International Journal for Multidisciplinary Research (IJFMR)
E-ISSN: 2582-2160 ● Website: www.ijfmr.com ● Email: editor@ijfmr.com

A Study on the Lived Experiences of Mothers Navigating their Child's Chronic Illness During PICU Admission at Varanasi Hospital, Uttar Pradesh

Sheela Sahu[1], Payal Saha[2], Nisha Bharti[3], Neelam Rajput[4], Ms. Aneeta Sharma[5], Sherin P. Alex[6], Silambarasu Chinnu[7]

[1]Sumitra Institute of Nursing and Paramedical Sciences, Greater'Noida, Uttar Pradesh
[2,3,4,7]Government College of Nursing, Baba Raghav Das Medical College, Gorakhpur, Uttar Pradesh, India
[6]Major SD Singh University, Farrukhabad, Uttar Pradesh, India
[5]T.S. Misra College of Nursing, T.S. Mishra University, Lucknow UP, India

ABSTRACT:
The Global Index of disease analysis highlights a substantially elevated risk of mortality and long-term complications among infants and children admitted to neonatal intensive care units (NICUs) and paediatric intensive care units (PICUs). The global burden of mortality in neonates remains critically high in low- and middle-income countries, where a significant proportion of newborn deaths result from conditions that are both preventable and treatable. Within the PICU environment, parents accompanying their critically ill children experience considerable psychological, emotional, and social strain, necessitating attention to their unique needs and challenges. Recognizing and addressing these needs is essential for delivering holistic, family-centred critical care. Against this backdrop, this study aims to examine and elucidate the experiences of mothers with children suffering from chronic illnesses in the PICU, to foster a more profound comprehension of the significance they attribute to these encounters.

KEYWORDS: Chronic Illness in PICU, Lived-in experiences, Children with chronic illness, Parental stress, Coping strategies, Qualitative phenomenological study

INTRODUCTION:

Children living with chronic illnesses often require frequent medical interventions, prolonged treatments, and episodes of critical deterioration that necessitate admission into the paediatric intensive care unit (PICU)[1]. For mothers, who commonly serve as the primary caregivers, the hospitalization of their child in such a high-dependency setting becomes an emotionally overwhelming and life-altering experience[2]. The environment of the PICU—marked by continuous monitoring, advanced life-support equipment, uncertain prognoses, and strict regulations—intensifies parental anxiety, fear, and exhaustion[3].

In India, particularly in regions like Uttar Pradesh, mothers of children with chronic illnesses also face

additional cultural, social, and financial challenges while navigating the complexities of treatment[4]. Varanasi, being one of the major healthcare hubs in Eastern Uttar Pradesh, receives a high influx of paediatric patients from rural and semi-urban areas[5]. Mothers accompanying their children during PICU admission often experience significant emotional distress, caregiving burden, and disruptions to family life, livelihood, and social responsibilities. Despite these profound challenges, their experiences remain underexplored and insufficiently documented in nursing research[6].

Understanding the lived experiences of these mothers is essential for nurses and healthcare professionals because it offers insights into their psychological needs, coping behaviours, expectations, and the support systems they rely upon[7]. Such understanding can help strengthen family-centred care, improve communication in PICU settings, and guide the development of targeted interventions that enhance maternal well-being and promote positive child outcomes[8].

The needs and emotions of mothers were unsatisfactory as they were not being able to be close to their babies, not being able to see their babies and not being part of a functional team; the most prevalent emotions associated with the parenting role are anxiety, helplessness, and loss of control, fear, uncertainty, and concerns about the prematurely born infant's outcome[9]. In India, women are heavily involved in initiatives to lower perinatal mortality, offer prenatal care, ensure safe deliveries, and provide day-to-day care for infants. Social scientists, epidemiologists, and health researchers have identified that added weight of physical, mental, and psychological stress among caregivers involving largely women; especially when care involves dependents, such as children, persons with disabilities, or older people[10].

Therefore, this study aims to explore and describe the lived experiences of mothers navigating their child's chronic illness during PICU admission at a selected hospital in Varanasi, Uttar Pradesh. Through a qualitative phenomenological approach, this research seeks to give voice to mothers' emotions, struggles, hopes, and coping mechanisms, thereby contributing to improved clinical practice and compassionate nursing care**.**

MATERIALS AND METHODS:

Study design: This retrospective investigation was carried out.

