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Caregivers Stress and Impact on Family in Paediatric Cancer Care

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ABSTRACT

This study aims to assess the psychological stress and family impact experienced by caregivers of paediatric cancer-affected children. Using a qualitative descriptive design, semi-structured interviews were conducted with 110 parents of children undergoing cancer treatment at a tertiary care hospital. The study focused on two key domains: psychological stress and family-social impact. Results revealed that a majority of caregivers experienced emotional challenges such as constant worry (54.5%), sadness (31.8%), anxiety (28.2%), and emotional exhaustion, with 48.2% expressing a strong need for support. Coping strategies varied, with caregivers relying on crying (40.9%), emotional withdrawal (40.9%), practical actions (39.1%), or spiritual practices (20.9%). Physical symptoms of stress included fatigue (34.5%), muscle tension (23.6%), and insomnia (22.7%). Socially, caregivers reported strained relationships with spouses (36.4% felt emotional distance) and increased conflicts with extended family (40.9%). Social isolation was prevalent; 41.8% withdrew from social life and 43.6% struggled to balance caregiving with attention to other children. Most caregivers (87.3%) relied on government support for treatment, and a significant number belonged to low-income (55.4%) and low-education backgrounds. These findings underscore the emotional toll and family disruption caused by paediatric cancer caregiving. The study highlights the urgent need for structured psychosocial interventions, including the role of Medico Social Workers in emotional counselling, caregiver support, and facilitating communication within families. Addressing both psychological stress and social dimensions is essential for improving the well-being of caregivers and ensuring holistic paediatric cancer care..

Keywords: Caregiver Psychological stress, Family impact, Childhood cancer, Psychosocial support, low- and middle-income countries (LMICs)

1. INTRODUCTION

Aim of the Study

The aim of this study is to assess the stress experienced by caregivers and understand how a child's cancer affects the family. The study focuses on the emotional and psychological problems faced by parents during their child's treatment and how it impacts their family life.

Introduction

According to World Health Organisation (WHO) Cancer is a leading cause of death for children and adolescents. The likelihood of surviving a diagnosis of childhood cancer depends on the country in which the child lives; in high-income countries, more than 80% of children with cancer are cured, but in many low- and middle-income countries LMICs less than 30% are cured. Although childhood cancer cannot generally be prevented or identified through screening, most types of childhood cancer can be cured with generic medicines and other forms of treatment, including surgery and radiotherapy. The reasons for lower survival rates in LMICs include delay in diagnosis, an inability to obtain an accurate diagnosis, inaccessible therapy, abandonment of treatment, death from toxicity (side effects) and avoidable relapse. Improving access to childhood cancer care, including to essential medicines and technologies, is highly cost-effective, feasible and can improve survival in all income settings. Cancer occurs in people of all ages and can affect any part of the body. It begins with genetic change in single cells that can then grow into a mass (or tumour), invade other parts of the body and cause harm and death if left untreated. Unlike cancer in adults, most childhood cancers do not have a known cause. Many studies have sought to identify the causes of childhood cancer, but very few cancers in children are caused by environmental or lifestyle factors. Cancer prevention efforts in children should focus on behaviours that will prevent the child from developing preventable cancer as an adult. When identified early, cancer is more likely to respond to effective treatment and result in a greater probability of survival, less suffering, and often less expensive and less intensive treatment. Significant improvements can be made in the lives of children with cancer by detecting cancer early and avoiding delays in care. A correct diagnosis is essential to treat.

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Objectives

To assess the psychological stress experienced by caregivers of paediatric cancer-affected children.

To examine the psychological challenges faced by caregivers, including anxiety, fear, helplessness, and depression.

To study the impact of a childhood cancer diagnosis on a family.

