International Journal on Science and Technology (IJSAT)

E-ISSN: 2229-7677 ● Website: www.ijsat.org ● Email: editor@ijsat.org

Voices of Mothers, Needs of Children: A Mixed-Method Study on Reported Outcomes and Palliative Care Need Expectations in Serious Childhood Cancer.

Siva Ragavan[1], Shankar Shanmugam Rajendran[2], Hema Chitra J[3], Vanitha Narayanasamy Naidu[4], Sowmiya Bellora benedict[5], Vijayalakshmi Sathish kumar[6], Kalaimani Thangamani[7].

[1,5,6,7] Post Graduate, [2] Principal, [3] Professor of Pediatrics, [4] Associate Professor

[1, 2, 4] College of Nursing, Madras Medical College, Chennai-03. (Affiliated to the Tamil Nadu Dr.MGR Medical University, Chennai).

[3] Professor of Pediatrics, Institute of Child Health and Hospital for Children, Chennai-8 (Affiliated to the Tamil Nadu Dr.MGR Medical University, Chennai).

Abstract

Background

Childhood cancer has a profound impact on children's overall quality of life and creates considerable emotional, psychological, and caregiving stress for mothers, who often assume the primary caregiving role. In paediatric oncology, gaining insight into mothers' views of their child's well-being, along with their expectations of palliative care, is crucial for providing comprehensive and family-centred care. Despite this need, there is a scarcity of evidence from Indian tertiary care hospitals that simultaneously explores outcome measures and palliative care expectations through a mixed-methods perspective.

This document is a template to provide guidance about formatting the research papers which are going to be submitted to the journal. Authors can get a general idea of formatting and various possible sections in the research paper.

Statement of the Problem

"A study to assess the mothers' reported outcome measures and palliative care need expectation of children with serious cancer disease in selected tertiary care hospital".

Objective: To assess mother-reported quality of life (QOL) in children with serious cancer, explore maternal expectations for palliative care, and identify demographic factors influencing these outcomes.

Materials and Methods: This mixed-methods study used an explanatory sequential design. Quantitatively, 60 mothers completed the PedsQL 3.0 Cancer Module. Qualitatively, five mothers participated in semi-structured interviews. Data were analyzed using descriptive/inferential statistics and thematic content analysis.

Results: The overall QOL was moderate (69.03%). Children scored highest in cognitive functioning and pain management but lowest in procedural anxiety (51.21%), indicating severe distress during medical interventions. QOL scores were significantly linked to maternal education, family income, and illness duration ($p < 0.05$). Qualitative themes highlighted heavy emotional burdens and a desire for palliative care that includes better symptom management and psychological/spiritual support.

Conclusion: The study highlights the need for integrated paediatric palliative care that addresses not only the physical symptoms of childhood cancer but also the emotional, psychological, and spiritual needs of both children and their mothers. Incorporating mothers' perspectives into care planning can enhance quality of life and promote holistic, compassionate cancer care in tertiary care settings.

Keywords: Childhood cancer, Mothers' reported outcome measures, Quality of life, Palliative care needs.

1. Introduction

Childhood cancer affects multiple aspects of a child's life and places a heavy emotional and caregiving burden on families, especially mothers who act as primary caregivers. Children with serious cancer often experience pain, fatigue, emotional distress, and functional limitations that reduce their quality of life. Mothers play a key role in recognizing these problems and supporting treatment. Understanding mothers' perceptions of their child's well-being and their expectations of palliative care is essential for planning holistic, family-centered paediatric oncology services.

Background of the Study

Globally, an estimated 400,000 children and adolescents (0–19 years) are diagnosed with cancer each year. Survival rates exceed 80% in high-income countries, whereas cure rates in low- and middle-income countries remain below 30% due to delayed diagnosis, limited treatment access, and inadequate supportive care. In India, nearly 75,000 children are diagnosed annually, contributing to about 20% of the global childhood cancer burden. Childhood cancers account for 1.6–4.8% of all cancers in the country, with five-year survival rates of 37–40%. Children often undergo prolonged treatment and repeated hospitalizations, affecting their quality of life. Mothers, as primary caregivers, closely observe treatment outcomes and care needs. Evaluating mother-reported outcomes and understanding their expectations of paediatric palliative care are therefore vital for strengthening comprehensive cancer care in Indian tertiary care settings.

