International Journal of Research in Paediatric Nursing 2025; 7(2): 30-37

E-ISSN: 2664-1305
P-ISSN: 2664-1291
www.paediatricnursing.net
IJRPN 2025; 7(2): 30-37
Received: 13-05-2025
Accepted: 16-06-2025

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A descriptive study to assess the stress and anxiety level of caregivers of children with oncological conditions in selected tertiary care center in Western Maharashtra

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DOI: https://www.doi.org/10.33545/26641291.2025.v7.i2a.234

Abstract

Background: Caregivers of children with oncological conditions experience significant psychological distress, especially stress and anxiety. Understanding the prevalence and contributing factors is crucial for designing support interventions. This study was conducted to assess the stress and anxiety levels among caregivers of children with oncological conditions in a tertiary care hospital.
Methods: A descriptive research design was employed. Data were collected from 50 caregivers using non-probability purposive sampling technique. The tools used included a structured demographic questionnaire, the Perceived Stress Scale (PSS-10), and Generalized Anxiety Disorder - 7 (GAD-7) Scale. The study was conducted in the Pediatric oncology OPD of a selected tertiary care hospital. Descriptive and inferential statistics were used to analyze the data, including frequency, percentage, mean, standard deviation, and chi-square test.
Results: Majority of caregivers were fathers (60%) in the 30-40 years age group (58%). Most of the caregivers resided in urban areas (76%) and 80% of caregivers were having nuclear families. Regarding the stress level, 78% of caregivers experienced moderate stress, while 22% had low stress. There was a significant association between education and stress level of caregiver. Concerning anxiety levels, 60% of caregivers falls into the mild category whereas 34% had moderate and 6% had minimal anxiety. The mean percentage was 40%, indicating that most caregivers experienced mild to moderate anxiety. A significant association was found between stress level and education of the caregiver and anxiety level and the caregiver's age, relationship with the patient, and type of family.
Conclusion: Caregivers of children with cancer experience elevated levels of stress and anxiety. This emphasizes the need for early psychological screening and implementation of supportive interventions for caregivers. Tailored counseling and structured support programs in pediatric oncology units are recommended to enhance caregiver wellbeing and quality child care.

Keywords: Stress, anxiety, caregiver, children, oncological condition

Introduction

Childhood cancer is a life-altering diagnosis that significantly impacts both the child and their caregivers. Caregivers, usually parents or close family members, experience high levels of stress and anxiety due to the emotional, financial, and physical demands of caring for a child undergoing cancer treatment. Their psychological well-being is crucial as it directly affects their ability to provide care and support for the child. This study aims to assess the stress and anxiety levels of caregivers of children with oncological conditions in a selected hospital in Western Maharashtra.

Background

Cancer in children is a devastating illness that not only affects the patient but also has profound psychological, emotional, and financial consequences on the caregivers [1]. According to the Indian Council of Medical Research (ICMR), childhood cancer accounts for 3-5% of all cancers in India [2]. The treatment process is often prolonged, requiring frequent hospital visits, chemotherapy, and even bone marrow transplants, which place immense pressure on caregivers. Studies suggest that caregivers experience heightened stress levels, anxiety, sleep disturbances, and even depressive symptoms. Understanding their psychological burden is essential to developing appropriate interventions and support systems for improving their mental well-being.

According to a study by Kazak *et al* (2007) parents of children undergoing cancer treatment showed clinically significant levels of psychological distress, with over 50% reporting symptoms of anxiety and stress severe enough to interfere with daily functioning [3]. Another study by Soni and Atram (2024) [4] in India used the Beck Anxiety Inventory and a stress rating scale to evaluate caregivers, finding that 26% had severe stress and 29% showed concerning levels of anxiety [4]. These results underscore the urgent need for systematic psychological assessment and support in pediatric oncology care settings.

In the Indian context, the caregiver burden is often compounded by factors such as limited healthcare accessibility, high treatment costs, low health literacy and minimal psychological support systems. A 2013 study by Alves *et al* demonstrated that young parents and caregivers with children recently diagnosed with cancer experience significantly higher stress and anxiety levels [5]. Similarly Lewandowska *et al* (2024) [6] found a strong correlation between caregiver anxiety and depression, especially in cases where the child's diagnosis had been recent treatment prolonged [6]. Parents mentioned experiencing stress arising from limited access to health facilities, long waiting times, prolonged hospital stays, lack of chemotherapy drugs, and limited or inadequate information about their child's disease condition and treatment. Other sources of stress were insufficient social support, stigmatization of cancer and financial problems [7].

