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Original Article

Assess the Burden of Caregivers of Cancer Patients at a Tertiary Care Hospital in Karachi, Pakistan

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ABSTRACT

The burden faced by caregivers of cancer patients is a critical aspect of healthcare, influencing both the well-being of the caregivers and the quality of patient care. **Objective:** To assess caregivers' burden of cancer patients at a Tertiary Care Hospital in Karachi, Pakistan. **Methods:** The cross-sectional study was conducted at Zareen Cancer and Research Centre (ZCRC) at Dr. Ziauddin Hospital Karachi, Pakistan. The target population for this study was adult informal family caregivers who were actively taking care of histologically diagnosed cancer patients receiving treatment. Moreover, a 22-item standardized validated Zarit Burden Interview (ZBI) questionnaire was used to collect data. **Results:** The study findings revealed that 18% of caregivers feel okay or have No to Mild Burden. The largest group 64%, is Mild to Moderate Burden. Around the same, 18%, Moderate to Severe Burden. **Conclusions:** Based on the findings, 64% face moderate burdens, with an additional 18% enduring higher, moderate to severe burdens. This reveals widespread challenges and stress among caregivers, emphasizing the need for enhanced support and resources to ease their strain and improve their well-being.

INTRODUCTION

Cancers are collections of abnormally multiplying cells that can arise anywhere in the body. These cells tend to spread throughout the circulation and lymphatic system [1]. Globally, there will be 19.3 million newly diagnosed cases of cancer and around 10.0 million cancer-related deaths in 2020, predicts GLOBOCAN 2020. Lung cancer is now less common than breast cancer in women, with an estimated 2.3 million new cases (11.7%). In order of incidence, stomach (5.6%), prostate (7.3%), colorectal (10.0%), and lung cancer (11.4%) are the next. Lung cancer was the most common cause of mortality from cancer, accounting for an estimated 1.8 million fatalities (18%). The most frequent cancer-related causes of death were colorectal (9.4%), liver (8.3%), stomach (7.7%), and female breast (6.9%) [2]. Pakistan has 0.18 million newly diagnosed cases, 0.11 million cancer deaths, and 0.32 million prevalent cases (5 years) according to data from the International Agency for Research on Cancer (IARC). In all of Asia, Pakistan has the highest rate of breast cancer. One in nine women in Pakistan are currently at danger of getting breast cancer at some point in their lifetime due to the rising incidence of the disease. Pakistan has one of the highest breast cancer death rates in the world. When considering both sexes together, lips and mouth cancer is highest among males

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(15.9%) and is the second most common cancer in Pakistan. The prevalence of severe lung tumors may grow with greater use of smokeless tobacco products, such as beetle nuts [3]. Thus, it has been concluded that cancer is becoming a more common cause of morbidity and death worldwide, including in Pakistan. Cancer patients require ongoing and prolonged support from carers due to the high cost and complexity of cancer treatments like radiation and chemotherapy. Therefore, psychological, physical, economic, and social problems are more likely to trouble carers of cancer patients. Taking care of cancer patients in low-middle-income countries such as Pakistan is much more difficult due to limited resources. If they come from a low-income family, have few resources, and are not well, the caregiver's burden becomes even more [4]. Cancer caretakers are those (friends or family) who provide ongoing care to patients with cancer who are somewhat incapacitated. Carers have a wide range of time- and energy-consuming tasks, including household, personal, and medical duties. A cancer patient's degree of fragility, which primarily builds over time, and the expected length of their illness—which, in the context of cancer therapy, can last anywhere from weeks to years—have an impact on the intensity of caregiving [5]. In the context of geographically dispersed families, declining marriage and divorce rates, smaller family sizes with fewer or no children are increasing challenges, and simultaneous domestic and professional responsibilities, finding and making a carer available may be difficult [6]. A family member's cancer diagnosis has an impact on the roles and relationships of other family members, who are crucial in providing care. A prior study demonstrated that family caretakers of cancer patients often had mild to moderate levels of caregiving load. It was discovered that carers' anxiety and despair levels rose along with the amount of care they had to provide. The load placed on family carers rises in tandem with the number of hours they provide care each day [7]. Hence, this study has assessed their burden. Therefore, this study aim was to assess the caregiver burden of cancer patients at a tertiary care hospital in Karachi, Pakistan. This study has helped tailor support services and interventions specifically aimed at addressing the unique needs of caregivers, ensuring their well-being and mental health.

