



CODEN [USA]: IAJ PBB

ISSN : 2349-7750

**INDO AMERICAN JOURNAL OF
PHARMACEUTICAL SCIENCES**

SJIF Impact Factor: 7.187

<https://doi.org/10.5281/zenodo.5546161>Available online at: <http://www.iajps.com>

Research Article

**A DESCRIPTIVE CROSS-SECTIONAL STUDY ON EVALUATION
OF CARE GIVERS BURDEN ON PALLIATIVE CARE OF ADVANCE
DISEASE PATIENTS**¹Nuzhat Aamina, ²Chanda Zulfiqar, ³Tahira Shaheen¹Charge Nurse, District Headquarters Hospital Kasur, Email ID: nuhataamina@gmail.com²Charge Nurse, Lahore General Hospital, Lahore, Email ID: chandamahnoor@gmail.com³Nursing Instructor, Post Graduate College of Nursing Punjab, Lahore,

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Article Received: September 2021

Accepted: September 2021

Published: October 2021

Abstract:

Background: Due to the recent advancements in diagnostic and molecular technology more and more patients are being screened and being managed for different types and stages of cancer. Although the life expectancy has been increased to some extent but the quality of life has further crippled. All these therapeutic approaches has mounted the burden on the family caregivers' within the field of palliative medicine. In this study, we have aimed to evaluate the prevalence and types of care givers burden on palliative care of advance disease patients. **Materials and Methods:** A cross-sectional study was conducted from January 2019 to March 2019 at Lahore General Hospital Lahore. The study included all the caregivers involved in the palliative care of the advance diseased patients. A self-structured questionnaire was designed consisting of demographic details, the Urdu translated version of Zarit Burden Interview to quantify the caregivers' burden, and the Caregiver Distress Scale to identify and evaluate the different types of burden among caregivers **Results:** The study included 200 caregivers of terminally ill cancer patients. Their ages ranged between 20 and 60 years, with an arithmetic mean of 35.5 years and a standard deviation of 4.5 years. The caregiver burden was reported among the majority of the participants (97.0%) and 21% were found to be severely burdened. **Conclusion:** Caregiving of a terminally sick patients is associated with a considerable psychological burden and warrants an empathetic and kind gesture from the health care professionals.

Keywords: caregiver, palliative care, terminally ill, psychological stress**Corresponding author:****Nuzhat Aamina,**

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Please cite this article in press Nuzhat Aamina et al, A Descriptive Cross-Sectional Study On Evaluation Of Care Givers Burden On Palliative Care Of Advance Disease Patients., Indo Am. J. P. Sci, 2021; 08(10).

INTRODUCTION:

The number of cancer patients and so is the life expectancy is increasing exponentially due to more sophisticated screening and therapeutic techniques and by 2030 it is predicted that the burden will balloon up to 5-7 times [1]. The dynamics prompt an adequate palliative care to cover the increase in the cancer burden. Palliation is not merely aimed to alleviate the pain and sufferings but also considered to uplift the quality of life for caregivers of advanced disease patients [2]. Handling a terminally sick patient in a family casts a major distress to the psychosocioeconomic outlook of the attendants [3-5]. Therefore, it is extremely necessary to evaluate the psychological state of the caregivers of a terminally ill patient.

Various studies have delineated a variable psychological response on the attendants involved in the palliative care of a patient with a terminal illness. In South Korea, Lee and Cha [3] observed a statistically significant correlation between psychological problems and the burden of care. The study of Yoo et al. [5] found that when a patient clinical condition warrants a high level nursing care the quality of life of the family gets compromised and ignites the stress level among caregivers. [6,7]. Chua et al. [8] documented that a caregiver burden was associated with advance stages of depression.

This cross-sectional study was conducted at Lahore General Hospital Lahore to explore the aspects of

palliative care. This included the quantification of psychological responses from the healthcare professional's point of view. Participants perceived level of stress and satisfaction associated with the quality of palliative care was studied. More research is warranted to establish the correlation between various physical and psychological elements [9].