Aim

To explore the level of stress and anxiety among caregivers of children with oncological condition

Objectives

- To assess the stress levels among caregivers of children with oncological conditions.
- To assess the anxiety levels among caregivers of children with oncological conditions.
- To determine the association between stress and anxiety levels with selected demographic variables

Operational definition

- **Stress:** Stress refers to the psychological and emotional strain experienced by caregivers of children with oncological conditions due to the demands of caregiving, uncertainty about the child's health, financial burden, and emotional exhaustion. It will be measured using the Perceived Stress Scale (PSS).
- **Anxiety:** Anxiety is defined as the feelings of worry, nervousness, or fear experienced by caregivers due to concerns about their child's illness, treatment outcomes, and future uncertainties. It will be assessed using the Generalized Anxiety Disorder-7 (GAD-7) Scale.
- **Caregiver:** A caregiver in this study refers to a parent, guardian, or close family member who is primarily responsible for providing physical, emotional, and financial support to a child diagnosed with an oncological condition.
- **Children:** For this study, children refer to individuals aged 0 to 18 years who have been diagnosed with any form of cancer and are receiving treatment in the selected hospital.
- **Oncological Condition:** An oncological condition refers to any type of cancer diagnosed in children, including but not limited to leukemia, lymphoma, brain tumors, and solid tumors. These conditions require medical treatment such as chemotherapy, radiation, surgery, or palliative care.

Review of literature

Nkwera RP, Mayige MT, and Mghamba JM (2022) [8] conducted a hospital- based cross-sectional study to assess the prevalence and factors associated with perceived stress among 384 caregivers of children with cancer at Muhimbili National Hospital, Tanzania. Published in the East African Health Research Journal, the study used the 10-item Perceived Stress Scale (PSS-10) and structured questionnaires. Findings revealed that 66.4% of caregivers experienced moderate stress and 10.7% had high stress. The authors emphasized the importance of psychosocial support programs for caregivers to reduce stress and improve care outcomes for children with cancer [8].

Alharbi M, Mohammed EO, Alsalloom EA, Alharbi HA, Alsogaihi JM, Almutlaq LY, Alwuhayd SA, Hameed SN (2025) [9] conducted a cross-sectional study to assess the prevalence of depression and anxiety among caregivers of pediatric cancer patients at Prince Faisal Bin Bandar Center for Pediatric Oncology in Buraydah, Saudi Arabia. The study included 67 caregivers between January and June 2023. Standardized tools such as the Patient Health Questionnaire-9 (PHQ- 9) and Generalized Anxiety Disorder-7 (GAD-7) were used for psychological assessment. Results showed that 25.4% of caregivers reported mild depression, 16.4% had moderate, 6.0% had moderately severe, and 4.5% had severe depression. For anxiety, 22.4% showed mild symptoms, 20.9% moderate, and 7.5% severe symptoms. Despite these notable psychological symptoms, no significant association was found between depressive or anxiety symptoms and sociodemographic variables (e.g., age, gender, occupation), with all p-values >
0.05. The study emphasizes the psychological vulnerability of caregivers and advocates for targeted mental health interventions.9

In a recent cross-sectional study conducted by Soni S and Atram D (2024) [4] in Nagpur, Maharashtra, India, the stress and anxiety levels among 100 caregivers of children with cancer were assessed using a standardized rating scale and Beck Anxiety Inventory (BAI). The caregivers were predominantly aged between 29-33 years (70%), with 61% experiencing moderate stress and 53% experiencing moderate anxiety. The mean stress ranges spanning from 14 to 48 and 14 to 62 for anxiety respectively. Statistical analysis revealed significant associations between stress and anxiety levels with demographic variables such as occupation, income, and stage of cancer ($p<0.05$), establishing a significant correlation between the two psychological variables. The study highlights the psychological burden borne by caregivers and underlines the need for targeted psychosocial interventions [9].