Need for the Study

Despite advancements in paediatric oncology, childhood cancer continues to pose significant challenges to children and their families, particularly in resource-limited settings. Children with serious cancer experience persistent physical symptoms and psychological distress, while mothers face emotional burden, caregiver strain, and uncertainty regarding their child's future.

Understanding mothers' reported outcome measures and their expectations regarding palliative care is essential for designing family-centred care models that address both medical and supportive needs. Mothers' perceptions influence care-seeking decisions, symptom reporting, and adherence to treatment plans. However, limited research has explored these dimensions simultaneously using a mixed-methods approach in tertiary care settings.

This study is therefore needed to assess mothers’ reported outcome measures of children with serious cancer disease and to explore their palliative care need expectations. By integrating quantitative assessment with qualitative exploration, the study aims to generate evidence.

Statement of the Problem

“A study to assess the mothers' reported outcome measures and palliative care need expectation of children with serious cancer disease in selected tertiary care hospital”.

Objectives of the Study

Primary Objectives

- ❖ Assess the mothers’ reported outcome measures (quality of life) of children with serious cancer disease.
- ❖ Explore the mothers’ reported palliative care need expectations of children with serious cancer disease.

Secondary Objectives

- ❖ Determine the association between quality of life and selected demographic variables of children with serious cancer disease.
- ❖ Integrate the quantitative and qualitative findings related to mothers’ reported outcome measures and palliative care need expectations of children with serious cancer disease.

Research Question

Do mothers’ reported outcome measures reflect the palliative care need expectations of children with serious cancer disease?

Hypothesis

H1: A significant relationship between mothers’ reported outcome measures (quality of life) and palliative care need expectations of children with serious cancer disease.

H2: A significant association between mothers’ reported outcome measures (quality of life) of children with serious cancer disease and their selected demographic variables.

Delimitations

✓ Mothers of children diagnosed with serious cancer disease.
✓ Limited to four weeks.
✓ The research was confined to clients attending the paediatric hematology department in ICH & HC, Egmore, Chennai, only.

2. Methods & Materials

A non-experimental descriptive design was used for the quantitative phase, whereas the qualitative phase followed an exploratory design. The target population included mothers of children diagnosed with serious cancer disease. The accessible population consisted of mothers who fulfilled the eligibility criteria and were present during the data collection period. For the quantitative component, **60 mothers** by convenience sampling method, while **5 mothers** were selected purposively for the qualitative component.

Mothers who served as the primary caregivers of children with serious cancer disease, were able to communicate in Tamil or English, were available at the time of data collection, and consented to participate were included in the study. Mothers who were experiencing severe emotional distress, declined participation, or whose children were critically unstable during data collection were excluded. The data collection instrument comprised three parts.

Section I gathered socio-demographic information related to both the child and the mother. Section II consisted of the standardized Paediatric Quality of Life Inventory (PedsQL – Cancer Module) to assess mothers' reported outcome measures of the child's quality of life. Section III included a semi-structured interview schedule designed to explore mothers' expectations regarding palliative care needs of children with serious cancer disease.

Content validity of the tools was established with input from experts in paediatric nursing, oncology, and palliative care. The reliability of the quantitative instrument was confirmed using Cronbach's alpha. Quantitative data were obtained through structured interviews, each lasting approximately **15–20 minutes**, while qualitative data were collected through in-depth interviews of **30–45 minutes** duration. Descriptive and inferential statistical methods, whereas qualitative data through thematic content analysis. Integration of quantitative and qualitative findings was undertaken during the interpretation stage.

Ethical Considerations

Approval for the study was obtained from the Institutional Ethics Committee. Prior authorization was obtained from the hospital administration before initiating data collection. Fundamental ethical principles such as beneficence, respect for human dignity, confidentiality, and justice were rigorously maintained throughout the study. Written informed consent was obtained from all participants, and their privacy was safeguarded at every stage. Participants were also clearly informed of their right to withdraw from the study at any point without facing any negative consequences.

Results

The demographic findings are shown in Table 1. The study findings revealed that children with serious cancer disease had varying levels of quality of life as reported by their mothers. The majority of children, 69.03% had a moderate level of quality of life, while 30.97% were reported to have a low level of quality of life. None of the children was reported to have a high level of quality of life shown in Table 2. Domain-wise analysis showed that cognitive functioning (84.68%), nausea (82.18%), and pain and hurt (80.24%) had comparatively higher scores, whereas perceived physical appearance (66.80%) and communication (67.61%) showed lower scores. Procedural anxiety (51.21%) was reported as the most affected domain, indicating significant distress related to repeated medical procedures.