The study was conducted at a selected hospitals of Varanasi , Uttar Pradesh, Northern India, which serves as a government tertiary care facility. The hospital caters to eastern Uttar Pradesh, Bihar and another country Nepal, with an average daily patient's visit of 3500-4000 out-patients and 350-400 in-patient admissions.

All patients were subjected to enrolled in this study was first screened in pediatric departments of each tertiary care hospital. The research adopted a phenomenological design to explore and interpret the lived experiences of mothers whose children were admitted to the Paediatric Intensive Care Unit.

The study was conducted peripheral community and primary health care center of Varanasi. A total of 100 participants were selected using a random sampling technique based on predefined inclusion criteria. In-depth interview sessions were carried out to capture the rich, subjective experiences of the mothers. The data obtained were analysed using a hermeneutic phenomenological interpretation approach, which facilitated the identification of themes and subthemes that reflected the mothers' perceptions, emotions, and meanings ascribed to their experiences[11].

RESULT:

Majority of mother were being shocked, worried, and anxious due to child admission in PICUs. Parent's needs and provisions from healthcare professionals where changed. If mother is listening her child health status is improving her emotional status is satisfied same time if deteriorating she was feeling hopeless. Mother's trying to adapt herself into an ICU environment with the positive recovery of child. Majority of parents were facing financial challenged and deprivation. Almost 50% mother participant where 25-30 year, 52% mother were graduate, 57% of mother having less than 1 child. 50% children were diagnosed with pneumonia /Respiratory disorder.63% child was less than one year and 60 % participant their children was hospitalized between 20-30 days as shown in Table 1.

Table: 1 Frequency and percentage of the demographic variables of mothers and children.

Demographic Variables of Mothers	Frequency (f)
Age of mother	
(a) <20	-
(b) 20 – 25	19
(c) 25 – 30	50
(d) >30	31
Educational Qualification of mothers	
(a) Illiterate	10
(b) High school	28
(c) Graduation	52
(d) Post Graduation	10
Occupational status of mothers	
(a) Unemployed	43
(b) Unskilled workers	37
(c) Skilled workers	20
No. Of children	
(a) 1	57
(b) 2	34
(c) 3	09
(d) 4 and above	-
Monthly income of family	
Below Rs.10000	30
Rs.10001-Rs.20000	60
Above 20001	10
Demographic Variables of Children	**Frequency (f)**
Age of child	
(a)>1 year	63
(b) 1-3 year	37
Sex of child	
(a) Male	63
(b) Female	37

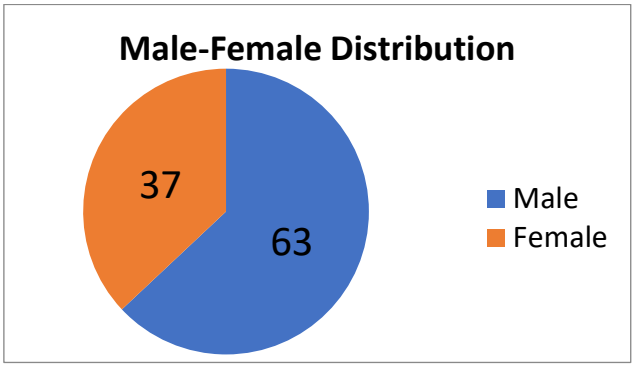
The above Table 1 shows frequency and percentage distribution of demographic variables of mothers and children. Total numbers of mothers 100 were assessed and almost 50 (50%) mothers with the age group of 25-30 year, 31 (31%) mothers with the age group of above 30 years, 19% mothers with the age group of 20-25 years age group and there are no mothers with the age group of below 20 years.

With respect to educational qualification of mothers 52% were graduate, 28% were high school, 10 (10%) was post graduate and 10 (10%) were illiterate as illustrated in Table 1. Occupational status of mothers 43 (43%) were unemployed followed by 37 were unskilled workers and 20 skilled workers.

Among all, 57 mother having 1 child, 34 mothers having 2 children followed by 09 having 3 children and no mothers having more than 4 children (Table 1). In respect to monthly income of family 60 (60%) having Rs.10001/-Rs.20000/-income, 30 (30%) having Rs.10000/-income and 10 (10%) having Rs.20001/-income.

