



Quality of Life among family caregivers of advanced cancer patients attending the palliative care clinic at National Cancer Institute, Maharagama - Sri Lanka: an observational descriptive cross-sectional study

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Abstract

Introduction: Caregivers of advanced cancer patients under palliation have many challenges. This is associated with a decline in their quality of life.

Objectives: This study was conducted to determine the quality of life among family caregivers of advanced cancer patients attending the palliative care clinic of the National Cancer Institute (NCI) Maharagama.

Methods: A total of 266 caregivers of advanced cancer patients under palliation participated in the study conducted. Patient's data and Socio demographic data were collected. The assessment of the quality of life was done using the World health organization quality of life shortened version WHOQOL-BREF. **Results:** Majority of patients in this study was between 61-70 years and were male, while most of caregivers were between 41-50 years and were female. The mean scores of the physical, psychological, environmental and social domains in the QOL were 74.8%, 63.53%, 62.67% and 56.67% respectively. The mean score of the total QOL was 64.43. The QOL in every domain was lower than 75% while they were greater than 50%. **Conclusion:** The quality of life of the family caregiver was most affected in the social domain, followed by the environmental, psychological and physical domain. Family caregiver quality of life should be assessed and this will be a positive step towards cooperating support towards caregivers.

Keywords: Caregiver burden. Advanced cancer. Palliative care. Caregiver. Quality of life.

Introduction

Cancer is the second leading cause of death in the world [1,2]. It is seen through global data that from the year 1990 to the year 2018 cancer deaths have increased by 66%. There have been 19.3% new cases and more than 10 million deaths due to cancer in the year 2020. The total incidence according to the National Cancer Registry in Sri Lanka (NCR-SL) in the year 2019 was 146/100000 population [3].

Cancer has countless challenges and needs special care. With advancements in treatment facilities and early detection, people tend to live longer and have had to accept living with a disease that has no cure. Although there was no cure, maintaining a good quality of life for the patient through the illness has become of paramount importance. Advanced cancer is defined as "cancer that cannot be cured or controlled with treatment" according to the National Cancer Institute. Newer modalities of treatment can increase survival time, which might be beneficial to some patients, but it also increases the time in the advanced cancer stage which requires more supportive care [4,5].

The occurrence of cancer is increasing in Sri Lanka and the Government of Sri Lanka has acknowledged the importance of incorporating primary health care and palliative care. This was seen in both the National Strategic Framework for Palliative Care Development done in 2019-2023 and the National Strategic Plan in the Prevention and Control of Cancer 2020-2024. It identified the importance of caregivers [4].

Palliative care is related to enhancing patient and family care. Higginson et al. (2002) [6], (2003) [7] showed in the systematic review of articles, that "hospital-based palliative care teams improved care for patients and their families". Studies have also shown that "early palliative care is associated with increased patient and caregiver quality of life" McDonald et al. (2017) [8].

Family caregivers are defined as "relatives and friends who provide care free of charge to individuals with chronic or debilitating conditions", They provide aid to the patient in the form of physical care, emotional care, and financial care thus it is time-consuming, physically and mentally draining and cause an impact on the caregiver's health [9,10] they experience a process of alteration and acknowledgment about the disease and this can affect their quality of life [11].

WHO defines the term quality of life as the insight of the individual of his status in the cultural and value system they are experiencing and is interrelated to the person's goals, expectations, and concerns the deduction of quality of life of the caregiver is a challenge because it must be assessed both subjectively and objectively in the domains of physical, mental, social, and spiritual wellbeing [12].

The caregiver's quality of life is especially a challenge in this subset of patients with advanced cancer requiring palliation as stated above they have a specific set of problems. This is shown in studies done by Grunfeld et al. (2004) [13]. The usual course in these patients would be a stable decline in their functioning and the handling of symptoms of the patient and side effects of treatment are some of the many responsibilities that the caregivers take on that might influence their quality of life [14]. The decrease in the quality of life of the caregiver directly impacts the care the patient receives [15,16]. To provide appropriate care for a patient with advanced cancer who is in palliation, the care should include the provision of support to the family caregiver as well [17].

Patients with incurable illnesses are generally taken care of by families in Southeast Asia and Sri Lanka follows the same social and cultural norms. The strong family ties strengthen the involvement of the family caregivers. This as discussed earlier can affect the family and primarily the caregiver and their quality of life. There is a paucity of data regarding this subject at present. This study aimed at assessing the caregiver quality of life of advanced cancer patients under palliation in the Sri Lankan setting.

Methods

Study Design

It was a descriptive cross-sectional study done at the palliative care clinic of the National Cancer Institute (NCI), Maharagama, between December 2021 to April 2022. All the family caregivers of patients registered to a palliative care clinic diagnosed with advanced cancer under palliation, who were eligible for the study were recruited to reach a sample size of 266.