A statistically significant association was observed between mothers' reported quality of life scores and selected demographic variables such as mother's educational status, family income, and duration of illness ($p < 0.05$). Children of mothers with lower educational levels and lower socioeconomic status demonstrated poorer quality of life scores.

Qualitative findings revealed that mothers expressed multiple unmet palliative care needs. Major themes that emerged included management of physical symptoms, emotional and psychological support for the child, emotional burden and stress experienced by mothers, need for clear communication and information, and expectations for holistic palliative care services, including spiritual support and family involvement. Mothers emphasized the importance of early integration of palliative care to improve comfort, reduce suffering, and enhance the overall quality of life of their children shown in Table 3.

Integration of quantitative and qualitative findings indicated that lower quality of life scores was closely aligned with mothers expressed expectations for comprehensive palliative care, highlighting the need for family-centered, holistic palliative care interventions in paediatric oncology settings shown in Table4.

FIG 1 SCHEMATIC REPRESENTATION OF THE STUDY

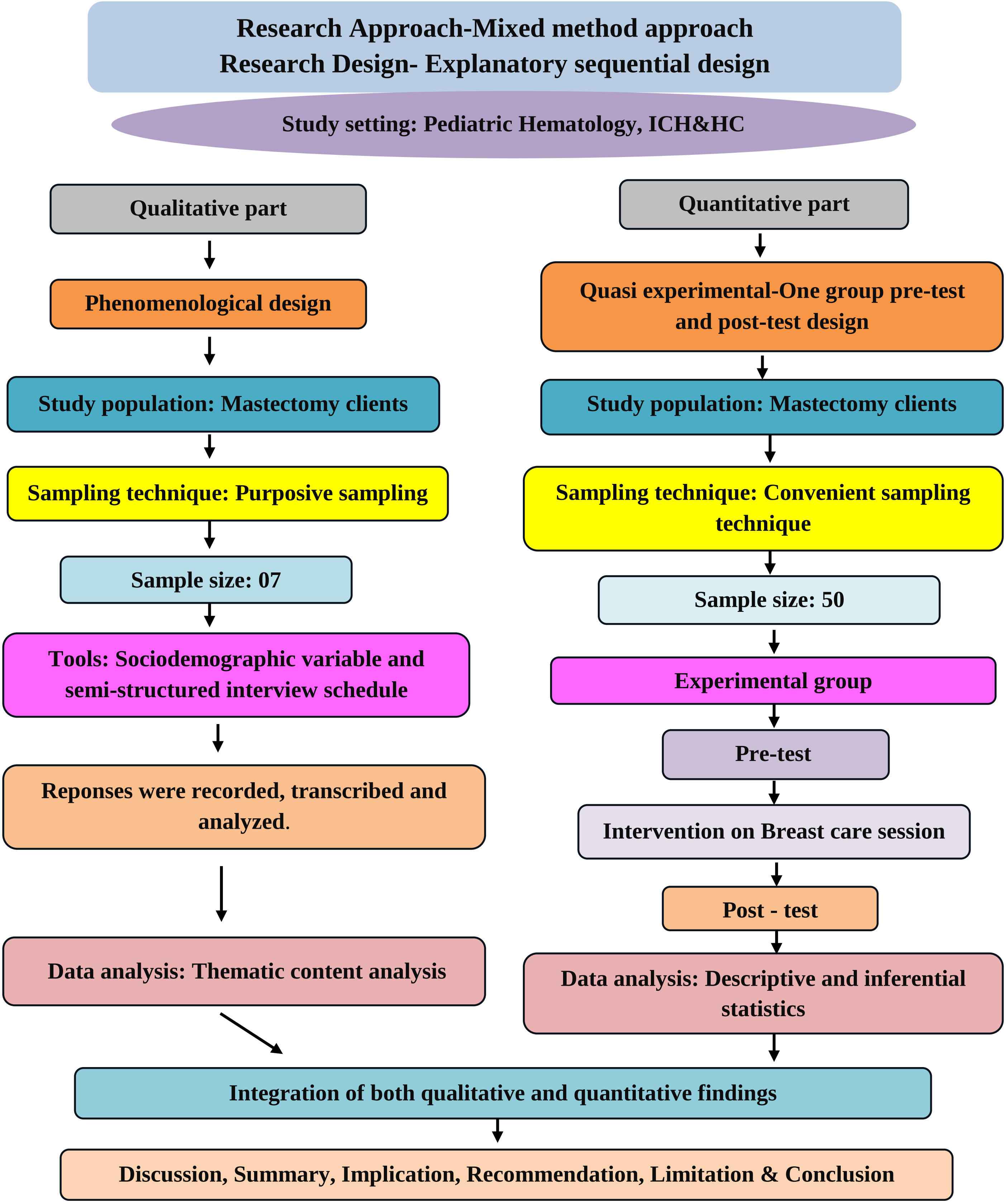

TABLE 1: SOCIO-DEMOGRAPHIC VARIABLES OF MOTHERS OF CHILDREN WITH CANCER

Demographic variables		**Number of mothers**	**%**
Age	21-25 years	8	13.33%
	26-30 years	24	40.00%
	31-35 years	18	30.00%
	above 35 years	10	16.67%
Education status	Informal education	8	13.33%
	Primary education	7	11.67%
	Higher secondary	31	51.67%
	Graduate	14	23.33%
Number of children	One child	15	25.00%
	Two children	34	56.67%
	Three children	11	18.33%
	Four or more children	0	0.00%
Monthly family income	Less than Rs. 54650	40	66.67%
	Rs. 54651- 68,454	14	23.33%
	Rs. 68,455 - 146,103	4	6.67%
	Rs. 146,104 and more	2	3.33%
Religion	Hindu	42	70.00%
	Muslim	5	8.33%
	Christian	13	21.67%
Occupation	Home worker	28	46.67%
	Semi-Skilled worker	10	16.67%
	Skilled worker	11	18.33%
	Professional worker	11	18.33%
Who is the primary caregiver for the children	Mother	57	95.00%
	Father	2	3.33%
	Grand parents	1	1.67%
	Relatives	0	0.00%
Nature of family	Adoptive family	3	5.00%
	Blended family	2	3.33%
	Nuclear family	43	71.67%
	Extended family	12	20.00%
Where do you currently reside	Remote area	8	13.33%
	Rural	25	41.67%
	Suburban	18	30.00%
	Urban	9	15.00%
How long has your child has been diagnosed with	Less than 1 year	40	66.67%

