

# Experiences of the Parents of Children Admitted to PICU

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## ABSTRACT

**Introduction:** A pediatric intensive care unit (PICU) is a highly technological and fast-paced setting in a hospital.

**Objective:** To explore the experiences of the parents in the critical care area of a selected tertiary care facility.

**Materials and methods:** In a qualitative study, we interviewed 10 purposively selected parents of the children admitted to PICU using a pre-validated in-depth interview schedule. All parents, whose children were admitted to PICU for more than 5 days, who understood Hindi or English and were willing to participate in the study, were enrolled in the study. Parents of critically ill children having readmission to PICU or prolonged stay of more than 15 days and not accompanied by parents were excluded.

**Results:** Parents had unmet needs, such as the need for information, counseling and education from the healthcare team (HCT) members, having trusting relationship with the HCT, and expecting receiving orientation of the routines and the protocols of PICU, and empathy from the various levels of PICU team. The majority of subjects expressed the desire to talk to a dedicated person for their queries. The parents had multiple feelings of distress, hopelessness, helplessness, guilt, and the fear of losing the child and used various coping strategies.

**Conclusion:** Parents of critically ill children in the PICU have unmet needs. Healthcare team members should take initiative in relieving parental distress and improving their coping abilities.

**Keywords:** Experiences, Hospitalized children, Parents, Pediatric intensive care unit.

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## WHAT THIS STUDY ADDS TO?

Introducing primary care nursing and family-centered care would be useful in strengthening the partnership between parents and the health care team.

## INTRODUCTION

A pediatric intensive care unit (PICU) is a highly technological, fast-paced setting in which advanced care is provided to critically ill children to restore their health.<sup>1,2</sup> Admission of a critically ill child to the PICU is a stressful situation that can have negative effects on parents in terms of emotional distress, and altered family roles and functions.<sup>3</sup> The intense environment of the PICU, medical equipment, complex nature of the disease, the uncertainty of diagnosis, management strategies, prognosis coupled with inconsistent and minimal communication from the ICU staff are the sources that may provoke anxiety and stress in the caregivers.<sup>4</sup> In the past, the pediatric critical care nursing goal was focused on the physiological impact of life-threatening illnesses on the sick but ignored the fact that the critical nature of the illness might lead to changes within the family system.<sup>5</sup> Several pieces of evidence suggests that the parents experience varying degrees of stress, anxiety, depression and delusional conflicts and identified the needs and the prevalence of psychological problems requiring further exploration.<sup>6-8</sup> World over, numerous studies have explored the needs and psychological problems and experiences of parents of critically ill patients,<sup>9-12</sup> similar literature on the experiences of parents of critically ill children in India is scanty. Therefore, the present study was conceptualized to explore these aspects in the critical care area of a selected tertiary care facility.

## MATERIALS AND METHODS

We conducted a qualitative study after receiving approval of the Institute Ethics Committee. The purpose of the study was explained

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to the subjects and written informed consent was obtained after assuring confidentiality and anonymity. We interviewed the parents of the children admitted to PICU (PJ, SB). The 8-bedded PICU admits 300-350 children per year and >75% needs invasive mechanical ventilation. The unit has a liberal visitation policy to allow the parents to be with their children. A purposive sampling technique was used to recruit the parents of children admitted to the PICU till the point of data saturation. All parents, whose children were admitted to PICU for more than 5 days, understood Hindi or English and were willing to participate in the study, were enrolled in the study. Parents of critically ill children having readmission to PICU or prolonged stay of more than 15 days and children accompanied by any other family member other than the parent were excluded. Data were collected one to one using a pre-validated in-depth interview guide with the parents at their convenience in the seminar room of the

ward used for counseling the caregivers. A pre-validated interview guide was given containing some triggered questions exploring the needs, reactions, and problems faced during their children's stay in PICU. The interview guide was shared with the experts to establish the internal validity. The interviews were tape-recorded using a digital voice recorder to capture the interview content. During the physical interview, notes were maintained to record the issues/aspects that could not be audiotaped like subjects' gestures and facial expressions during the interviews.

### Data Analysis

A thematic analysis approach was used to generate themes. Data analysis was done along with the ongoing data collection, which helped to further shape the interview and the subsequent data collection procedure. Each interview was held for around 40–45 minutes. All interview recordings were transcribed verbatim (PJ, SK, JK). This required checking through each transcript against the taped recordings to ensure the accuracy of the content and that the translations of terms and/or words were consistently used throughout. The raw data were read several times to identify the emerging themes, and grouped into categories independently developed by two researchers (PJ, JK). Responses relevant to each category were examined and analyzed. The identified themes were compared and agreed upon by all the researchers for common coding and categorization.

### RESULTS

The study included parents of 10 children. The demographic profile of the parents along with the clinical profile of the admitted children in the PICU, who were interviewed, is described in Table 1.

