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Community Support and Hospital Experiences of Caretakers of Paediatric Cancer Patients

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Abstract

Caretakers of paediatric cancer patients navigate a uniquely challenging journey that is profoundly influenced by the support of the community and the experiences within hospitals. Community support, essential for these caretakers, often manifests in emotional, logistical, and financial assistance, ranging from local fundraisers to support groups that provide a platform for sharing experiences and coping strategies. A mixed method approach was employed convergent parallel design. A total of 50 questionnaire responses and 5 interviews were included in our analysis. Quantitative findings revealed that among caretakers 80% received moderate support, 10% received High support and 8% received low support, The qualitative study findings explored the hospital experiences with the theme and subtheme Impact on daily living and Navigating Health care system.

Keywords: Mixed analysis, Community support, Hospital experiences, Caretakers.

INTRODUCTION

“We’re all here to help one another… when we are together, we can make things happen” -Stephanie

Caretakers of Paediatric cancer patients navigate a uniquely challenging journey that is profoundly influenced by the support of the community and the experiences within hospitals. Community support, essential for these caretakers, often manifests in emotional, logistical, and financial assistance, ranging from local fundraisers to support groups that provide a platform for sharing experiences and coping strategies. Such solidarity can significantly alleviate the isolation and overwhelm that caretaker may feel. Hospital experiences are equally pivotal, as they shape the trajectory of both patient and caretaker well-being. A hospital that provides a holistic approach, including access to child life specialists, psychological support, and clear communication from the medical team, can profoundly impact the caretaker's ability to navigate the complexities of cancer care. The quality of these interactions, the availability of resources, and the environment of care can either compound the stress for caretakers or serve as a crucial buffer against the multifaceted challenges they face. Therefore, the interplay between community support and hospital experiences is central to the resilience and endurance of caretakers, affecting their capacity to provide care and maintain hope in the face of paediatric cancer.

Background of the Study

Global Perspective: Approximately 300,000 children and adolescents aged 0-19 years are diagnosed with cancer worldwide each year. In 2023, the American Cancer Society in the U.S. reported that there will be an estimated 1,9108,310 new cancer cases and 609,820 cancer deaths. The 5-year survival rate for all childhood cancers combined has increased from around 58% in the mid-1970s to over 80% in recent years, although this varies significantly by cancer type and geographic location. Incidence and survival rates vary globally, with higher-income countries generally having better outcomes due to more advanced healthcare systems and access to treatment.

National Perspective (India): In India, the overall incidence of childhood cancer is 38 to 124 per million children, per year. An estimated 52,366 children (0-14years) and 76,805 children and adolescents (0-19 years) develop cancer every year in India. The four leading group of cancers among 0-14year olds are Leukemia(40%), Lymphoma(12%), Central nervous system tumor(11%) and bone cancer (8%)1.6 to 4.8% of all cancer in India is seen in children below 15years of age per year is lower than in the developed country.

Tamil Nadu Perspective: According to Tamilnadu Cancer Registry Project, A total of 610,1090 cancer cases were diagnosed in 2016 in Tamil Nadu and the estimated cancer burden in 2020 was 78,641. There are many treatments done in Chennai with 36 centres for each type of leukaemia according to specific and accurate diagnosis.

Need for the study

- Effective community support systems have the potential to significantly reduce the emotional and financial burdens on caretakers, fostering resilience and providing essential resources.
- Conversely, inadequate support can exacerbate stress, leading to caretaker burnout and adverse health outcomes.
- Hospital experiences are equally critical, as they directly influence treatment adherence, the child's recovery, and the caretaker's psychological state.
- A hospital environment that is attuned to the needs of families, including empathetic communication, comprehensive care, and psychological services, can greatly ease the caretaker's journey.
- On the other hand, negative experiences can hinder the child's access to optimal care and erode the caretaker's trust and confidence in the healthcare system.
- A study in this area could identify gaps in support and care, inform policy and hospital practice, and ultimately contribute to the development of more effective support networks and healthcare environments that are sensitive to the unique challenges of paediatric cancer care.
- Understanding these dynamics is essential for improving outcomes and ensuring that caretakers are empowered and supported as they fulfill their critical role.

