The cross-sectional nature of the study design does not allot a causal relationship between caregivers' distress and other factors taken into consideration. Moreover, no specific intervention was assessed to manage caregivers' symptom burden.

Conclusion

The findings of this study suggest that there is an association between patient-reported severity of symptoms and caregiver symptoms. These data suggest delivering support to those caregivers who express higher levels of symptoms. Unfortunately, in the vast majority of cases caregivers do not undergo regular assessment. Supportive interventions may help reduce their psychological distress. There is a need for further research to explore the benefits identified, and to assess the interventions effects on physical health and potential harms.^{22–24} It should be interesting to document how the use of these tools helps modify clinical and/or health service utilization outcomes, and how caregiver burden may change over time. Finally, the quality and type of support made available to family caregivers should be explored.

Declaration of Conflicting Interests

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