MATERIALS & METHODS:

A cross-sectional study was conducted from January 2019 to March 2019 at Lahore General Hospital Lahore. The study included all the caregivers involved in the palliative care of the advance diseased patients. After formal approval from the ethical review committee of Lahore General Hospital, Lahore/Ameer-ud-din Medical College 200 caregivers of advance stage disease patients with poor prognosis and clinical outcome having at least one month experience were included. A self-structured questionnaire was designed after literature review consisting of demographic details, the Urdu translated version of Zarit Burden Interview to quantify the caregivers' burden, and the Caregiver Distress Scale to identify and evaluate the different types of burden among caregivers. Informed consent was taken by all the participants before the commencement of the study. Responses were graded and scored according to a five-point Likert scale. Confidentiality and privacy was ensured during the study. The data was analyzed by SPSS version 21.

RESULTS:**Table.1 Socio demographic data of the participants**

Characteristics	Frequency (n)	Percentage (%)
Age Years		
20-29	72	36
30-39	60	30
40-49	48	24
50-59	20	10
Gender		
Male	92	46
Female	108	54
Qualification		
Uneducated	44	22
Primary	76	38

<i>Secondary</i>	44	22
<i>Intermediate</i>	20	10
<i>Bachelors</i>	16	08
Occupation		
<i>Daily Wager</i>	64	32
<i>Private Job</i>	76	38
<i>Government Job</i>	04	02
<i>Unemployed</i>	56	28
Monthly income PKR		
<i><25,000</i>	40	20
<i>25,000-50000</i>	88	44
<i>>50,000</i>	72	36
Residence		
<i>Urban</i>	124	62
<i>Rural</i>	76	38
Duration of care		
<i>1 month</i>	44	22
<i>2 months</i>	46	23
<i>3 months</i>	50	25
<i>>3 months</i>	68	34
<i>>6months</i>	32	16

36% of the participants were having age 20-29 years, 54 % were female, 38% had attained primary level of education, 38% were doing private jobs as a source of income, 44 % had a monthly family income of less than 25,000-50,000 PKR and 62 % belonged to the urban population of Lahore and 34% reported to be involved in caregiving for more than 3 months. (Table.1)

DISCUSSION:

The statistics depicts a high magnitude of caregivers' burden. Since all types of cancer have poor prognostic value and the clinical outcome is highly dependent on the stage of presentation, comorbidities and the overall health of the individual therefore the caregivers mostly gets emotionally drained and hopeless ignoring their self-care in due course of time. [8]. Identifying caregivers' burden and needs is equally important for the medical team [15] because this may ignite depressive disorders and chronic fatigue syndrome and even melancholy and despair leading to suicidal tendencies. [8,16,17]. This study may enlighten the

way forward for useful interventions regarding the health and wellbeing of the caregivers.

Similar to the others [6-8,18-21] this study has identified that majority of the caregivers feel burdened (97.0%). 21.0% of the caregivers were found to be severely burdened. In a study carried out in the United States [7], the burden was linked to only 15% of caregivers attending advanced stage cancer patients. This difference may be because of the lack of medical and socioeconomic resources reserved for the providing the end of life care in our healthcare setups.

It was observed that elder caregivers suffered from higher degree of mental stress than younger caregivers which contradicts other studies [7,22,23]. This may be due the fact that the seniors are the head of families and the decision makers regarding the course of treatment bearing all expenses of the life saving procedures.

In the present study, caregivers' mean age was 35.5 ± 4.5 years, which constituted a young sample size even if the elders were not that much older where as in the studies [7,22,23] the caregivers' age ranged between 43.8 and 63.1 years. The current study also showed the burden was more among participants who had lower education, jobless and shorter caregiving duration.

Our study revealed that the males experienced a higher burden than females which is identical to the another study [26]. In South Korea, Yoon et al. [27] reported that longer duration of care, fewer visits by the blood relations, poor financial status and low self-respect are the disease modifying factors that can change the outlook of a caregiver's perception. A caregiver's burden can also arise from the unaddressed social, economic, religious, and mental and spiritual needs [3]. Therefore it is the obligation of the healthcare professional to identify and mobilize resources to fulfil the above needs [5]

CONCLUSIONS:

The situation of a caregiver dealing with any advanced stage disease of poor prognosis warrants an empathetic and kind gesture from the health care professionals. Older caregivers are more vulnerable to suffer the backlash than younger caregivers. Being a first degree blood relative further adds to the spark. Mother > father and son > daughter were found be affected. Similarly the ones involved in short duration of care < 3months and males were more prone to experience the emotional drainage.

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