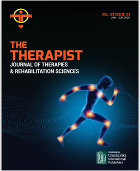
THE THERAPIST

JOURNAL OF THERAPIES & REHABILITATION SCIENCES

https://thetherapist.com.pk/index.php/tt

Volume 4, Issue 1 (Jan-Mar 2023)



Original Article

Psychological Well-Being and Care Giver Burden of Parents Having Child with Leukemia

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ARTICLE INFO

Key Words:

Psychological Wellbeing, Care Burden, Leukemia

How to Cite:

Ghaffar, R. ., Ali, A. ., & Sarwar, H. . (2023). Psychological Well-Being and Care Giver Burden of Parents Having Child with Leukemia : Psychological Well-Being & Care Giver Burden of Parents. THE THERAPIST (Journal of Therapies &Amp; Rehabilitation Sciences), 4(1). https://doi.org/10.54393/tt.v4i1.108

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Received Date: 9th February, 2023

Acceptance Date: 22nd March, 2023

Published Date: 31st March, 2023

ABSTRACT

Leukemia is one of most prevalent type of cancer among the children with age less than 15 years. Worldwide, Leukemia represents 32.5% of all types of cancer among the children. In Pakistan, 46.5% child with cancer diagnosed with leukemia. Both the mother and father are involved in the direct and indirect care of their child with leukemia Direct care is the tasks with the care of the child with leukemia and indirect care is the financial support and the facilities provided to the patients. **Objective:** To determine the psychological wellbeing and Care burden among parents having Children with Leukemia. **Methods:** A cross-sectional study designed was used. A sample of n=81 participants was recruited from Sadiq Abbasi Hospital Bahawalpur, through convenient sampling. The psychological wellbeing and care burden questionnaires were used to measure care burden and psychological wellbeing among parents having children with leukemia. Filled questionnaires were entered and analyzed through SPSS version-21. **Results:** Findings revealed that 71.60% participants had poor psychological wellbeing, 18.51% had fair and only 38.27% had good wellbeing during their children leukemia care. Similarly, 12.34% had low care burden, 38.27% had moderate and majority 49.38% were having high care burden.**Conclusions:** Majority of the parents of children with leukemia in this study were having high care burden and poor psychological wellbeing while taking care of their children.

INTRODUCTION

Childhood cancer is the cancer among children with age between 0 to 14 years old. Cancer is the main cause of death among children. Approximately, 80% cancers in children have been reported in low- and middle-income countries due to the limited treatment resources [1]. Cancer is the basic health problem of concern worldwide and considered among the leading cause of mortality and morbidity. Cancer is among chronic diseases and is the second leading cause of death [2]. Worldwide, approximately, 443.4 per 100,000 children affected from cancer every year. Eventually, the mortality rate of cancer is estimated 158.3 per 100,000 men and women [3]. Among the children population the mortality rate is very high. In develop the mortality rate among the children with cancer is around 20% while the low and middle-income countries the mortality rate among the children population with cancer is around 80% [4]. Similarly, the mortality rate varies on the early screening of cancer and treatment regimen to the patients [5]. In developing countries like Pakistan, cancer represents high statistics. A total of 22,858 cases of cancer among children were registered in Pakistan during 2010-2019 [6]. Leukemia is one of most prevalent type of cancer among the children with age less than 15 years. Worldwide, Leukemia represents 32.5% of all types of cancer among the children [7]. In Pakistan, 46.5% child with cancer diagnosed with leukemia [8]. Chemotherapy is the basic and primary treatment option for pediatric leukemia patients. Chemotherapy prevents the proliferation of cancerous cells and prevents the spread of cancer. Similarly, chemotherapy is a cytotoxic medication with severe side effects and problems [9]. Among these problems the most common are Oral mucositis, weakness, hair loss and gastrointestinal problems which increase the care burden of caregivers [10]. Similarly, Leukemia is a chronic disease with a variety of symptoms and severe problems. The children with leukemia experience a variety of problems with is associated with the disease and its treatment. These complications are nausea, fatigue, vomiting, fever, weight loss, pain, bladder and bowel dysfunction, skin changes, oral sores and thrushes, bleeding and tissues masses [11]. Both the mother and father are involved in the direct and indirect care of their child with leukemia [12]. Direct care is the tasks with the care of the child with leukemia and indirect care is the financial support and the facilities provided to the patients [13]. The parents are mostly involved in the care of the children and to deal with all the complications associated with the disease and treatment. Therefore, similar to other chronic diseases, parents of children with leukemia also experience mental and physical problems such depression, anxiety and disappointment [14]. Care burden among parents of children with leukemia effect the quality of life and psychological wellbeing of parents. Several psychological problems such as stress (21%), mild anxiety and depression (95%) is commonly prevalent among the parents of children with leukemia [15]. Different studies reported that leukemia among the children affect the psychological wellbeing of the parents. The majority (60%) of the parents of children with leukemia experience psychological consequences. Several psychological distresses such as transitioning back to life as it was before the diagnosis, Emotional scars, Uncontrollable fears and worries of diseases, and new perspectives on life among the parents are experienced [16]. Similarly, various studies reported that caregivers especially the parents experience high level of care burden. The care burden results in painful experiences such as weeping, social isolation, avoidance, social relationship reduction, fatigue, unwilling to talk, decline in quality of life and decrease appetite [17]. The parent's role changes after the involvement in the care of the children with leukemia. Also, the parents adopt a new role as a member of the caring and treatment team [18]