Methodology

Research Design

A descriptive cross-sectional study design was employed to assess the level of stress and anxiety of caregiver of children with oncological conditions

Study Setting

The study was conducted in the Pediatric Oncology department of a tertiary care hospital in Pune, Maharashtra, catering to a large population of patients with oncological conditions.

Population

The target population for the study included the caregivers - a parent, guardian, or close family member of children diagnosed with oncological conditions.

Sample, Sampling Technique, and Sample Size

- **Sample:** The study sample consisted of primary caregivers directly involved in the care of children with oncological conditions.
- **Sampling Technique:** Purposive sampling technique was adopted to enroll the subjects into the study. Eligibility of enrolled subjects will be assessed based on inclusion and exclusion criteria.
- **Sample Size:** Based on previous literature and feasibility, a sample size of **50 caregivers** was chosen for this study.

Sample Criteria

Inclusion criteria

- Caregivers of children (aged 1-15 years) diagnosed with any oncological condition.
- Caregivers who have been actively involved in the child's treatment for at least one month.
- Caregivers who are mentally and physically capable of responding to the questionnaire.

Exclusion criteria

- Caregivers who have pre-existing diagnosed psychiatric disorders.

Tool Preparation and Description Tool Used for Data Collection

- The tool used for the study was a **structured questionnaire** comprising three sections:
- **Section A:** Socio-demographic profile of the caregiver (age, gender, relationship to patient, education, occupation, income, duration of care giving, etc.) and clinical profile of the patient (duration of disease condition, age of the child)
- **Section B: Perceived Stress Scale (PSS-10)** - it is a psychological instrument for measuring the perception of stress. It consists of 10 items that assess how unpredictable, uncontrollable, and overloaded respondents find their lives. Each item is rated on a 5-point Likert scale ranging from 0 (Never) to 4 (Very Often). The total score reflects the individual's level of perceived stress which ranges from 0 to 40
- **0-13:** Low stress
- **14-26:** Moderate stress
- **27-40:** High perceived stress

Section C - Generalized Anxiety Disorder Scale (GAD-7)

The GAD-7 is a 7-item tool designed to assess the severity of generalized anxiety disorder. Each item is rated from 0 (Not at all) to 3 (Nearly every day), with a maximum score of 21. It is a valid, brief measure for screening anxiety levels in clinical and research settings.

- **0-4:** Minimal anxiety
- **5-9:** Mild anxiety
- **10-14:** Moderate anxiety
- **15-21:** Severe anxiety

Tool preparation & Validation

- The tool was prepared based on an extensive literature review.
- Content validation was done by a panel of experts
- A pilot study was conducted on 10% of the sample to test clarity, reliability, and feasibility, and the results were included only after refinement

Data Collection Technique

- Data were collected using face-to-face interviews in the Pediatric Oncology department waiting area to ensure confidentiality and comfort.
- Each session took approximately 10-15 minutes per caregiver.
- Written informed consent was obtained before participation.
- Ethical considerations such as confidentiality, voluntary participation, and the right to withdraw at any time were strictly adhered to.

Feasibility of the Study

The study was found to be **feasible** based on the following factors:

- The hospital had a sufficient patient load with a consistent number of caregivers attending Pediatric OPD.
- Cooperation from hospital staff and access to the Department facilitated smooth data collection.
- Caregivers were willing to participate and appreciated the opportunity to share their experiences.
- The tools used were simple, culturally adapted, and did not cause emotional distress to participants.
- The pilot study confirmed the practicality and reliability of the tool, ensuring full-scale data collection was achievable.

Data Analysis

The data were analyzed using SPSS version 18. Descriptive statistics, including frequency, percentage, mean, and standard deviation, were used to summarize the data. Chi-square tests were performed to determine associations between caregiver burden and selected demographic and clinical variables. A p-value less than 0.05 was considered statistically significant.