Materials and Methods: A qualitative descriptive design using a semi-structured interview schedule developed by the researcher, comprising 24 questions across two key domains: psychological stress and family impact. This approach allowed for in-depth exploration of parents' experiences while maintaining flexibility. Face-to-face interviews were conducted individually in hospital wards and counselling rooms to ensure confidentiality and participant comfort. The study was conducted over one month in a tertiary care cancer hospital and involved 110 parents (both mothers and fathers) of paediatric cancer patients undergoing treatment. Informed written consent was obtained from all participants, and ethical clearance was granted by the Institutional Ethics Committee prior to data collection

Results: -

Table No. – 1, Frequency Distribution by Age Category:-

Age Category	**Age Range**	**Frequency**	**Percentage %**
Young Adults	21-30	45	40.9%
Middle-Aged Adults	31-40	43	39.1%
Older Adults	41-54	22	20.0%
Total No. **of respondents and %**		110	100.00%

Table No. 1 shows the distribution of respondents based on age categories. Out of the total 110 respondents, 40.9% (45) individuals were in the young adult age group (21–30 years), making it the largest group. This was followed by 39.1% (43) individuals who belonged to the middle-aged adult category (31–40 years). The remaining 20.0% (22) respondents were categorized as older adults (41–54 years). These findings suggest that the majority of caregivers were from the younger and middle-age groups.

Table No. – 2, Distribution of Education Level:-

Education Category	**Frequency**	**Percentage%**
No Formal Education and Primary Education	42	38.1%
Secondary School Certificate and Intermediate	40	36.3%

Above Degree	28	25.4%
Total no of respondents and %	110	100.00%

Table No. 2 shows the distribution of respondents based on their education level. Out of the total 110 respondents, 38.1% (42) had no formal education or studied only up to the primary level. This was followed by 36.3% (40) who were secondary school certificate or intermediate education. The remaining 25.4% (28) had education above the degree level. The data indicates that a majority of respondents had education limited to the primary or secondary level, while only a smaller portion had completed higher education. This suggests the need for healthcare communication to be clear, simplified, and easily understandable, considering the educational background of caregivers involved in paediatric cancer care.

Table No. – 3, Distribution of Employment Status

Employment Category	**Frequency**	**Percentage%**
Unemployed	17	15.4%
Housewife	36	32.7%
Daily wage earners, Farmers, and Skilled workers	24	21.8%
Employed	33	30.0%
Total no of respondents and %	110	100.00

Table No. 3 presents the distribution of respondents according to their employment status. Among the 110 respondents, 32.7% (36**)** were housewife, forming the largest group. This was followed by 30.0% (33**)** who were employed in various sectors. About 21.8% (24) were engaged as daily wage earners, farmers, or skilled workers, while 15.4% (17) reported being unemployed. The data highlights that a significant portion of respondents were either involved in informal work or not formally employed, which may have implications for their financial stability and caregiving responsibilities

Table No. – 4, Distribution of Annual Family Income

Income Category	**Frequency**	**Percentage%**
₹50,000 – ₹99,999	35	31.8%
₹1,00,000 – ₹1,49,999	61	55.4%
₹1,50,000 and above	14	12.7%
Total no of respondents and %	110	100.00%

Table No. 4 shows the distribution of respondents based on their annual family income. A majority of respondents, 55.4% (61)**,** reported an income between ₹1,00,000 – ₹1,49,999, followed by 31.8% (35) in the ₹50,000 – ₹99,999 income range. A smaller proportion, 12.7% (14)**,** reported an annual income of ₹1, 50,000 and above. The findings indicate that most families fall within the lower-middle income group.