Statement of the Problem

"A MIXED ANALYSIS ON COMMUNITY SUPPORT AND HOSPITAL EXPERIENCES OF CARETAKERS OF PAEDIATRIC CANCER PATIENTS"

Objectives

- To assess the level community support among the caretakers of paediatric cancer patients.
- To associate the level of community support among the caretakers of paediatric cancer patients with their selected sociodemographic variables.
- To explore the hospital experiences of caretakers of paediatric cancer patients.
- To integrate the qualitative and quantitative findings.

Research Question

How do the levels of community support impact the well-being of caretakers of Paediatric cancer clients, and what are the specific aspects of hospital experiences that most significantly affect their overall satisfaction among caretakers of Paediatric cancer clients ?"

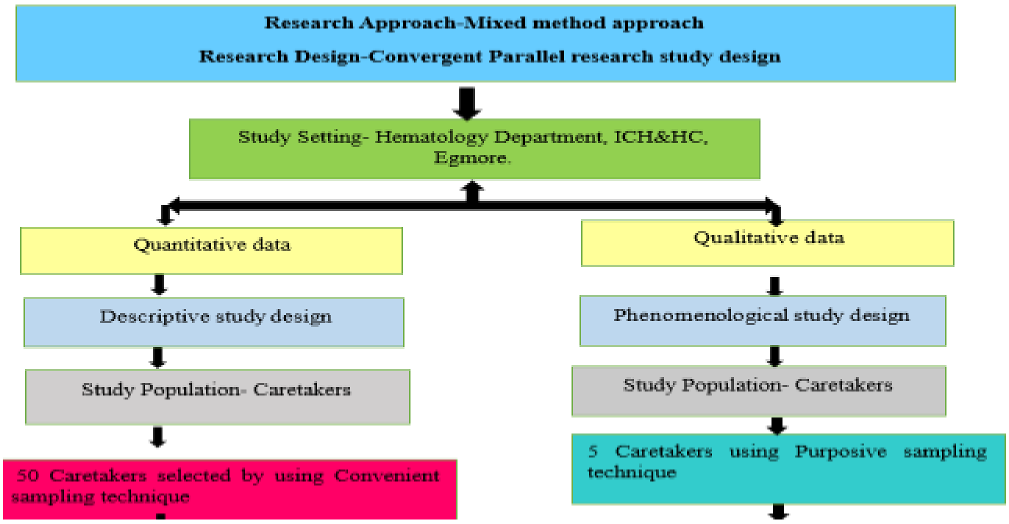
Assumption

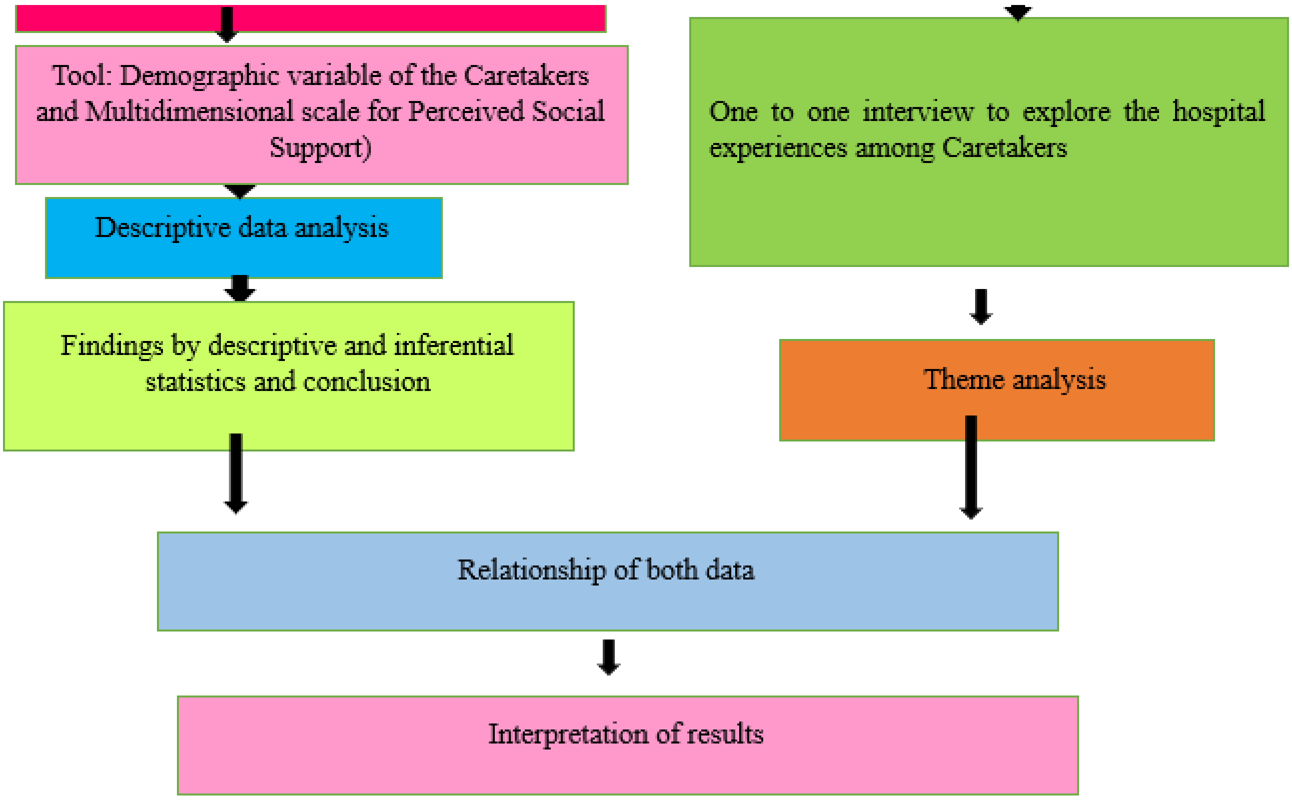
The researcher assumed that there will be low level of community support among the caretakers of paediatric cancer clients and also that caretakers of paediatric cancer clients may have positive hospital experiences.

Methods & Materials

In this study, the researcher adopted Mixed Method approach with a Convergent parallel research design to assess the community support and to explore the hospital experiences among caretakers of paediatric cancer patients conducted in Oncology department at Institute of Child Health and Hospital for Children, Egmore, Chennai. In that Descriptive survey design for quantitative part and phenomenological design for qualitative research. A Convenient sampling