The inclusion criterion for the family caregivers was defined as follows, being a caregiver for the patient for at least 3/12, being older than 20 years, and providing at least 4 hours of supervision or direct care per day for the care recipient. The exclusion criteria were caregivers undergoing active treatment for cancer, caregivers suffering from diagnosed psychiatric diseases and receiving treatment, and caregivers supporting the patient through a professional role i.e. clergy.

An interviewer-administered questionnaire was used for data collection and the questionnaire consisted of socio-demographic data of the patient and caregiver, caregiving data, functional status of the patient, and the WHO-QOL BREF. The quality of life of the caregiver was assessed using the WHOQOL-BREF. The WHOQOL-BREF is assessed in 4 domains which are physical, psychological, social relationships, and environmental. It was validated for Sri Lanka and was translated into the local language. It has good validity and reliability. Cronbach's alpha was >0.7. WHO BREF interpretation and scoring tool was used to calculate the score in the domains of physical, physiological, social, and environment separately [18].

The functional status of the patient was assessed as the ability to perform all activities of daily living (ADL) or the inability to perform (ADL). Patient's medical records were utilized to ascertain data, such as confirmation of diagnosis, date of referral to palliative care, history of illness, treatments done, and medications used.

Ethical Approval

Ethical clearance was obtained from the ethical review committee of the Postgraduate Institute of Medicine.

Data Analysis

Data analysis was done by SPSS version 20. General information about the samples was presented in graphs. The socio-demographic factors and other main variables were analyzed to obtain the mean and standard deviation for continuous variables and frequencies and percentages for categorical variables.



The domain scores are calculated using a linear transformation from the four-point Likert scale and the raw score was then transformed. The mean score for the total quality of life was also calculated.

Results

General characteristics: cancer patients

Data was collected from 266 patient caregivers with a response rate of 100%. Out of the 266 patients enrolled in the study, 135 patients were male (50.8%) and 131 patients were female (49.2%). The majority of the patients (30.1%) were between the 61-70 year age group. The mean age was taken as 62.19 years. Of the participants in the study a majority of patients (27.1%) were diagnosed with gastrointestinal cancers, followed by (17.7%) with head and neck cancers, (15.4%) with gynecological cancers, and (12.0%) with breast cancer (Figure 1).

There were (25.2%) of the patients were able to perform all their activities of daily living while a majority of (74.8%) of patients were unable to perform their activities of daily living (Table 1).

Figure 1: Cancer diagnosis in patients in the study

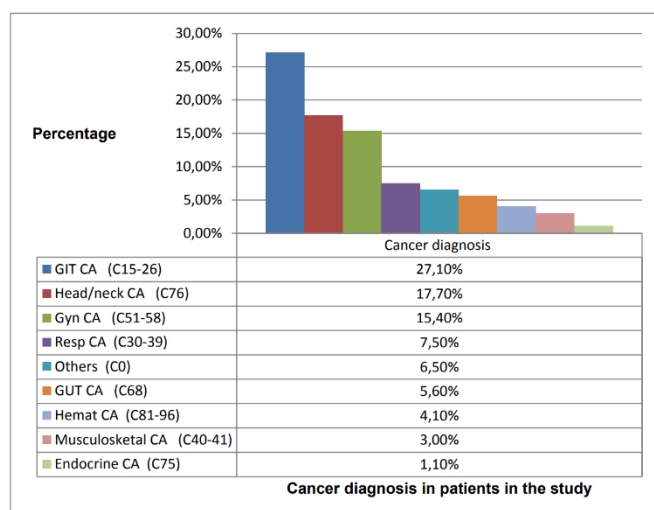


Table 1: Functional status of patients in the study population.

Variable	Frequency	Percentage
Ability to perform *ADL (all six components)	67	25.20%
Inability to perform ADL	199	74.80%

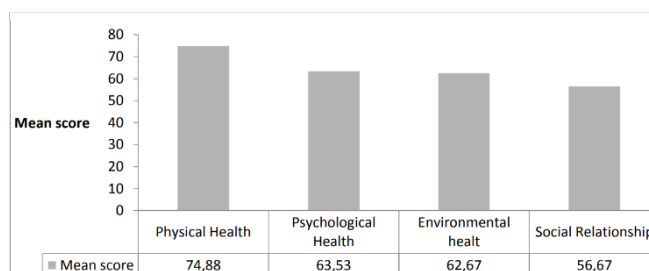
*Activities of daily living

General Characteristics: Caregivers

Out of the sample of 266, the majority of caregivers were found to be female (66.9%), and (33.1%) of caregivers were male. Most of the caregivers were found to be between the age ranges of 41-50 years (28.9%) with the mean caregiver age taken as 46.86. The majority of the caregivers were the patient's spouses (42.9%), while children who were caregivers were found to be (39.8%). It was seen that most (56.4%) of caregivers were employed and (30.8%) of the caregivers were unemployed.