The major findings of the study revealed that parents had many needs to be addressed by the healthcare team (HCT), described as verbatim along with the generated themes in Table 2. Need for information, counseling and education from the HCT members, having trusting relationship with the HCT, and expecting receiving orientation of the routines and the protocols of PICU, and empathy from the various levels of hospital staff including PICU team were the expressed needs of the parents. The majority subjects appreciated the concept of involving parents in the child's care in the unit. They were very happy with their involvement in the care of the children and expressed the desire to talk to a dedicated person who could answer their queries. However, two parents expressed that their

knowledge was not given due attention. Parents also expressed various psychological reactions at the time of the interview described in Table 3. The parents had multiple feelings of distress, hopelessness, helplessness, guilt, and the fear of losing the child. Some parents had financial constraints due the hospitalization of their children. Parents were coping with the distress by surrendering to the God, talking to co-patients' caregivers and their own family members.

### DISCUSSION

The major findings of the study reveal that the parents' needs revolved around psychological, social, economic, and physical domains. The parents exhibited reactions, such as distress, hopelessness, helplessness, guilt, and the fear of losing the child. They were coping with the distress by surrendering to God, talking to co-patients' caregivers and their own family members.

**Table 1:** Demographic and clinical profile of parents and the children  $n = 10$

Variable	Frequency
Age of parent (years)*	32.5 (27.5–40.5)
Gender (female: male)	6:4
Education (illiterate: primary: secondary: above)	2:1:6:1
Occupation (housewife: job: farmer)	5:3:2
Residence (Delhi: outside Delhi)	2:8
Monthly family income (Rs)*	20,000 (13,750–30,000)
Number of children*	2 (1–3)
Related to admitted child	
Age (years)*	3.5 (1.6–5.2)
Gender (female: male)	6:4
Admitting diagnosis (respiratory: cardiac: renal: MIS-C: gastrointestinal: hematological)	4:1:2:1:1:1
Duration of stay (days)** (on the day of interview)	8 ± 1.71
Respiratory support (invasive)	10
Ventilation (days)**	7 ± 1.9

\*median (IQR), \*\*mean ± SD

**Table 2:** Needs of the parents

Need for information	The person inside the ICU didn't tell me the condition of the child. Even though I asked them they didn't tell me. They replied to me that all are looking after him. They didn't mention the doctor's name (P1) I met the doctors and nurses. They didn't mention about the child's condition for the past 3 days. They kept saying, "we can't say anything right now". For 3 days they did not tell me anything about my child (P1) We do not know the medical terms so I think they might not tell us everything about the baby sometimes as they might not be able to explain us, might be they are not doing it intentionally but it happens (P3) When we were told that the child will be intubated and put on a ventilator, I cried, my wife also cried followed by the whole family cried. We did not know the purpose of putting the tube in his mouth. We thought that we would have to buy it from a medical store, but we did not buy it as we didn't know what it was? and what it looked like. The child was kept on a ventilator for the whole day, and we were afraid whether our child could survive or not (P2) I felt that somebody should tell me about my child's status when I visited the child in the PICU (P3) They explained to me, but I did not understand their English. So, I couldn't get what they were saying. I walked away quietly. Since they didn't understand my language, I couldn't ask them also. My brother called me if I had asked the staff about the child's condition. I replied to him that I couldn't ask the staff as they could not understand my language (P4)
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(Contd...)

Table 2: (Contd...)

