Research paper

Burden on family caregivers of the elderly in oncologic palliative care

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A B S T R A C T

Objective: To identify the perception of burden of caregivers of elderly patients in oncologic palliative care.
Methods: A cross-sectional survey with an exploratory non-probabilistic, quantitative methodology conducted on a sample of 100 subjects stratified according to the score obtained by applying the Karnofsky Performance Scale (KPS) to the elderly in oncologic palliative care. Group 1: 25 family caregivers of elderly subjects with a KPS score below 40%; Group 2: 25 caregivers of elderly subjects in oncologic palliative care with KPS scores of 70%, 60% or 50%; Control Group: 50 family caregivers of elderly subjects in oncologic palliative care with a KPS score of 80% or more. A clinical and sociodemographic questionnaire and the following protocols were applied: Brazil Economic Classification Criteria and the Caregiver Burden Scale. For data analysis, descriptive statistics and group comparisons by Fisher's exact test and a Regression Quantiles Model were used. Data were analyzed using the SAS 9.0 and Stata version 13 software.
Results: Family caregivers are mostly middle-aged to older women, daughters or wives predominantly in the 56–71 age group, poorly educated, belonging to social class C and performing no remunerated activity. The largest burden rates were seen in female caregivers and caregivers of seniors who have lower functional capacity scores.
Conclusions: The aggravation of the disease, the functional decline of the elderly and the possibility of death increase the burden, indicating the need to offer support services to this population as early as possible.

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1. Background

Chronic disease rates have increased considerably as a result of aging of the global population, with the elderly population being the most susceptible. Among chronic diseases, cancer is responsible for the major causes of death worldwide, causing a high socioeconomic impact and requiring treatment of high complexity [1].

The growing numbers of the elderly population often lead to the increase of physical, emotional and social incapacities and reduced performance, resulting in the need for constant care by a caregiver [2]. As a consequence, care tasks may cause a burden that can result in caregiver suffering and loss of health [3,4].

The caregiver burden tends to be further aggravated when the elderly subject has a severe and advanced chronic disease and approaches the end of life [5].

Palliative care appears as a necessary form of intervention in the healthcare field [6]. A support model for personalized care is being developed in the field of geriatric palliative care to satisfy the needs of the vulnerable and severely ill frail elderly population [7].

Research has been focused on the needs of caregivers in general, the effects of care and support interventions that can assist them in their tasks. Some studies published in the international literature have evaluated the family burden of people in palliative care using several measuring instruments to identify which areas of family life are most affected and the factors associated with burden [8–12].

However, few articles have reported the experience of caregivers of elderly people in palliative care at different stages

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of oncologic diseases leading to the decline of the elderly's functional status. Further studies are essential for the understanding of the interventions that can reduce the burden and suffering of caregivers. An investigation of this topic would bring important benefits for the sick, the family caregivers and the health care system.

This, the aim of this study was to identify and analyze the perception of burden on the part of caregivers of elderly patients in oncologic palliative care.

2. Methods

This was a cross-sectional exploratory survey using quantitative non-probabilistic methodology (convenience sampling), whose researched element was selected for being available at the local and moment of the gathering. The subjects were family caregivers of elderly patients in oncologic palliative care, with no compromise on the central nervous system and without a dementia state, which could result in cognitive compromise, selected during an outpatient visit to the Chemotherapy Center, Geriatric Oncology Clinic, Group of Palliative Care, or during hospitalization on the Geriatrics and Oncology wards in a large high-complexity university teaching hospital. Through verifying the records of the patient in palliative care and according to the inclusion and exclusion criteria previously established, their caregivers were approached and invited to participate in this study, during the period from May to September 2015.

The family caregivers included were those considered to be the most involved and responsible for the tasks of caring for the elderly (60 years or older) in oncologic palliative care. Subjects of both sexes, aged 18 years or more and conscious, no comorbidity and cognitively oriented were included in the study. A total of 100 family caregivers agreed to participate.