cancer	1-3 years	18	30.00%
	4-6 years	2	3.33%
	More than 6 years	0	0.00%

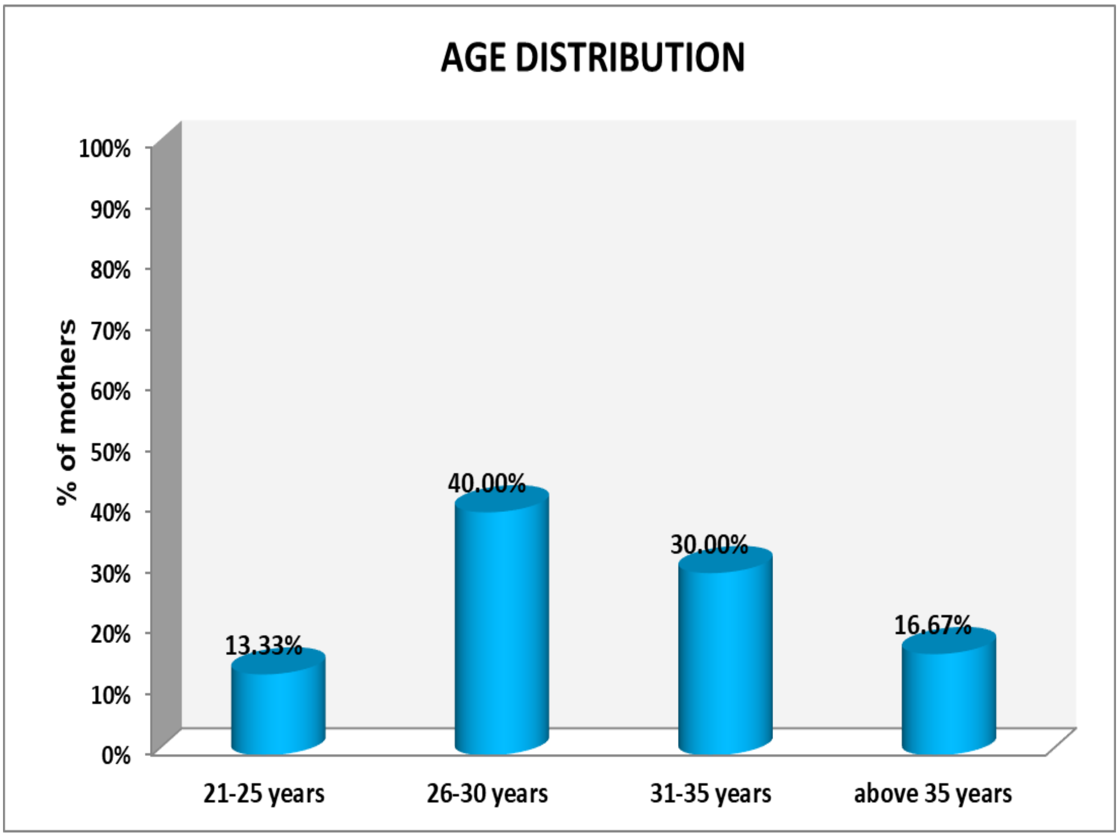

FIG.NO 2.AGE DISTRIBUTION OF THE MOTHERS

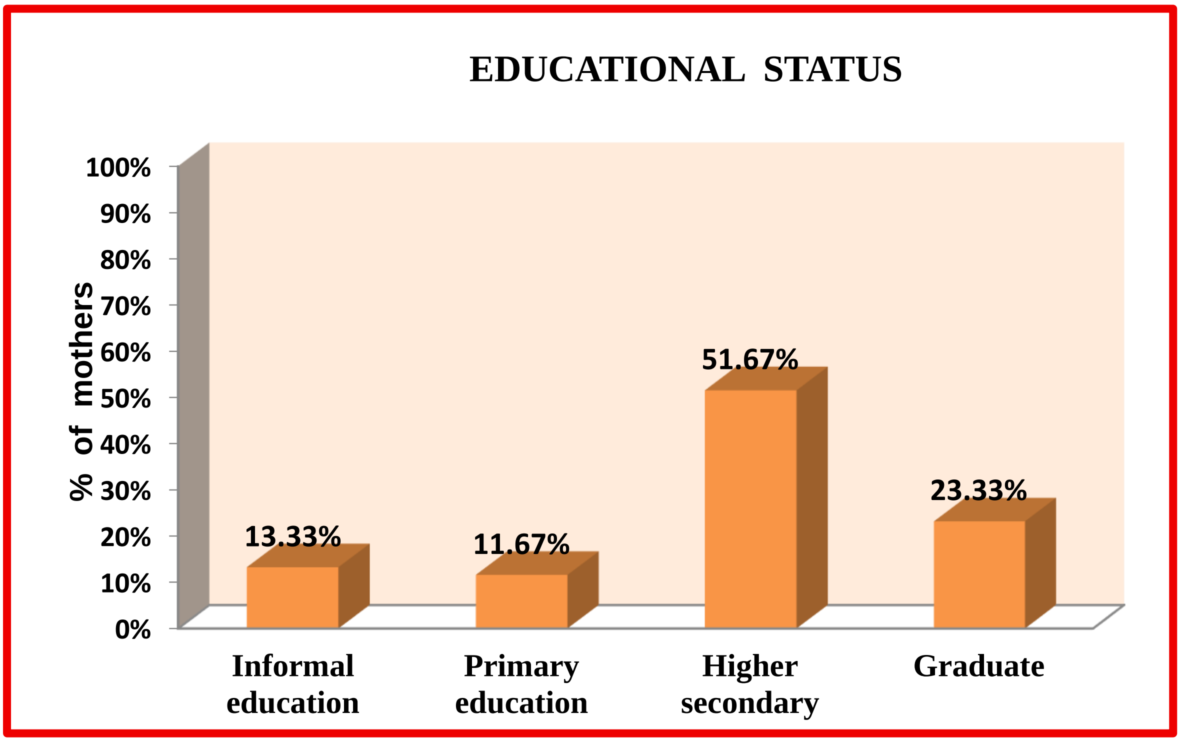

FIG.NO 3. EDUCATIONAL STATUS OF THE MOTHERS

TABLE.2. LEVEL OF QOL SCORE

Level of score	**No. of mothers**	**Percentage**
Low	0	0.00%
Moderate	49	71.67%
High	11	18.33%
Total	60	100.00%