	<p>We were not sure whether our child will survive or not, and my wife did not want it..., my father also told and refused the doctor to put the pipe in my child's mouth (ET tube) because we saw one child dying after putting the pipe within 2 hours. My sister-in-law also insisted on not putting the pipe, because we believed that after putting the pipe, every child expired (P2)</p> <p>Just about whether he will recover or not? People get scared by the name of ICU only. I was also scared for my baby. Whether my baby will recover or not (P7)</p> <p>If something happens to my baby, they should inform us. We have to wait for the senior doctor to tell us about the condition of our baby (P5)</p> <p>She drank milk in the past two days but they have stopped now as she has problems but they never told her anything. We don't ask much also as we don't understand much. They said we don't understand it. So, we don't ask (P10)</p>
Need for counseling and education	<p>The only problem is with breast milk for the child. I do not have adequate milk... (P6)</p> <p>As the child is sick, I don't feel hungry or eat. No one to help me in this regard... (P5)</p> <p>My breast milk secretion is not there, I don't know how to do it in the best possible way. I have never done manual removal of milk earlier as I directly used to feed him. Maybe I don't know the right process (P6)</p>
Involvement in child care (family-centered nursing care)	<p>Today I fed him, I changed his diaper. I checked if he was having a fever and put water-filled gloves near his ankles, as advised by the nurse (P1)</p> <p>Since they do not prohibit me from meeting him, I didn't feel that they have separated me from him. They told me, "I can visit him and I can sit by his side too, whenever I want (P6)</p> <p>I feel good that they involve me. They told me that the diaper is there, to bring it and change it for him. They ask me to hold his leg while changing the diaper. She (the nurse) cleaned one side and I cleaned the other side. I felt good that they involved me in his care. Nothing can be compared to a mother's care in this world. For example, you will take care of your phone much better than anyone else, this phone we can buy again, but the baby cannot be replaced. They asked me to bring a comb and set his hair as it had grown long and messy. Somebody had made a ponytail and he was looking cute. Who even cares for tying his hair, combing is enough but they made a ponytail. These are little gestures but I really liked them. Though later they removed it, it was giving a tidy look to my child, I liked it. Everything that is tidy looks good. It doesn't appear good when things are messy (P5)</p> <p>I feel good doing while taking care of my baby for my baby (P10)</p> <p>I do think that because if he is in front of my eyes, I can see my baby. If a nurse is not giving attention to the baby, then I will take care of him (P4)</p> <p>I do take care of her. I wipe her face, change her diaper and clean her as well. Feed her milk and apply oil. I do my best as much as I can. I try my best not to miss anything, as a mother's care is the best of all. But she cannot come. She can't stand like that (P8)</p>
Need for developing trusting relationship/Need for consistent and accurate information	<p>It happened for 2–3 days. They said we cannot say anything about the child's condition. Then they called me on the 3rd day and told me the child's condition has improved to 30%. Initially, I thought they are hiding something from me as I might get scared (P9)</p> <p>It was very cold, They told me to do sponging, and I felt, "if I do sponging now, the child will become sicker. It was very cold. I was also feeling cold, so I thought if I remove his clothing and do sponging, the baby might get pneumonia or something might happen. So, yes, I feel there is a little bit of negligence here (P8)</p>
Need for empathy of healthcare team and support staff	<p>Now you are late, you won't get food, they use to shout like that (P2)</p> <p>They do not empathize, they are blunter, they needed to be given training on these things; they are very straightforward when we need some support. Otherwise no issues. I feel like they are blunt, I don't know who gave them the authority to say, you go out, take your child and go out. Because people who come here are already in problems, they do not enjoy being here (P3)</p>
Need for dedicated personnel	<p>Many times this has happened. There is a problem with their structure. We have come across this when they change the shift and handing over. We thought this is not between the doctors but it was between them (Nurses). I work in electronics, so when we give laptops for repair. I feel that it should be given only to the same person for repair; similarly, we feel that if we give it to another person for repair, it may get worse (P3)</p> <p>There is no responsibility. They don't understand and take it very casually. They say to one another, "It was instructed to you to do, didn't check the blood reports." They say these things to one another (P9)</p> <p>No, they have to answer. Whether we are educated or not, if our baby is admitted we have the right to ask if we have any queries (P3)</p>
Meeting the unmet physiological needs of parents	<p>I'm not comfortable sleeping at night outside in the patient waiting area... just because of mosquitoes and bed bugs (P3)</p> <p>No fans are there. There are mosquitoes in summer; I do feel hot as it is summer (P4)</p> <p>The whole night the bugs bite us and we cannot sleep, it's very noisy here. There is a lot of disturbance as people keep talking, and then we try to pass time by using the phone, only 2–3 hours can we sleep (P7)</p>

(Contd...)

**Table 2:** (Contd...)

Breaking the news	I feel they are blunt sometimes but not every time if we know the inside scenario. They say the baby is critical if they are critically ill, but they don't say it every time. They also say the baby is sick. So I feel they are not that blunt but some people who cannot analyze the situation will feel that they are blunt because they say it to their faces (P5)
Looking for support to cope with the situation	I was much panicked. A ventilator is very painful. Along with this in an emergency, it was difficult to get his veins to start intravenous injections. It is painful for the parents to see their baby pricking with needles multiple times. We thought that he is so critical that he has to be put on a ventilator. We don't know how to cope, we felt hopeless because during those moments we were not confirmed whether it is MIS-C or not. We didn't understand the situation, or why this was happening to us. So, we panicked (P7)
Need for orientation to the PICU routine	They told me to wear the gown, go outside, wash hands and sanitize them, then come inside. I was not touching my baby but they told me don't touch the baby without sanitizing hands. So, all these instructions I received after I went inside the ICU. They told me to maintain distance. The people who were outside didn't know that it was my fault. It was my fault that I didn't know about this and how things were inside. I took out my phone and took the picture; they strictly prohibited me from taking the picture. They said, "no, this is not at all allowed. You either leave your phone outside or keep it inside your pocket. We cannot allow you." They scolded me, but I admit it was my fault. I'm happy that they pointed out my fault and corrected me (P5)
Need for consistent responses from HCWs	When the child was planned for dialysis, we need to give a signature. There was one lady doctor and one male doctor, I don't know his name. They called us earlier and asked for signing the consent form. They said, maybe we may need it later and we don't want to delay while we look for you later as you may be out here and there. So, put your signature on this form now. But there was the lady doctor, she said "No" we will take the signature when we are sending for the procedure, she is not going anywhere, she will be here only. Though they are in the same team, the approach is different from person to person. I find the lady doctor very helpful (P8)
Need for redressal of grievances	If some negligence happens, then someone should be answerable for what has happened. There should be a professional with whom we can address our issues. It is a great thing to do and we would appreciate that (P3)