METHODS

This Cross-sectional study was conducted at Zareen Cancer and Research Centre (ZCRC) at Dr. Ziauddin Hospital Karachi, Pakistan. The target population for this study was adult informal family caregivers actively taking care of histologically diagnosed cancer patients receiving treatment at Dr. Ziauddin Hospital at the time of this survey. The study duration was two months, i.e., from September 2023 to 3rd December 2023. In this study, a sample of 100 participants was chosen through a random selection process due to the unavailability of information regarding the total population size. The aim was to ensure a representative subset that could provide valuable insights despite the uncertainty about the overall population characteristics. The Inclusion Criteria consist of An adult aged 18 years and above, An informal individual as an unpaid person (blood relatives or friends) actively taking care of a cancer patient, and Willingness to participate in the study and provide informed consent. Moreover, the Exclusion Criteria were Age less than 18 years, Individuals who cannot provide informed consent or have cognitive issues, and Any paid caregiver like nursing aids and maids. The questionnaire consists of two components, I and II; component I covered demographic data, and component II contained an adopted 22-item standardized validated Zarit Burden Interview (ZBI) questionnaire. The 22 items on the modified ZBI scale represented the range of emotions that people experienced when providing care for others. The ZBI scale is a 22-item assessment with a rating range of 0-88, where a higher score indicates a heavier burden for that specific item. The total of all the recommended items' scores represents the subject's overall load. The scale's overall score, on a five-point Likert scale, varied from 0 to 88. The following scale was used to gauge the level of burden experienced by carers: 0–20 indicates little to no burden; 21–30 indicates mild burden; 31–40 indicates moderate burden; and 41–88 indicates high burden level. The ZBI scale's psychometric qualities included convergent validity and acceptable inter-item reliability, as demonstrated by a correlation coefficient of 0.71 between carer global appraisal and scores and a Cronbach alpha of 0.79. After the approval of the proposal from the faculty of Horizon School of Nursing and Allied Health Sciences, the researchers' team pursued permission from the Zareen Cancer and Research Centre (ZCRC) at Dr. Ziauddin Hospital. Data were collected after obtaining written informed consent by distributing a ZBI questionnaire among participants. After that questionnaires were distributed among the participants in hard copies in both English and Urdu language for better understanding. The data were analyzed using SPSS version 25.0; Descriptive statistics was used to summarize the data. Frequencies and percentages are used for the demographic data as well as for the level of burden. Permission was sought from the Horizon School of Nursing and Allied Health Sciences with reference number (HSNHS/2023/433, Dated 11th October, 2023) before initiating the data collection process. Before data collection, written informed consent was obtained from each participant. This ensured that the caregivers were aware of the study's purpose, their involvement, and the confidentiality of their information.

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RESULTS

This study was conducted on 100 caregivers, of which 55% were males and 45 % were females. The age groups included were 20-25 years (6%), 26-30 years (9%), 31-35 (25%), 36-40 (39%) and 21 % of them were Above 40. Qualification of caregivers was Primary (13%), Secondary (7%), Higher Secondary (10%), Bachelors (43%), Master (24%), PhD (3%). The Cancer types were Breast Cancer (32 %), Lung Cancer (11%), Colon / Rectal Cancer (9%), Prostate Cancer (8%), and 40 % of other cancer types (Table 1).