Table No – 5, Distribution of Treatment Support Sources for Paediatric Cancer Care

Treatment Support Source Category	**Frequency**	**Percentage%**
Self/Private	9	8.2%

Government	96	87.3%
NGO's	5	4.5%
Total no of respondents and %	110	100.00%

Table No. 5 presents the distribution of treatment support sources among paediatric cancer families. The majority of respondents 87.3%, (96) reported that treatment expenses were supported by government-sponsored schemes, while 8.2% (9) relied on self or private funding, and a small proportion 4.5%, (5) received assistance through non-governmental organizations (NGOs). The predominance of government support reflects the critical role of state-sponsored health schemes, particularly the Aarogyasree Health Care Trust programs implemented by both Telangana and Andhra Pradesh governments, which provide free tertiary care for BPL (Below Poverty Line) card holders. These public health financing models have significantly improved access to specialized cancer treatment for socioeconomically disadvantaged families. The data indicate the effective utilization of Aarogyasree by eligible beneficiaries**,** demonstrating its reach and relevance in alleviating the financial burden associated with paediatric cancer care. However, the presence of families still depending on out-of-pocket or private sources 8.2% (9) suggests possible gaps in scheme coverage, eligibility barriers, or delays in claim processing**.** Moreover, the minimal contribution of NGOs 4.5% (5) points to the need for strengthening collaborations between public health systems and civil society organizations to enhance comprehensive care and non-medical support services.

Table No. 6, Distribution of Caregiver Psychological Stress and Family-Social Impact

Section 1: Caregiver Psychological Stress	**No of Respondents**	**Respondents %**
1) When you feel emotionally overwhelmed, what best describes your reaction?		
I isolate myself to process my emotions alone	42	38.1 %
I cry or express my feelings openly	45	40.9 %
I turn to prayer, meditation, or spiritual practices	23	20.9 %
2) What emotion do you experience most frequently since your child's diagnosis?		
Hopefulness and determination	23	20.9%
Anxiety and constant worry	31	28.2%
Sadness or grief	35	31.8%
Anger or frustration	21	19.1%
3) How do you typically respond when you feel powerless about your child's condition?		
I reach out to family or friends for support	22	20.0%
I engage in distracting activities to avoid thinking about it	28	25.5%
I seek advice from medical professionals	42	38.2%
I turn to spiritual or religious practices	18	16.4%
4.)When your child is in pain or discomfort, how do you emotionally respond?		
I feel helpless and unsure how to respond	18	16.4%
I feel anxious but try to appear calm	28	25.5%
I focus on practical actions to help my child	43	39.1%

I stay calm and comfort my child	21	19.1%
5.) When you experience intense sadness, how do you cope?		
I isolate myself until the sadness fades	21	19.1%
I talk to someone I trust about my feelings	33	30.0%
I cry to release my emotions	32	29.1%
I focus on positive memories or moments	24	21.8%
6.) How do you typically react when someone asks how you're feeling?		
I don't react	23	20.9%
I become defensive or irritated	39	35.5%
I answer honestly and express my emotions	16	14.5%
I downplay my feelings to avoid worrying others	13	11.8%
I share only positive thoughts to stay strong	19	17.3%
7.)What is your biggest emotional struggle as a caregiver?		
Feeling isolated and unsupported	18	16.3%
Constant worry about my child's future	60	54.5%
Feeling guilty for not doing enough	32	29.0%
8) How do you express your emotions when overwhelmed?		
I cry or experience emotional outbursts	34	30.9%
I become quiet and withdrawn	45	40.9%
I talk openly about my feelings	31	28.1%
9) What thoughts often arise when you feel emotionally exhausted?		
"I feel like I'm failing my child	22	20.0%
"I'm not sure how much longer I can keep going."	35	31.8%
"I need someone to help me through this."	53	48.2%
10) What situations cause you the most stress as a caregiver?		
Financial concerns related to treatment	24	21.8%
Conflicts with healthcare providers or family	38	34.5%
Managing my child's medical care	48	43.6%
11) When you feel mentally overwhelmed, what do you do?		
I lose focus and struggle to manage tasks	24	21.8%
I ask for help from family or friends	14	12.7%