The caregivers were divided into three groups according to the functional performance of the elderly, measured by the Karnofsky Performance Status (KPS) protocol, with a 100-10 score, with 80 to 100 scores meaning that the individual has the ability to perform daily activities and work without the need for specific care. Scores of 50–70 suggest incapacity to work, although the person is able to stay at home and satisfy most personal needs with a varying amount of assistance needed. Scores below 40 indicate inability for self-care and the need for institutional or hospital care, with rapid disease progression [13].

The KPS is widely referred in literature and used in palliative care services, since it allows the classifying and stratification of patients, whose clinical conditions are complex, according to the level of functional compromise presented; it represents the capacity for performing activities of daily life, for performing working activities and the need of receiving special care [13,14].

Thus, the family caregivers of the elderly in oncology palliative care were stratified into the following groups: Group 1: (G1), 25 family caregivers of elderly with KPS below 40%; Group 2: (G2) 25 caregivers of elderly with KPS of 70%, 60% or 50%; and Control Group (CG): 50 family caregivers of elderly with KPS of 80% or more.

During data collection, a clinical and sociodemographic questionnaire was applied in addition to the KPS, together with the protocols Brazil Economic Classification Criteria (BECC) and the Caregiver Burden Scale (CBScale). The CBScale, consisting of 22 questions, has been validated for Brazilian Portuguese, The questions are divided into 5 groups: general strain; isolation; disappointment; emotional involvement; and environment. The responses are given on a Likert scale ranging from 1 to 4.

The study was approved by the Ethics Committee of Ribeirão Preto College of Nursing, University of São Paulo and by the Ethics Committee of University Hospital, Ribeirão Preto

Medical School, University of São Paulo, under protocol no. CAAE 39104314.5.0000.5393, on February 11, 2015.

2.1. Analysis

Means (standard deviation) and median (minimum, maximum values) were calculated to describe the sociodemographic and clinical data and the scores of the CBScale. Group comparisons involving qualitative variables (sociodemographic and clinical data) were made using Fisher's exact test. The associations of caregiver bond and gender with patient gender and the interaction with the caregiver age range were also determined. A Regression Quantiles Model was proposed to compare the groups regarding the domains of the questionnaire [15].

The G1, G2 and CG groups were homogeneous regarding gender, age, education and BECC, with no significant difference between them ($P > 0.05$). The analyses were performed using the SAS 9.0 and Stata version 13 software, with the level of significance set at 5%.

3. Results

The characterization of the caregiver sample showed that 68% were women in all groups, predominantly (37%) aged 56 to 71 years. The predominant marital status was married and most had children.

Most caregivers had a low educational level (48% in G1, 52% in G2, and 46% in CG) and the catholic religion was prevalent in all groups. Regarding occupation, 42% did not perform any gainful activity and 33% were retired. According to the BECC, the sample mainly consisted of people belonging to the lower economic classes (64%). The results are presented in Table 1.

For a better understanding of the relationship between the caregivers and the sick elderly patients and their care tasks, the family bond between them was identified. All caregivers live with the elderly and in the three groups studied, most have the bond of children of the elderly (52%). Caregivers perform their care tasks full time, mostly for 24 hours per day (63%). Only in the G1 (56,0%) there was a predominance of those who received assistance from other family members. The remaining caregivers stated that they did not receive such support.

The person receiving care in the three groups were mainly elderly men (57%). The most prevalent types of cancers diagnosed according to ICD-10 (International Diseases Classification) [16] involved the digestive organs (39%). The time since diagnosis was predominantly less 6 months in all groups (42%).

There was a predominance of palliative chemotherapy in G2 (76%) and CG (90%). G1 mainly consisted of elderly patients receiving no type of chemotherapy (64%). None of the patients in the three groups are followed or treated by any specific palliative care service (88.0%). The results are shown in Table 2.

3.1. Caregiver burden assessment–CBS scale

When analyzing the medians obtained with the CBS scale, G1– which had the lowest KPS scores – showed the highest burden score among the three groups with the greatest difference from CG.

The domains with higher burden rates in G1 were isolation, general strain, environment, disappointment and emotional involvement, with a total median value of 2.0. In G2, the higher burden rates were general strain, disappointment, isolation, environment and emotional involvement in this order, with the overall median for this domain being 1.9. Finally, the burden rates for the CG were environment, disappointment, general strain, isolation and emotional involvement, with a median value of