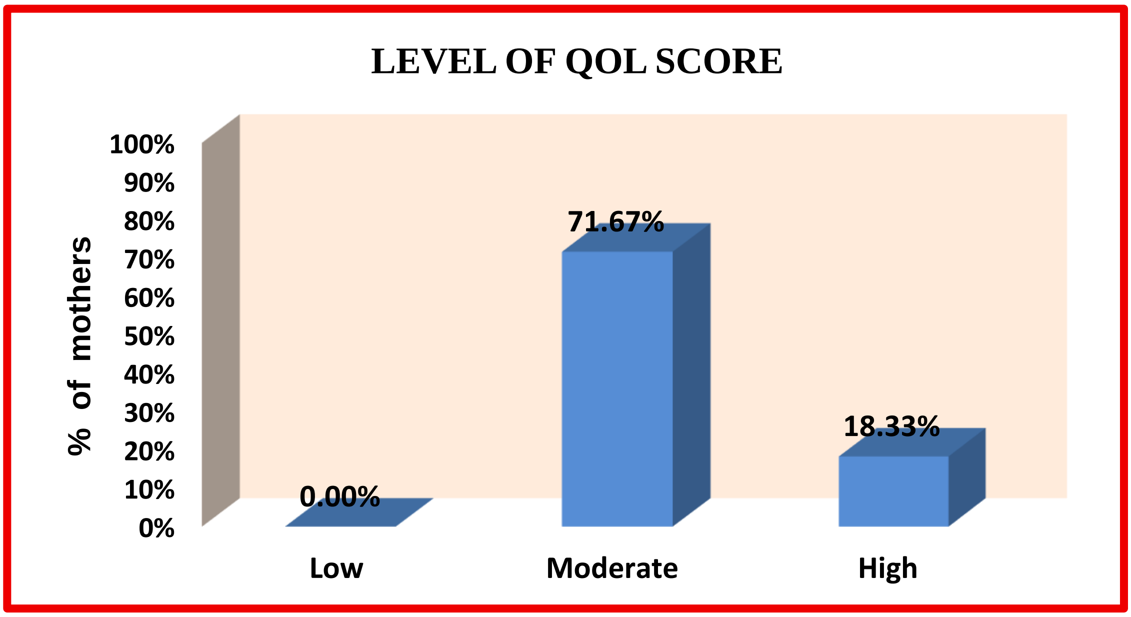

FIG.4.LEVEL OF QOL SCORE

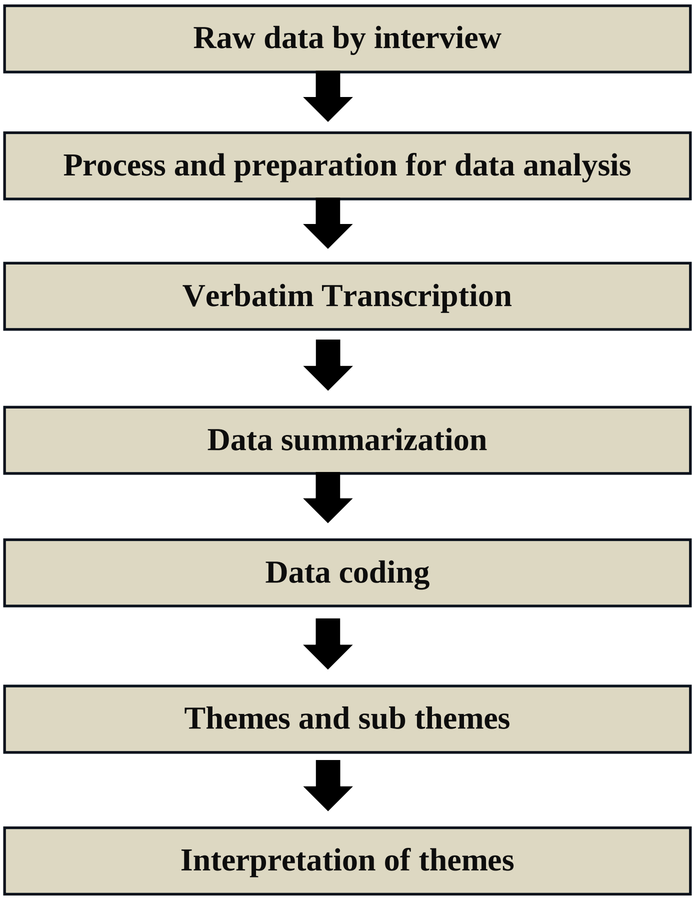

FIG. 5. PROCESS OF THEMATIC ANALYSIS

TABLE 3. THEMES, SUBTHEMES

S.NO.	THEME	SUBTHEME
1.	Emotional impact on mothers	Lack of Hope
		Acceptance Issues
2.	Emotional and Physiological Impact on the Child	Fatigue
		Loss of Interest
		Care in the Final Stage
		Physical Pain
		Emotional Pain
		Isolation
3.	Coping mechanism	Medication helps
		Family Support
		Spirituality

TABLE 4. INTEGRATED QUANTITATIVE AND QUALITATIVE FINDINGS

QUANTITATIVE FINDINGS(PedsQL)	QUALITATIVE THEMES AND SUB THEMES	INTEGRATED INTERPRETATION
Procedural anxiety 51.21% (lowest domain)	Children feared injection, hospital visits, and repeated procedures. Mothers narrated distress over “needle pain” and hospital routines.	Numerical scores confirm anxiety as the lowest QOL domain, while narrative explain the emotional trauma and fear.
Pain & Nausea- 80.24 % & 82.18% (high impact domain)	Sub-themes: Fatigue, physical pain, loss of interest. Mothers described exhaustion, children crying through nights and withdrawal from play.	Quantitative scores highlight frequent symptoms; qualitative findings deepen understanding by showing how these symptoms drain children emotionally and socially.
Worry – 57.39 % (moderate domain)	Sub- themes: emotional pain, isolation, children feared relapse, separation and being “different from peers”	Integration shows that worry od not only about treatment outcomes but also about social isolation and fear of future uncertainties.
Cognitive Functioning– 84.68% (Highest domain)	Despite illness, some children retained interest in mental tasks, though fatigue led to gradual withdrawal from learning/play.	Numbers show preserved cognitive ability; mothers’ accounts explain the slow decline and the emotional weight of lost childhood interests.
Perceived Physical Appearance – 66.8% (Moderate domain)	Children expressed embarrassment about scars and body changes.	Quantitative data indicates moderate concern; qualitative data captures the lived stigma

		and self-image struggles.
Communication – 67.61% (Moderate domain)	Mothers noted difficulty in children expressing fears or asking questions to doctors.	Integration shows that while communication scores are moderate, narratives reveal silence and avoidance as coping responses.