METHODS

The aim of this descriptive study was to determine the Psychological Well-Being and Care Giver Burden among parents having children with leukemia. In this regard, a descriptive cross-sectional study was conducted to determine this care burden and psychological wellbeing. A cross sectional descriptive study was conducted to carry on this study. This study was conducted at the oncology unit of Sadiq Abbasi Hospital Bahawalpur. All the parents of pediatric patients with leukemia visit oncology unit of Sadiq Abbasi Hospital Bahawalpur were the targeted population. A convenient sample of n=81 participants was recruited. Sample size of 81 cases is calculated with 95% confidence interval, 7% margin of error and expected percentage of post interventional psychological well-being among parents having child with leukemia is 88.3% (Mahmoud & Elaziz, 2015).

$$n= [z^2_{1-\alpha/2} P(1-P)] / d^2$$

Where,

$1-\alpha$	95
P	0.883
d	0.07
n	81

Bothe parents who were primary caregivers were recruited with following characteristics. All the parents of children who were diagnosed with acute leukemia and on chemotherapy treatment. Parents between age 25 to 55 years. Participants of both gender male and female parents. Parents who were able to read and write. Parents without any mental illness. Individuals with following characters were excluded. Terminally ill parents were excluded from the study. The parents who were unwilling to participate in the study. The parents who were not actively participating in the care of the child. The rules and regulations set by the ethical committee of The University of Lahore were followed while conducting the research and the rights of the research participants were respected. Permission was taken from head of the Department of Pediatric Oncology wards of Saadiq Abbasi Hospital Bahawalpur. Written informed consent was taken from all the participants. All information and data collection were kept confidential. Participants were kept anonymous throughout the study. Data were collected using three parts of a questionnaire. Part "A" consisted of socio-demographic profile of the participants. Part B consisted of Physiological well-being using Ryff's Psychological Well-Being Scales (PWB). Ryff's Psychological Well-Being Scales was an 18 items Likert scale questionnaire. The questionnaire was answered in 5 points ranging from strongly disagree to strongly agree. The reliability of the questionnaire was checked, and it was 0.91. Care burden of the parents was assessed using Care Burden Scale (CBS). The scale was developed from a study carried out by Hossein Karimnejad. Caregiver burden scale consisted of 22 questions. Each question was answered as Never, Rarely, Sometimes, Frequently and Nearly Always. The caregiver burden was categorized as: 0 to 20 = little or no burden; 21 to 40 = mild to moderate burden; 41 to 60 = moderate to severe burden; 61 to 88 = severe burden. The reliability (Cronbach's alpha) of the scale was 0.94. All participants were given close ended questionnaires along with further detailed sheet of information. A written consent was implied to every participant along with the questionnaire. Introduction to every participant was done.

DOI: https://doi.org/10.54393/tt.v4i1.108

Participants were questioned individually at the pediatric oncology department of the given hospital where the assessment of the participants was done using data collection tool. After data collection it was entered and analyzed in SPSS version-21. Quantitative variables were presented in the form of mean ± standard deviation. Qualitative variables were presented in the form of frequency and percentages. Frequency distribution tables were used to present the psychological wellbeing and care giver burden among the study participants.