With respect to age of children 70 (70%) children were less than one year and 30 (30%) children were 1-3 years of age. With respect to sex of children 63% were male and 37% were female as shown in Figure 1.

Fig. 1 Graph showing the gender distribution of children



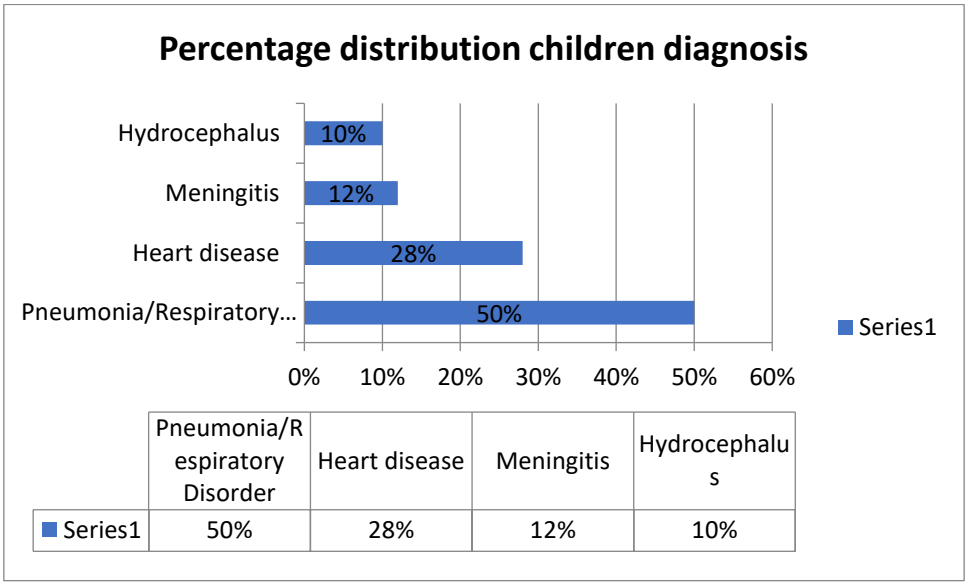
With respect to children diagnosis 50 (50%) children were diagnosed with pneumonia /Respiratory disorder, 28 (28%) of children were diagnosed with heart disease, 12 (12%) child were diagnosed with meningitis, 10 (10%) child were diagnosed with hydrocephalus and children diagnosed with jaundice were not found as illustrated in Figure 2. With respect to children's length of hospitalization 60 (60 %) was hospitalized between 20-30 days, 40 (40%) was hospitalized more than 30 days and below 20 days not found (Table 2).

Table: 2 Frequency and percentage of the clinical diagnosis and hospital stay of children

Children diagnosis	
(a) Pneumonia/Respiratory Disorder	50
(b) Heart disease	28
(c) Meningitis	12
(d) Hydrocephalus	10
(e) Jaundice	-
Children's length of hospitalization	
(a) < 10 Days	-
(b) 10 - 20 Days	-

(c) 20 - 30 Days	60
(d) > 30 Days	40

Fig. 2 Graph showing the frequency and percentage distribution children diagnosis.



DISCUSSION:

Children with chronic diseases who are admitted to the hospital with an acute episodic sickness may cause additional stress for their mothers. To date no research were discovered that studied mothers' perceptions of their experience during a 3–6-year-old child's episodic hospitalization that also has a chronic disease. The treatment of episodic conditions is the subject of much of the literature[12,13]. Ignoring the chronic illness of the children, health care practitioners tend to accept responsibility for the episodic problem omitting to take into consideration the influence the child's chronic ailment has on the overall family constellation[14].

Data will be analysed using the hermeneutic phenomenological interpretation approach. The content analysis method is commonly utilized in nursing research[15]. Content analysis is one approach of understanding text documents[16]. The goal of content analysis is to reduce a great volume of chaotic information to compacted, more manageable material in order to emphasize significance and translate it into theoretical generalization. The analytical process begins with brief texts and progresses to hidden meanings within categories and topics[17]. The inductive method was chosen because it is congruent with the goal of my research, which was undertaken to discover new knowledge. The researcher moved from discrete semantic units to general themes[15].