Results

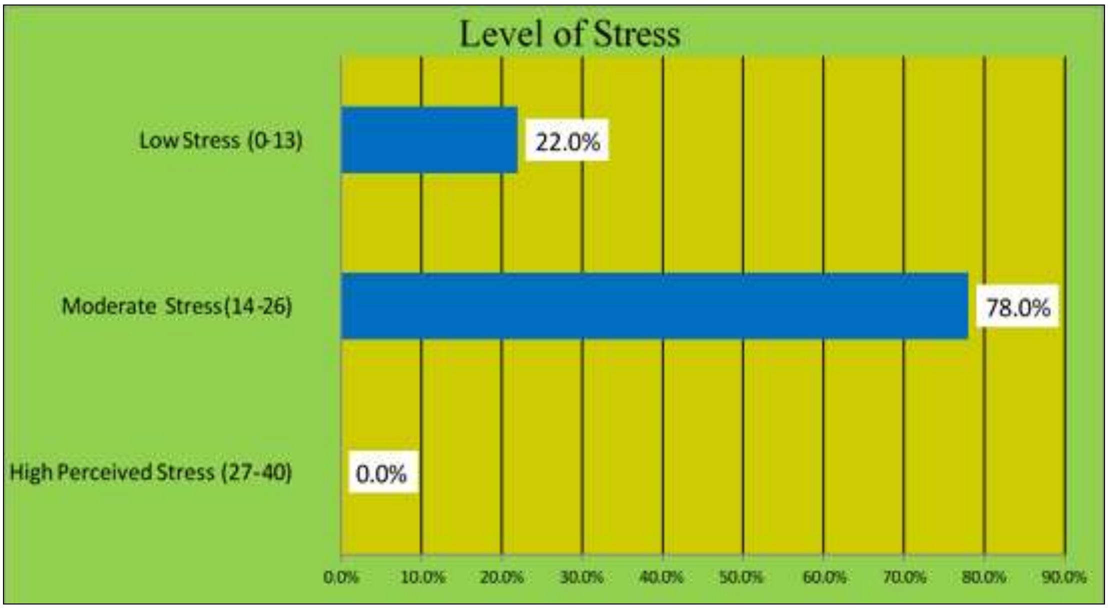
Table 1: Distribution of caregivers according to socio demographic data, **n**=50

Section-1SOCIO Demographic Proforma		**Percentage (%)**	**Frequency(f)**
Relationship With Patients	Father	60.0%	30
	Mother	40.0%	20
	Sibling	0.0%	0
	Grandparents	0.0%	0
	Others	0.0%	0
Age of Caregiver	20- 30- years	20.0%	10
	30- 40 years	58.0%	29
	40- 50 years	22.0%	11
	50- 60 years	0.0%	0
	60 and above	0.0%	0
Education of Caregiver	Illiterate	0.0%	0
	Primary education	32.0%	16
	10+ 2	44.0%	22
	Graduation and above	24.0%	12
Occupation of Caregiver	Government job	48.0%	24
	Private	12.0%	6
	Part time	6.0%	3
	Home- maker	34.0%	17
Caregivers Residence	Rural	24.0%	12
	Urban	76.0%	38
Health Status	Healthy	96.0%	48
	Minor health issues	4.0%	2
	Chronic illness	0.0%	0
	Serious health issues	0.0%	0
Type of Family	Nuclear	80.0%	40
	Joint	18.0%	9
	Extended family	2.0%	1
Religion	Hindu	94.0%	47
	Muslim	6.0%	3
	Sikh	0.0%	0
	Christian	0.0%	0
	Others	0.0%	0
Marital Status	Married	100.0%	50
	Divorce	0.0%	0
	Widowed	0.0%	0
Age of The Child	0-5 year	54.0%	27
	6-10 year	30.0%	15
	11-15 years	16.0%	8
	16-18 years	0.0%	0
Duration Since Diagnosis	Less than 2 years	34.0%	17
	2- 3 years	32.0%	16
	3-4 years	14.0%	7
	More than 4 years	20.0%	10
Socioeconomic Status	Upper class	62.0%	31
	Upper middle	18.0%	9
	Lower middle	16.0%	8
	Upper lower	4.0%	2
	Lower class	0.0%	0

Table 1.1 describes that out of 50 samples, fathers (60%) and mothers (40%), majority of caregivers were in the 30-40 years age group (58%), 40-50 years (22%) and 20-30 years (20%), education level was 10+2 education (44%), primary education (32%) and graduation or above (24%). Occupation of caregivers were Government jobs (48%), homemakers (34%), private sector employees (12%), part-time work (6%). Caregivers resided in urban areas (76%), while 24% were from rural backgrounds. Health status of caregivers, 96% were healthy. 80% were having nuclear families and 2% were living in extended families and 18% joint family. All caregivers in the study were married (100%). Socio economic status showed caregivers belonged to the upper class (62%), upper middle (18%), lower middle (16%), and upper lower (4%) classes. Age of Children with oncological condition were 1-5 years old (54%), followed by 6-10 years (30%) and 11-15 years (16%). The duration since diagnosis varied, with 34% of children diagnosed within the last 2 years, 32% diagnosed 2-3 years ago, and 14% 3- 4 years ago, and 20% more than 4 years ago.