3. Discussion

The present mixed-methods study assessed mothers' reported outcome measures (quality of life) of children with serious cancer disease and explored mothers' palliative care need expectations. The findings revealed that the majority of children had a **moderate level of quality of life**, while a considerable proportion experienced **low quality of life**, particularly in domains related to procedural anxiety, physical appearance, and communication. These findings are consistent with studies by **Eshaghian-Dorcheh et al. (2019)** and **Feudtner et al. (2019)**, which reported that children undergoing cancer treatment commonly experience physical discomfort and emotional distress that adversely affect overall quality of life.

Domain-wise analysis showed higher scores in cognitive functioning and symptom-related domains such as pain and nausea, while procedural anxiety was the most affected domain. Similar findings were reported by **Donnelly et al. (2018)**, who emphasized that repeated invasive procedures contribute significantly to anxiety and distress among paediatric oncology patients. The present study also demonstrated a significant association between quality of life and selected demographic variables such as mother's education, family income, and duration of illness. This aligns with findings by **Nazzal and Al-Rawajfah (2018)**, who highlighted that socioeconomic status and caregiver education influence caregiving capacity and child well-being.

Qualitative findings provided deeper insight into mothers' experiences and expectations. Mothers expressed unmet palliative care needs related to symptom control, emotional and psychological support, clear communication, and family involvement in care. These findings support the work of **Winger et al. (2020)** and **Lindemann et al. (2020)**, who reported that parents of children with life-limiting illnesses often feel emotionally overwhelmed and require comprehensive palliative care support. Integration of quantitative and qualitative findings revealed that **lower quality of life scores were closely linked to higher expectations for palliative care**, underscoring the need for early and holistic integration of paediatric palliative care services.