RESULTS

Table 1 revealed that 9.87% of the research participants were between the ages of 25-35 years age group, 76.54% were 35-45 years of age and remaining 13.58% were 45-55 years of age. It was also found that 90.13% participants were mothers and 9.87% were fathers. Furthermore, it is also shown that that in according to educational status 12.34% of the study participants were illiterate, 35.80% were primary, 38.27% higher secondary and 13.58% participants were graduated and above.

Table 1: Demographic characteristics of the participants (n=81)

Demographic	F (%)
Age	
25-35 Years	8 (9.87%)
35-45 Years	62 (76.54%)
45-50 Years	11 (13.58%)
Gender	
Father	8 (9.87%)
Mother	73 (90.13%)
Gender	
Illiterate	10 (12.34%)
Primary	29 (35.80%)
Higher Secondary	31 (38.27%)
Graduation& above	11 (13.58%)

Above table 2 indicated the psychological wellbeing among the study participants. Findings revealed that 71.60% of the participants had poor psychological Wellbeing while caring for leukemia child, 18.51% were having fair psychological Wellbeing and only 10.89% of the study participants had good psychological wellbeing regarding leukemia care and caring children with Leukemia. This finding indicated that a majority of the participants who were having children with Leukemia were having poor psychological wellbeing.

Table 2: Psychological Wellbeing among parents Having Children with Leukemia n=81)

Demographic	Frequency (%)
Poor Psychological Wellbeing	58(71.60)
Fair Psychological Well being	15(18.51)
Good Psychological Well being	08(10.89)

Above table 3 indicated the care burden among parents having children with Leukemia. Findings revealed that 12.34% of the participants were having lower care burden while caring for their Leukemia children, 38.27% were having moderate care burden while taking care of their Leukemia children and almost half only 49.38% were having high care burden during taking care of their Leukemia children. This finding indicates that a majority of the participants caring for their leukemia children were having high care burden during care.

Table 3: Care Burden among Parents Having Children with Leukemia(n=81)

Status	Frequency (%)
Low Care Burden	10(12.34)
Moderate Care Burden	31(38.27)
High Care Burden	40(49.38)

DISCUSSION

The results of the present study as demonstrated in table 1 that the majority of the study sample 76.54% were aged (35–45) years old. Also, majority 90.13% participants were mothers and more over it was also shown that 35.80% were primary and 38.27% higher secondary. A similar study was found conducted by Mohamed Mustafa *et al.*, where 56% were age 30 to 45 years of age. Similarly, 69.90% of the care providers were females in same way as in current study [19]. Similarly, education status was also consistent with the current study where 12.6% of the study participants were till primary education and 66% were middle and high [20]. In contrast, a previous study found that the majority of the study sample 52.9% (99/187), and 11.8% (22/187) of parents were diploma and academic education, respectively. aged (18–27) years old; that their level of education was read and write estimating as 67 (45.3%) [21]. Findings of this current study revealed that 71.60% of the participants had poor psychological wellbeing while caring their leukemia children, and only 10.89% of the study participants had good wellbeing regarding leukemia and caring children with leukemia. This finding indicated that majority of the participants who were having children with leukemia were having poor psychological wellbeing during care of leukemic children. In consistent to the current study, a past study found that 84.83% parents of children with leukemia experience some sort of psychological problems associated with the disease and treatment. Besides, physiological distress, depression, poor relation among the spouses, incompetence, and fear of child loss was reported by the parents of child with leukemia [22]. Similarly, the findings of the study by Wiener *et al.*, reported that cancer of child effect three main domains of parents such as parental behaviors, spouse relationship, and mental health [23]. Findings of this current study revealed that 49.38% of the participants were having high care burden regarding caring their Leukemic children, 38.27% were having moderate care burden during care of their Leukemic children. This finding indicated that a majority of the participants caring for their Leukemia children were having high care burden. Similarly, a past study by Arab *et al.*, found that care burden score was 56.43+9.32 and ranged from 0 to 88. 10.7%, 79.7%, and 9.6% of parents had low, moderate and high care burden, respectively. Another study found that the findings of the study revealed that the parents experience significant care burden(p=0.000)[24].

CONCLUSIONS

The majority of the parents of children with leukemia in this study were having high care burden and also poor psychological wellbeing. The nature of disease and parents' role and responsibilities make it difficult for them to manage and their care burden increases, and they become weak psychologically.

Authors Contribution

Conceptualization: RG
Methodology: AA
Formal analysis: HS
Writing-review and editing: RG, AA, HS

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

The authors received no financial support for the research, authorship and/or publication of this article.

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