I try to organize my thoughts calmly	17	15.5%
I focus on practical steps to manage stress	55	50.0%
12) When you feel anxious, what helps you feel calm?		
I avoid thinking about what's making me anxious	27	24.5%
Distracting myself with activities	33	30.0%
Spending time with my child to stay grounded	50	45.5%
13) What physical symptoms do you experience from stress?		
Headaches or migraines	10	9.1%
Muscle tension or body aches	26	23.6%
Digestive issues or stomach pain	11	10.0%
Fatigue and constant tiredness	38	34.5%
Insomnia or restless sleep	25	22.7%
14) How do you manage feelings of guilt as a caregiver?		
I reflect on positive moments with my child	22	20.0%
I remind myself I'm doing my best	24	21.8%
I focus on actions that improve my child's well-being	64	58.2%
Section 2: Social and Family impact		
15) How has your child's illness impacted your relationship with your partner or spouse?		
1. I am solely responsible for care giving without support	23	20.9%
2. I feel emotionally distant from my partner	40	36.4%
3. Our relationship has become strained due to stress	22	20.0%
4. We struggle to find time for each other	25	22.7%
16) How your child's illness affected your relationship with extended family?		
My family supports me, but they don't fully understand my challenges	33	30.0%
Family conflicts have increased due to stress	45	40.9%
I rely heavily on extended family for care giving support	32	29.1%
17) How your social life changed since your child's diagnosis?		
I feel socially isolated with no meaningful connections	30	27.3%
I avoid social events because I feel emotionally drained	11	10.0%
I rarely attend social events due to care giving demands	36	32.7%
4. I maintain a social life with some adjustments	33	30.0%

18) What is your biggest challenge in maintaining communication with family members?		
Family members often misunderstand my emotions	19	17.3%
I avoid sharing my feelings to prevent conflict	28	25.5%
I struggle to explain my child's condition to others	45	40.9%
I maintain open communication with few difficulties	18	16.4%
19) How your child's illness affected your ability to attend family gatherings or events?		
I no longer participate in family events altogether	16	14.5%
I avoid gatherings because I feel emotionally overwhelmed	33	30.0%
I rarely attend events as my child's needs come first	47	42.7%
I miss some events due to care giving demands	14	12.7%
20) How your relationship with your child's siblings been affected?		
My other children feel neglected at times	15	13.6%
I rely on others to care for my child's siblings	47	42.7%
I struggle to balance attention between all my children	48	43.6%
21. What has been your biggest challenge in finding time for your own social needs?		
I struggle to prioritize my own social connections	21	19.1%
I avoid social activities due to exhaustion	43	39.1%
I have completely withdrawn from social connections	46	41.8%
22) How your relationship with healthcare providers affected your family dynamics?		
My family feels disconnected due to hospital stays	14	12.7%
I struggle to balance medical needs with family bonding	25	22.7%
Frequent medical visits have created family tension	43	39.1%
Healthcare providers have strengthened our coping skills	28	25.5%
23) How your child's illness impacted your partner or spouse's well-being?		
My partner and I frequently argue about care giving matters	12	10.9%
My partner struggles to balance work and care giving	30	27.3%
My partner has distanced themselves emotionally	15	13.6%
My partner feels emotionally overwhelmed	17	15.5%
My partner and I support each other well	36	32.7%
24) How your extended family responded to your child's diagnosis?		
I feel isolated from my extended family	15	13.6%

Family conflicts have increased since diagnosis	22	20.0%
I feel misunderstood or judged by extended family	10	9.1%
Some family members provide emotional support only	24	21.8%
They have been incredibly supportive and engaged	36	35.5%
Total no of respondents & percentage	**110**	**100.00%**