Assessment of Level of Stress of caregivers

The stress level of caregivers was assessed by Perceived Stress Score which consisted of 10 characteristics with a maximum score of 40 and minimum score of zero.



n = 50

Fig 1: Level of Stress Scores among caregivers

Table 2: Descriptive Statistics showing the level of stress among caregivers

Descriptive Statistics	Mean	SD	Median	Maximum	Minimum	Range	Mean %
Stress Score	17.08	4.75	18.00	25	5	20	42.7

Table no 1.2 and Figure 1.1 shows that the majority of caregivers (78%) experienced moderate stress (scores 14-26), while some (22%) had low stress (scores 0-13). The mean stress score among caregivers was 17.08 (SD = 4.75), with a median of 18 and giving a mean percentage of 42.7%. This indicates that most caregivers experienced some level of stress, it generally remains at a moderate-not severe-level.

Assessment of Anxiety level of caregivers

The Anxiety level of caregivers were assessed by GAD-7 Anxiety scale which consisted of 07 characteristics with a maximum score of 21 and minimum score of zero.

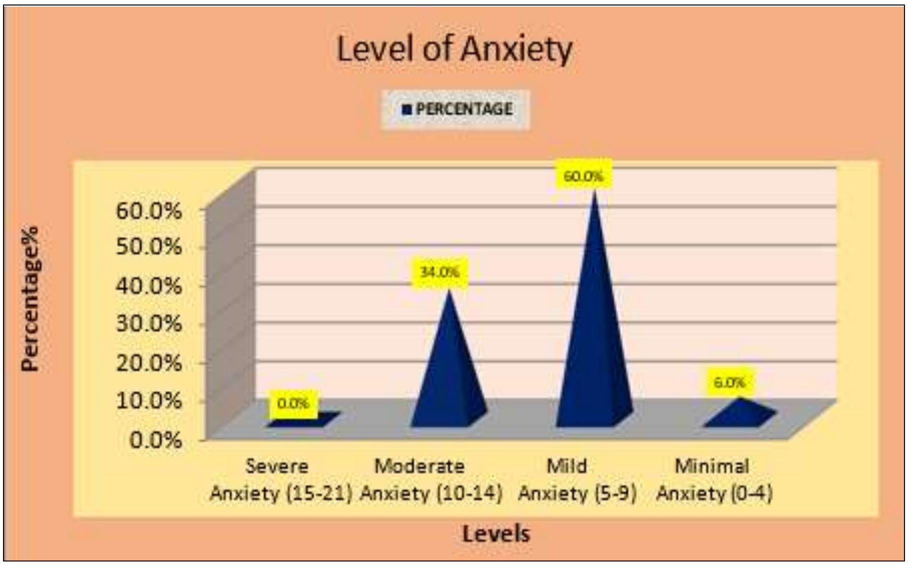


Fig 2: Anxiety level of caregivers

Table 3: Anxiety level of caregivers

Descriptive Statistics	Mean	SD	Median	Maximum	Minimum	Range	Mean %
Anxiety Score	8.40	2.53	9.00	14	2	12	40.0

Table No 1.3 and Figure 1.2 depicts that 60% of caregivers falls into the mild category whereas 34% has moderate anxiety and 6%, has minimal anxiety. It also shows that the mean anxiety score among caregivers was 8.40 (SD = 2.53) out of 21, with a median of 9. The mean percentage was 40%, indicating that most caregivers experienced mild to moderate anxiety.