Recommendations

- Early integration of paediatric palliative care alongside curative treatment
- Development of standardized protocols for assessing mothers' reported outcome measures
- Training programs for nurses focusing on communication, emotional support, and family-centred care
- Inclusion of mothers in decision-making and care planning
- Conducting multicenter studies with larger sample sizes to enhance generalizability.

4. Limitations

The study was limited by a relatively small sample size and the short duration of data collection. Findings were based on mothers' self-reported responses, which may be influenced by emotional state and subjective perceptions. The study was conducted in a single tertiary care hospital, limiting the generalization of results.

5. Conclusion

The present mixed-methods study highlights the importance of assessing mothers' reported outcome measures and understanding palliative care need expectations in children with serious cancer disease. The findings emphasize that quality of life is influenced not only by disease and treatment factors but also by caregiving experiences and unmet supportive needs. Integrating paediatric palliative care with routine oncology services and adopting a family-centered approach can significantly enhance the quality of life of children with cancer and provide meaningful support to mothers as primary caregivers.

References

1. World Health Organization. Cancer in children. Geneva: World Health Organization; 2023.
2. World Health Organization. Palliative care for children. Geneva: World Health Organization; 2018.
3. Varni JW, Burwinkle TM, Katz ER, Meeske K, Dickinson P. The PedsQL™ in paediatric cancer: Reliability and validity of the cancer module. *Cancer*. 2002;94(7):2090–2106.
4. Feudtner C, Kang TI, Hexem KR, Friedrichsdorf SJ, Osenga K, Siden H, et al. Paediatric palliative care patients: A prospective multicenter cohort study. *Paediatrics*. 2011;127(6):1094–1101.
5. Weaver MS, Heinze KE, Kelly KP, Wiener L, Casey RL, Bell CJ, et al. Palliative care as a standard of care in paediatric oncology. *Pediatr Blood Cancer*. 2019;66(5):e27612.
6. Lindemann H, Verkerk MA, Uhl K, Schouten M. Parents' experiences of paediatric palliative care: A systematic review. *Palliat Med*. 2020;34(4):486–498.
7. Nazzal MS, Al-Rawajfah OM. Experiences of parents caring for children with life-limiting illnesses. *J Pediatr Nurs*. 2018;43:e1–e6.
8. Winger A, Kvarme LG, Løyland B, Kristiansen C, Helseth S. Parents' experiences of caring for children with a life-threatening illness. *J Pediatr Nurs*. 2020;52:e21–e28.
9. Verberne LM, Schouten-van Meeteren AY, Bosman DK, Colenbrander DA, Grootenhuis MA, van Delden JJ. Parental experiences with paediatric end-of-life care. *Palliat Med*. 2017;31(10):953–963.
10. Oliveira Barros A, Maia E, Santos M, Almeida F. Family caregiving experiences in childhood cancer: An integrative review. *Rev Lat Am Enfermagem*. 2019;27:e3138.
11. Donnelly JP, Huff SM, Lindsey ML, McMahon KA, Schumacher JD. The role of paediatric palliative care in oncology. *J Pediatr Nurs*. 2018;43:1–9.
12. Eshaghian-Dorcheh A, Hosseini MA, Rahgozar M, Dadgari A. Quality of life in children with cancer receiving palliative care. *Iran J Nurs Midwifery Res*. 2019;24(4):280–285.
13. Bourke-Taylor H, Jane F. Mothers' experiences caring for children with chronic illness. *Aust Occup Ther J*. 2018;65(3):200–208.
14. Rosenberg AR, Wolfe J. Palliative care for children with cancer. *Clin Adv Hematol Oncol*. 2013;11(12):767–773.

15. Watson J. Nursing: The philosophy and science of caring. Rev ed. Boulder (CO): University Press of Colorado; 2006.

Acknowledgement

I thank the Almighty for His guidance and strength in completing this study. I sincerely acknowledge **Prof. (Dr.) R. Shankar Shanmugam** for his valuable guidance, encouragement, and support. I extend my gratitude to the faculty members for their continuous assistance throughout the research process. I am thankful to the hospital authorities and healthcare professionals for granting permission and support to conduct the study. My heartfelt thanks go to all the mothers who participated and shared their experiences. I also express my sincere appreciation to my appa & amma (V.Ragavan & Jagatha.R) sisters (Vijayalakshmi & Monisha), mama (Vijayakumar.E) and my soul mate for their encouragement, patience, and constant support in every stage of this stu