The quality of life of the caregiver was measured by a QOL-BREF. This quality of life was measured under four domains namely physical, psychological, social, and environmental. The physical domain consists of seven questions, the psychological domain consists of six questions, the social domain consists of three questions and the environmental domain consists of eight questions. It shows that the sample of caregiver's quality of life in the physical domain had a score of 74.88, followed by a score of 63.53 in the psychological domain, a score of 62.67 in the environmental domain, and a score of 56.67 in the social domain (Figure 2).

Figure 2: Quality of life of caregiver in each domain



Discussion

The socio-demographic data of the patients and caregivers were assessed by the first part of the questionnaire. The study population in this study met data in previous studies done in Sri Lanka. Accordingly, the majority of the patients were males with a mean age of 61-70 years. About the socio-demographic data from caregivers, the mean age of the caregivers was revealed to be between 41-50 years, and the majority of the caregivers were females. Among these females most were the spouse of the patient. The above-mentioned data on the caregivers were similar to studies done in Sri Lanka on family caregivers [19] and international studies done by Abbasi et al. [20] and Castilla-Soto J et al. [21]. In the study done by Cengiz et al. [22] the mean age was higher.

The essential support system was the family structure and the nurturers in families are mainly the female spouses who take on the caregiver's role most



readily [19,24]. This was an observation made in international studies. This is similar to the present study. Most studies show a decrease in the quality of life of caregivers in this subset of patients, while providing care [11, 23, 25, 26].

The mean score for total QOL in our study was 64.43. The mean scores in each domain were 74.88 in the physical, 63.53 in the psychological, 62.67 in the environmental, and 56.67 in the social domain. It was seen that caregivers had the highest score in the physical domain followed by psychological, environmental, and social domains. An Iranian study done by Abbasi et al. [20] showed a mean QOL score of 59.79 which is similar to our study.

In a local study done by Pavithra Warnakulasooriya and Kaushalya Kasturiaratchi (2020) [24], It was revealed lower mean scores in the physical domain (<50%) with impairment in scores in social relationship, environment, and psychological domains in the quality of life of caregivers of children with congenital heart disease and cancer patients [13] in Sri Lanka respectively. Similarly, an Indian study done by Mishra et al. (2021) [22] revealed that QOL scores in the physical, psychological, social, and environmental domains were 49.4, 51.8, 59.3, and 58.73 respectively. These differences could be attributed to the different care groups used in the study. The present study did not search for factors that may contribute to the caregiver's QOL such as perceived health and satisfaction of care [27]. This could be one explanation for the findings. When working with families it is observed that caregivers often disregard their bodily restraints, and deny pain in the act of caring. Contrastingly the caregiver has perceived a higher physical health status when the caregiving is high [13].

Emotional support offered by a family network and healthy family functioning can promote a better quality of life for the caregiver [28]. Joint families are more common in Sri Lanka which might provide an extension of social and financial support. It offers more recompense and patience during illness. Studies done by Rha et al. (2001) [23] and Ribe et al. (2018) [29] have found the highest QOL in the physical domain followed by the psychological domain. This is similar to the observation in the present study.

Limitations

The main limitation of this study is the plausible selection bias; caregivers who had a worse quality of life may have declined to participate in the study. The nature of the study being cross-sectional as opposed to being longitudinal is also a limitation.

Conclusion

These study findings have crucial clinical inferences. The study revealed the characteristics of a population of caregivers of palliative care patients with advanced cancer. It was observed that the majority of caregivers of advanced cancer under palliation had acceptable levels of quality of life. The quality of life of the family caregiver was most affected in the social domain, followed by the environmental, psychological, and physical domain. Family caregiver quality of life should be assessed and this will be a positive step towards cooperating support towards caregivers. The scores of quality of life are higher than the studies done in Western parts of the world. This could be attributed to the family network, bonds, and cultural and social norms in the Sri Lankan setting. Further research should be done in this subset of patients to find the factors that can contribute to the caregiver's QOL such as the support systems, family bonds, functional status of the patient, and factors affecting the quality of life of the caregiver and prove the causal relationship between these factors.

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Ethical Approval

Ethical clearance was obtained from the ethical review committee of the Postgraduate Institute of Medicine.

Informed consent

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Data sharing statement

No additional data are available.

Conflict of interest

The authors declare no conflict of interest.

Review Process

This article has undergone peer review.



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