Statistical Associations

Study revealed that the chi square value 7.982 of p value 0.018 at df (2) is more than the table value 5.991 showing a significant association between education of caregiver and the patient stress. Caregivers with only primary education were more likely to experience moderate stress, while those with graduation and above had an equal distribution between moderate and low stress. Other factors like relationship with patient, age of the caregiver, family type and duration of caregiving was not significantly associated with caregiver stress.

Study showed significant association between the caregiver's relationship with the patient and their anxiety where chi square value 10.482 with p value 0.005 at df (2) is more than table value 5.991. There was a statistically significant association between the caregiver's age and their anxiety level where chi square value 10.801 with p value 0.029 at df (4) is more than table value

9.488. A significant association was found between the type of family and anxiety levels where chi square value 12.068 with p value 0.017 at df (4) is more than table value 9.488. No significant association was observed between education level, age of the child, duration since the child's diagnosis, socioeconomic status and caregiver anxiety.

Research Hypotheses and Corresponding Evidence

Primary Hypothesis

The hypothesis of the study were.

- **H_0.1:** There is no significant association between demographic variables and the levels of stress among caregivers of children with oncological conditions.
- **H_1.1:** There is a significant association between demographic variables and the levels of stress among caregivers of children with oncological conditions.
- **H0.2:** There is no significant association between demographic variables and the levels of anxiety among caregivers of children with oncological conditions.
- **H_1.2:** There is a significant association between demographic variables and the levels of anxiety among caregivers of children with oncological conditions.

The present study states that,

- Majority of caregivers experienced elevated stress levels. The mean stress score on the PSS-10 reflected a 42.7% of moderate level of perceived stress, underscoring the emotional strain associated with caregiving responsibilities for children undergoing cancer treatment.
- Regarding anxiety, 60% of caregivers were found to have mild anxiety, followed by 34% with moderate anxiety and 6% with minimal anxiety. None of the participants scored in the severe anxiety range on the GAD-7 scale.
- Study showed a significant association between education of caregiver and the patient stress.
- Significant association were also found between anxiety and specific demographic variables like age of the caregiver, relationship and the type of family.

As the associations with certain demographic variables were statistically significant, null hypothesis H0.1 and H0.2 were rejected and Alternative hypothesis H_1.1 and H_1.2 were accepted. Which stated that stress and anxiety levels are significantly associated with demographic variables.

Discussion

The present study assessed the level of stress and anxiety among caregivers of children with oncological condition. The results revealed that a substantial proportion of caregivers experienced moderate levels of stress and anxiety. There were no high perceived stress or severe anxiety among caregivers confirming findings from earlier studies conducted globally and within India. The demographic profile in this study indicated that most caregivers were males (59%) and between the ages of 30 - 40 years.

The study findings reveal that while stress levels among caregivers were not completely but partially significantly influenced by demographic characteristics, anxiety levels were significantly associated with variables such as age, relationship to child, and family type. This highlights that anxiety is more sensitive to personal and contextual factors, whereas stress may reflect a more uniform psychological response to the caregiving role. Demonstrated that caregiver anxiety is influenced by the caregiver's age and duration of caregiving. Which supports the current study's result where age was a significant variable affecting anxiety. Soni and Atram (2024) [4] found that caregivers living in joint family settings experienced increased stress due to overlapping responsibilities and limited privacy, which corresponds to the association found in the present study between joint family structures and higher anxiety [4].

These conclusions underscore the importance of early psychological screening and the implementation of targeted support services, particularly for young caregivers, mothers, and those in complex family environments.

Conclusion

In conclusion, this study emphasizes the substantial emotional burden experienced by caregivers of children with oncological conditions, with a notable proportion reporting mild to moderate levels of anxiety and stress. Although severe psychological distress was not observed, the prevalence of emotional strain remains a significant concern, given its potential impact on caregiver well-being and the quality of care provided to the child. The associations identified between anxiety and demographic factors-such as the caregiver's relationship to the patient, age, and family structure-underscore the need for targeted psychosocial support. Furthermore, the link between lower educational attainment and higher perceived stress highlights a particularly vulnerable subgroup that may benefit from tailored interventions. These findings advocate for the integration of caregiver mental health support into pediatric oncology care frameworks.