technique was used to select the 50 caretakers who aged above 20 years who met the inclusion criteria for quantitative part and Purposive sampling technique was used to select 5 caretakers for qualitative part. Data were collected using Multidimensional perceived social support scale to assess community support and unstructured face to face interview schedule to explore the hospital experiences. Ethical approval and necessary permissions were obtained, and participant confidentiality was strictly maintained throughout the study. Data collection was conducted over four weeks, recorded using an audio recorder, transcribed verbatim, and coded for thematic analysis.

FIG1: SCHEMATIC PRESENTATION OF METHODOLOGY





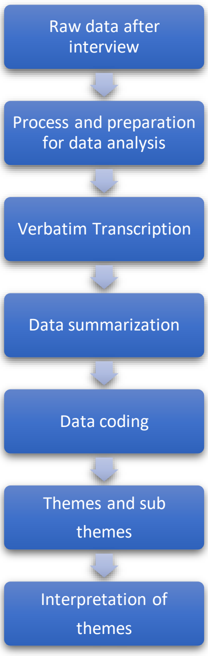


FIG 2: THEMATIC ANALYSIS

Results

A total of 50 questionnaire responses and 5 interviews were included in our analysis. Quantitative findings revealed that among caretakers 80% received moderate support, 10% received High support and 8% received low support. Additionally age, sex and participation of support groups influenced community support as confirmed by chi- square tests. The qualitative study findings explored the hospital experiences with the theme and subtheme Impact on daily living and Navigating Health care system. These insight reveals that, sociodemographic datas, combined with Changing family dynamics, perception of hospitalization, coping strategies and communication, illustrate intricate interplay of community support, hospital experiences and personal emotions of the caretakers for caring paediatric cancer patients.