The study analysed the lived experiences of 100 mothers of children with chronic illnesses admitted to the PICU. Five major themes emerged from the data. Theme 1 showed that 42% of mothers experienced changes in their needs and expectations from healthcare professionals, with 8% gradually adapting to the PICU environment as their child's condition improved. Theme 2 revealed that the majority (72%) experienced intense emotional distress, including shock, fear, and anxiety during the initial phase of admission. Theme 3 indicated that 50% of mothers reported significant disruptions in family routines, caregiving roles, and daily functioning due to prolonged hospitalization. Theme 4 demonstrated that 71% of mothers experienced emotional fluctuations closely aligned with their child's clinical status,

reporting hope during improvement and hopelessness during deterioration. Theme 5 highlighted that 69% of mothers faced substantial financial strain, resource limitations, and economic instability. Overall, the findings reflect a high emotional, social, and financial burden among mothers, underscoring the need for enhanced communication, psychological support, and family-centred care in PICU settings.

CONCLUSION:

This study was conducted to interpret the lived in experiences of mothers having children with chronic illness. Study has concentrated on the verbatim narrations and developed themes. Most of the mothers reported about their financial crisis and shows their satisfaction towards health care settings for the first time. The mothers experienced about their child's admission and their first visit to the PICUs were shocking and unforgettable events for them. Furthermore, situations faced by them were full of stress, anxiety and unhappiness in-regard with the condition of their child and that they were concerned for their child' health and life

REFERENCE:

1. Chhabra P, Sharma N, Gupta S. Caregiver burden among parents of children with chronic illnesses in India. Indian Journal of Pediatrics. 2020; 87(9):716–722.
2. Meyer EC, Ritholz MD, Burns JP, Truog RD. Improving the quality of end-of-life care in the pediatric intensive care unit: Parents' priorities and recommendations. Pediatrics.2006;117(3):649–657.
3. Franck LS, McQuillan A, Wray J, Grocott M, Goldman A. Parent stress levels during children's hospital recovery following cardiac surgery. Pediatric Cardiology.2010;31(7):961–968.
4. Singh K, Nath A. Barriers to healthcare access among rural caregivers of children with chronic illness in Uttar Pradesh. Indian Journal of Community Medicine.2021;46(1):123–129.
5. Cousino MK, Hazen RA. Parenting stress among caregivers of children with chronic illness: A systematic review. Journal of Pediatric Psychology.2013;38(8):809–828.
6. Board R, Ryan-Wenger N. Stressors and stress reactions identified by parents of critically ill children. Journal of Pediatric Nursing. 2002;17(3):214–221.
7. Foster M, Whitehead L, Maybee P. The parents' experience of pediatric critical care: A meta-synthesis. International Journal of Nursing Studies.2016;61:63–72.
8. Santos RP, et al. Maternal stress and coping in PICU admissions. Journal of Clinical Nursing.2014;23(7–8):1030–1039.
9. Bornstein MH, Suwalsky JTD, Breakstone DA. Emotional Relationships between Mothers and Infants: Knowns, Unknowns, and Unknown Unknowns. Dev Psychopathol. 2012;24(1):113–23.
10. Shah U. Improving neonatal care: women as health providers. Mothers Child. 1989;8(2 Suppl):3–4.
11. Ethel A. Santiago, Brown C, Mahmoud R, Carlisle J. Hermeneutic phenomenological human science research method in clinical practice settings: An integrative literature review. Nurse Education in Practice. 2020;47:102837. https://doi.org/10.1016/j.nepr.2020.102837.
12. Robinson CA. Interpreting family stress in chronic illness: A comparative study of families of children with cancer and diabetes. Journal of Pediatric Nursing. 1987;2(6):354–361.
13. Thorne S, Robinson CA. Health care relationships: The chronic illness perspective. Research in Nursing & Health. 1988;11(5):293–300. https://doi.org/10.1002/nur.4770110505
14. Hobbs N. The futures of children: Categories, labels, and their consequences. Jossey-Bass.1975.

15. Elo S, Kyngäs H. The qualitative content analysis process. Journal of Advanced Nursing. 2008;62(1):107–115. https://doi.org/10.1111/j.1365-2648.2007.04569.x
16. Bengtsson M. How to plan and perform a qualitative study using content analysis. NursingPlus Open. 2016;2:8–14. https://doi.org/10.1016/j.npls.2016.01.001
17. Erlingsson C, Brysiewicz P. A hands-on guide to doing content analysis. African Journal of Emergency Medicine.2017;7(3):93–99. https://doi.org/10.1016/j.afjem.2017.08.001