Healthcare professionals-particularly nurses-are uniquely positioned to recognize early indicators of caregiver strain and to initiate timely, evidence-based support interventions. This underscores the urgent need for healthcare policies that prioritize caregiver well-being as an integral component of chronic disease management. Integrating such measures into pediatric oncology care can promote more holistic, compassionate, and sustainable support for both the child and their family.

Implications

The findings of the study have implications for Nursing practice, Nursing Administration, Nursing education and Nursing Research

Nursing Practice

Holistic Family-Centered Care can be provided by nurses by recognizing the caregiver as a secondary patient and include emotional assessments in routine pediatric oncology care. By using validated screening tools like the GAD-7 and PSS-10, nurses can identify early signs of anxiety and stress in caregivers and initiate timely interventions. The study underscores that caregivers often face stress due to isolation or inadequate support. It is essential to create structured support networks, indicating peer support groups, community linkages and access to social services, to provide emotional backing and reduce caregiver burden. Understanding the caregiver's family structure, socio-economic status, and educational background is essential in delivering tailored nursing interventions.

Nursing administration

Policy Formulation by Nurse Administrators should integrate caregiver psychological assessment as part of standard operating procedures (SOPs) in pediatric oncology units. There is a need to increase the availability of psychiatric or mental health nurses in pediatric units. Training programs on communication and emotional support should be regularly conducted. Nursing administrators should foster collaboration between nursing staff, psychologists, social workers, and palliative care teams to develop comprehensive support systems for caregivers. Take a lead in establishing structured caregiver support services within pediatric oncology units. This include the creation of caregiver lounges, scheduling regular workshops and ensuring availability of counselling services. Caregiver satisfaction and emotional wellbeing should be incorporated as indicators in hospital quality audits and patient-centered care evaluations.

Nursing Education

Nursing curricula should include modules on caregiver psychology, stress management, and psycho-oncology to prepare nurses for real-world caregiving challenges. Nursing students should be exposed to pediatric oncology wards with supervised opportunities to interact with caregivers, fostering understanding of family dynamics and emotional care. Emphasize training in therapeutic communication, empathy, and family systems theory to enhance student competency in addressing caregiver needs

Nursing Research

Futuristic research in nursing is possible as this study provides a foundation for further research on caregiver burden, particularly in resource-constrained settings and diverse sociocultural contexts. Future research should focus on evaluating the effectiveness of structured interventions-such as caregiver support groups, mindfulness training, and mobile mental health apps-in reducing caregiver anxiety and stress. There is a need for longitudinal research to track emotional changes in caregivers over time, from diagnosis to survivorship or palliative phases.

Limitations of the Study

- The cross-sectional design of the study limits the ability to examine changes in caregiver burden over time or in relation to fluctuations in the child's health status.
- The use of convenience sampling from a single healthcare institution restricts the generalizability of the findings, particularly when considering diverse geographic or socio-demographic contexts such as rural versus urban populations.
- Additionally, the exclusive use of quantitative methods may have overlooked the rich, contextual insights that qualitative approaches could offer regarding caregivers' emotional experiences and coping mechanisms.

Recommendations of the study

Based on the findings and interpretations, the following recommendations are proposed for clinical practice, policy, and future research.

- Introduce standardized anxiety and stress screening tools (e.g., GAD-7, PSS- 10) as part of caregiver assessments in pediatric oncology settings. Conduct periodic reassessment during follow-ups to detect escalating distress early.
- Deploy trained mental health professionals in pediatric oncology wards to provide individual and group counseling. Provide referrals to clinical psychologists when necessary.
- Organize structured health education sessions focusing on understanding cancer prognosis and treatment plans and managing emotional distress
- Future studies should aim to adopt longitudinal designs to track changes in caregiver burden across different stages of treatment.
- Incorporating qualitative methodologies such as in-depth interviews or focus group discussions can offer richer insights into the emotional and cultural dimensions of care giving.
- Researchers are encouraged to explore caregiver experiences in varied demographic settings, including rural areas, different socioeconomic strata, and across cultural backgrounds.

Conflict of Interest

Not available

Financial Support

Not available

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How to Cite This Article
Jeevanthika P, Shilpa S and Rituparna G. A descriptive study to assess the stress and anxiety level of caregivers of children with oncological conditions in selected tertiary care center in Western Maharashtra. International Journal of Research in Paediatric Nursing. 2025;7(2):30-37.