LEVEL OF COMMUNITY SUPPORT	NO. OF. CARETAKERS	%
Low support	4	8%
Moderate support	41	82%
High support	5	10%
Total	50	100%

TABLE 1: LEVEL OF COMMUNITY SUPPORT SCORE

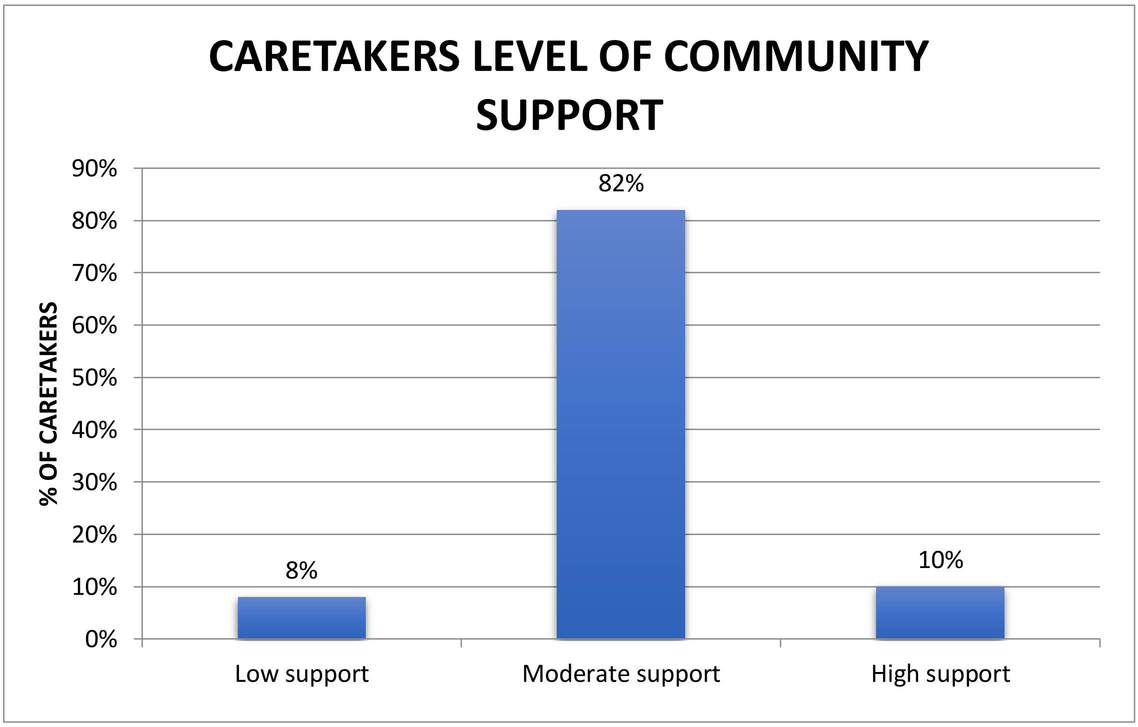


FIG 3: CARETAKERS LEVEL OF COMMUNITY SUPPORT

FOR QUALITATIVE

The study revealed two major themes: Impact on Daily living and Navigating the Healthcare system, each with significant subthemes highlighting the hospital experiences and perspectives of caretakers of paediatric cancer patients.

Theme 1: Impact on Daily living

Impact on daily living emerged as the most prominent theme, emphasizing the religious, emotional and coping strategies of caretakers.

Subtheme: Changes in family dynamic

Respondents faced lot of changes in their family dynamics, Many parents report that they have learned to value the present moment and celebrate small victories, strengthening their emotional bonds.

Subtheme: Coping Strategies

Family members provided assistance in daily activities, emotional encouragement, and support to build a strong coping and believe that they will lead a happy life with their children.