Table no. 6 shown the analysis of caregiver psychological stress among the respondents reveals that a significant proportion of caregivers experience emotional overwhelm in various forms. About 40.9% reported crying or expressing their feelings openly when emotionally distressed, while 38.1% chose isolation to process emotions, and 20.9% turned to spiritual coping mechanisms. The most commonly reported emotional state since the child's diagnosis was sadness or grief 31.8%, followed by anxiety and worry 28.2%. When facing feelings of powerlessness, 38.2% sought professional medical advice, while 25.5% engaged in distracting activities. In situations of their child's discomfort, 39.1% of caregivers focused on practical actions, although 25.5% admitted to feeling anxious but tried to remain calm. Coping with intense sadness varied: 30.0% spoke to someone they trusted, and 29.1% relied on emotional release through crying. When asked about reactions to inquiries on emotional state, 35.5% became defensive or irritated, whereas only 14.5% responded honestly. The predominant emotional burden was constant worry about the child's future 54.5%, with 29.0% struggling with guilt. In expressing emotional overwhelm, 40.9% became withdrawn, 30.9% had outbursts, and 28.1% spoke openly. Regarding emotional exhaustion, 48.2% frequently felt the need for support, while 31.8% doubted their ability to continue caregiving. The main caregiving stressor was managing the child's medical care 43.6%. When mentally overwhelmed, 50.0% reported organizing thoughts through practical coping, whereas 21.8% lost focus. To calm anxiety, 45.5% spent time with their child. Common stress-induced physical symptoms included fatigue 34.5% and muscle tension 23.6%. To manage guilt, 58.2% focused on actions that benefitted their child. In terms of social and family impact, caregivers reported notable strain on relationships. About 36.4% felt emotionally distant from their partner, and 22.7% reported a lack of time with them. Relationships with extended family were also strained; 40.9% noted increased family conflict, and 30.0% felt unsupported emotionally. Social isolation was reported by 27.3% of caregivers, and 32.7% reduced social engagement due to caregiving responsibilities. Communication challenges were also evident, with 40.9% struggling to explain the child's condition to others, and 25.5% avoiding conflict by withholding emotions. Family participation in events declined; 42.7% rarely attended gatherings, prioritizing caregiving. Balancing attention among children was a major issue, with 43.6% admitting difficulty, and 42.7% relying on others to support siblings. Regarding personal social needs, 41.8% had withdrawn socially, and 39.1% avoided social activities due to fatigue. Frequent medical visits led to family tension 39.1% and 22.7% found it difficult to balance treatment with family bonding. While 32.7% reported mutual spousal support, 27.3% indicated their partners struggled with caregiving and work. Emotional withdrawal by partners was also observed 13.6%. Extended family responses varied, with 35.5% showing support, but 20.0% contributing to conflicts.

2. DISCUSSION

The findings underscore the urgent need for systematic psycho-social support mechanisms within paediatric oncology settings. In this context, Medico Social Workers (MSWs) play a pivotal role in identifying at-risk caregivers, offering emotional support, coordinating multidisciplinary care, and facilitating access to financial or institutional resources. MSWs can bridge the gap between the healthcare system and families, ensuring that caregivers are not only informed about the child's condition but are also emotionally equipped to manage their role. Regular individual and family counselling sessions are essential to help caregivers' process grief, anxiety, and stress, while also enhancing communication within families. Counselling can also help prevent caregiver burnout, reduce the psychological toll of long-term care, and strengthen coping strategies. Additionally, support groups led by MSWs or Counsellors can serve as a platform for caregivers to share experiences, reduce feelings of isolation, and build emotional resilience.

3. CONCLUSION

The present analysis reveals a significant level of psychological stress and social disruption among caregivers of children diagnosed with cancer. Caregivers frequently experience overwhelming emotions, persistent anxiety, and emotional exhaustion. The most common emotional struggles include constant worry about the child's future, feelings of helplessness, and challenges in coping with emotional outbursts or isolation. Many caregivers adopt practical strategies or spiritual practices to cope, but the sustained caregiving burden leads to physical symptoms such as fatigue, sleep disturbances, and somatic complaints. Socially, the caregiving role significantly affects family dynamics, leading to emotional distancing from spouses or partners, communication barriers with extended family, and a decline in participation in social life. Notably, the ability to maintain relationships with other children in the family is also compromised, often resulting in feelings of guilt and emotional strain. Despite these difficulties, a portion of the respondents reported mutual spousal support and emotional assistance from extended families.

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