Table 1: Demographic data of the participants n=100

Variables	Frequency (%)
Age	
20-25	6 (6)
26-30	9 (6)
31-35	25 (25)
36-40	39 (39)
Above 40	21 (21)
Gender	
Male	55 (55)
Female	45 (45)
Qualification	
Primary	13 (13)
Secondary	7 (7)
Higher Secondary	10 (10)
Bachelors	43 (43)
Master	24 (24)
PhD	3 (3)
Cancer Type	
Breast Cancer	32 (32)
Lung Cancer	11 (11)
Colon / Rectal Cancer	9 (9)
Prostate Cancer	8 (8)
Others	40 (40)
For how long your patient has been diagnosed with cancer	
Less than year	45 (45)
1-3 Years	31 (31)
More than years	24 (24)
Total	100 (100)
Stage	
Stage 1	1 (1)
Stage 2	15 (15)
Stage 3	43 (43)
Stage 4	41 (41)

Table 2 shows how caregivers caring for cancer patients are handling the responsibility. About 18% of caregivers feel okay or have No to Mild Burden. The largest group, around 64%, is Mild to Moderate Burden. Around the same, 18%, Moderate to Severe Burden.

Table 2: Level of Burden

Level of Burden	Frequency (%)
No to Mild Burden	18 (18)
Mild to Moderate Burden	64 (64)
Moderate to Severe burden	18 (18)

DISCUSSION

This study assessed caregiver burden, including physical, mental, emotional, and psychological distress in informal caregivers of cancer patients at a tertiary care hospital in Karachi, Pakistan. The current findings revealed that the majority of the participants were male. While another study found almost the same result: 56% were male [8]. In contrast, another study found that 66% were female [5]. Based on these findings, gender norms may dictate that men are more likely to be the primary caretakers for ailing family members, such as cancer patients. The current results show that 43% had a Bachelor's degree. At the same time, another study found that 63% had a high level of education [8]. The present findings show that 39% are aged between 36 and 40. In contrast, another study found that the majority were from = 29-84 years [9]. In our study, most (64%) caregivers were under moderate caring burden. One of the probable reasons for this finding may be that most patients were somehow capable of taking care of themselves and had less caring dependency. Another study found that 70.22% of caregivers reported mild-to-moderate burden [4]. Similarly, another study found a mild to moderate burden of 36.1% [10]. In this regard, earlier studies reported a moderate level of caring burden in caregivers of cancer patients, which is consistent with our results [10, 11]. Another study shows that the overall population's mean scores on the ZBI Scale were 22.8 ± 17.3 and 72.8 ± 11.2, respectively, indicating low-to-moderate burden and moderate-to-high satisfaction. A number of burden items were linked to lower satisfaction: feeling resentful of the patient, believing that the patient needs more assistance than they do, and wanting to hand off the care to someone else. Loss of control, personal time, social interaction with others, and anger towards the patient were also identified [12]. There was moderate evidence to suggest that solid tumors, younger carers, and help with daily living tasks were significantly linked to high caregiving burdens. The data showed that younger family carers who looked after patients with solid tumors and helped the patients with their everyday activities reported having a significant caretaker burden [13]. However, our data Observed a moderate to severe burden in 18% of all caregivers in this study. In contrast, a study found that Nearly half of the caretakers (48.1%) reported having a severe burden [14]. Another study found that 21.38% reported moderate-to-severe burden [4]. The physical and mental well-being of carers, their financial burden, their social isolation, and the lack of family and social assistance they get all remained significant contributors to high carer burden levels. Male gender, the changeable nature of cancer therapy, and carers' self-esteem were less well-known characteristics associated with the increased burden [15]. Prior research, using various assessment tools, revealed that between 55 and 90% of family carers had moderate to severe distress at various stages of the patient's incurable cancer disease [16-19]. Patients' declining functional status is correlated with increased provider depression and perceived load. Strategies are required to lessen the psychological, occupational, and financial strain of providing care [20].

CONCLUSIONS

The data highlights that a significant portion of caregivers for cancer patients experience a notable burden. Most caregivers, approximately 64%, face a moderate burden, while an additional 18% endure a higher, moderate to severe burden. This suggests that most caregivers encounter challenges and stress in their caregiving role, signifying the need for support and resources to alleviate their burdens and enhance their well-being.

Authors Contribution

Conceptualization: SA[1]
Methodology: AB, SH
Formal analysis: SA[1], AB
Writing-review and editing: SJ, TM, SA[2], MA, SN, NS
All authors have read and agreed to the published version of the manuscript.

Conflicts of Interest

The authors declare no conflict of interest.

Source of Funding

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