Subtheme: **Religious beliefs about illness**

Respondents relied on influencing mixture of religious feelings and beliefs. Many mothers had verbalized because of their sin, child got such life threatening disease, Their religious beliefs make them strong along with their family support.

Theme 2: Navigating the Health care system

This theme highlighted the supportive role of the school environment, particularly the staff.

Subtheme: Perception of Hospitalization

Most of them felt hospital admission of the child made them feel apart. Once the child diagnosed as Cancer, mothers experienced overwhelming stress and loneliness during treatment process and hospitalization.

Subtheme: Communication with Health care professionals

Relationship between caretakers and health care professionals become more empathetic, supportive and confidential, once they had strong communication.

Subtheme: Support system

Respondents replied positively about the support of the health team and peer mothers. Some of them are receiving help financially whereas others are receiving help in terms of giving extra hand.

Discussion

The present study revealed that 82% of Caretakers had moderate social support with 41 numbers of caretakers, 10% of caretakers had high social support and 8% of caretakers had low social support respectively. The association between the level of community support and sociodemographic variables. The age, sex and participation of social groups were highly significant among others.

The findings align with the **Roozbeh et al. (2022) reported** The mean of the care burden of parents was 52.19 2.48 and the social support of them was higher than that (78.78± 13.21). The study concludes that There was a correlation between social support and care burden in the parents of children with cancer. Furthermore, **Golden et al.** The results showed that seven themes emerged in this study: financial concerns, emotional concerns, barriers to cancer care, need for improved cancer care, need for information, need for tangible support, and gratitude and hope. The study concludes that guardians of children with cancer experience challenges during initial stages when seeking a diagnosis and have concerns and needs related to cancer care and treatment, study findings shared to conduct one to one interview and get themes and explored the hospital experiences among caretakers of paediatric cancer patients.

Implications of the Study

This study provides practical insights into nursing education, practice, administration, and research.

Nursing Education

- Foster critical thinking and problem-solving skills in nursing students.
- Nurse Educator should plan and implement the in-service education to all nursing students to update their knowledge in cancer.
- Encourage inter professional collaboration to enhance teamwork in healthcare settings.
- Strengthen communication skills for effective patient and team interactions.
- Incorporate the use of technology and informatics in nursing curricula.

Nursing Practice

- Foster an environment that encourages open communication between caretakers and nurses.

- Ensure continuity of care through effective discharge planning and follow-up.
- The paediatric field of healthcare has a different landscape than that of adult because the nurse‘s role is child and family centred care.

Nursing Administration

- Advocate for policies that support patient and caretakers to integrate in healthcare systems.
- Promote awareness of the emotional challenges faced by the caretakers.
- Establish guidelines for nurse-led initiatives addressing paediatric cancer patient care.
- Encourage administrators to allocate resources for staff training in paediatric cancer care.

Nursing Research

- Promote research on the psychosocial impacts of paediatric cancer treatment.
- Encourage studies that explore the relationship between community support and hospital experiences.
- Support the development of evidence-based guidelines for psychosocial care.
- Foster partnerships with academic institutions for innovative research initiatives.

Limitations

- Sample size may not represent all caretakers.
- Interventions may be used to show the effectiveness.
- Emotions status of the caretakers during the study may influence the response.
- Short study period limits long-term analysis.

Recommendations

- A similar study can be done on a large scale.
- This study can be conducted as a comparative study in urban and rural areas.
- A similar study can be done to assess knowledge & practice level among nursing students.
- A similar study can be conducted by using various instructional media i.e. simulation.

Conclusion

Caretakers are regarded as the most important people in the child’s support system, children are very sensitive to their behavioral, mental, and emotional state and often mimic their behavior in stressful situations as a way of coping. Based on this study, caretakers plays an important role in child’s life. The role of caretakers, especially mothers, as the primary and main caregivers, is crucial in comforting the sick child and taking care of him/her because parental anxiety after cancer diagnosis is one of the factors that lowers the quality of life in a sick child. Therefore, understanding the experiences of parents, especially mothers, in managing and planning for the care of these children seems essential.

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