**Table 3:** Parental reactions and coping

Parental distress	<p>I was extremely scared; you must understand how a mother feels when her child is sick. I was worried about my child then they told me that the child's life is in the hands of God. My husband consoled me at that time, for 3 days they did not tell me anything about my child (P1)</p> <p>While my child was being shifted to PICU, I could not calm myself (P2)</p> <p>I was very panicked. A ventilator is very painful. Along with this in an emergency, it was difficult to get his veins to start intravenous injections. It is painful for the parents to see their baby being pricked with needles multiple times. We don't know how to cope, we felt hopeless because during that time, we were not confirmed whether it is MIS-C or not. We don't understand the situation, why this is happening to us. So, we panicked (P3)</p> <p>I do not see any improvement in the condition of my baby. I do not know what to say. If they had admitted earlier, this might not be the condition (P4)</p> <p>He is too young to suffer these things, he is receiving many injections. Seeing these makes me feel like crying. I was uncertain whether he will survive or not. He is just 3 years old. He has to bear so much suffering. I used to cry a lot. Getting so many injections. We were consoling each other (P5)</p> <p>This was the first time we saw our child with many tubes, we feel bad about it. As it was happening for the first time and we had never seen it in any of our family members. We were worried if our child will survive or not. So everybody was crying (P3)</p> <p>Just about whether he will recover or not? People get scared by the name of ICU only. I was also scared for my baby. Whether my baby will recover or not (P4)</p> <p>I was crying every day when I saw my baby. He was in so much pain. I wish I could take her pain. So he would recover (P6)</p> <p>We felt very sad and painful. We feel sorry. Whatever it is, it's God's will. We can't leave her like that also (P7)</p>
Perceived seriousness of the disease	<p>We believed that as long as the child is put on the machine he survives. If they remove the machine, he is dead (P1)</p> <p>We thought that he is so critical that he has to be put on a ventilator (P3)</p>
Guilt feeling	<p>We feel guilty; we could have come here straight away. Out there doctors were also not able to find the problem with him (P4)</p> <p>We might be blaming ourselves for our whole life thinking that this is our fault. we could not take care of our baby (P8)</p>
Hopelessness	I do not see any improvement in the condition of my baby. I do not know what to say. If they have admitted earlier this might not be the condition
Helplessness	I do not know what to do; I cannot call anybody else to stay here. They have their reasons. My mom is old now and cannot stay here

(Contd...)

**Table 3:** (Contd...)

Surrendering to God (No control over the situation)	<p>If it is in our fate he will survive.</p> <p>It's every mother's wish to hold her child and feed with her own hands. By the grace of God if we have fate he will be saved. Everything is in God's hands (P1)</p> <p>I was wishing him to get better in God's name. I wish that all his pain be relieved.</p> <p>I was just praying to God to heal my child; (P1)</p> <p>I don't want to lose my boy.</p> <p>While my child was being shifted to PICU, I could not calm myself that time, (P2)</p> <p>Life is in the hand of God, He is the giver, and He takes away. Life is like sparks from the fire that disappears in a moment. We are just a puppet of God we do whatever he says. He can pull us out from the deep (P3)</p> <p>The whole day we were sitting in the park and crying the whole day, we did not eat anything that day. We were thinking the whole day whether he will survive or not. We kept praying for him. We prayed to many God so that our child will be saved. In medical, now he is fine (P5)</p> <p>Sometimes that thought came to me. That time we just kept praying for him day and night. I remembered and prayed to every God, I knew (P6)</p> <p>It's only God who knows how long she will survive. The doctor told us that she will not survive till we reach home. The child may die on the way. Then, I thought what should I do, the child was put on the ventilator. She is surviving as long as she is on the ventilator, so, we decided to get her treatment here (P6)</p>
Support from co-patient's relatives and own family	<p>Crying is not the solution and it does not make things better, so, do not cry. We have to be courageous and keep praying that God will cure our child (P2)</p> <p>I went outside and talked to everyone. Called my family. They said everything will be alright, have faith, and be positive. Then I felt relaxed. Yes, I started praying and worshipping more (P2)</p>
Confidence in the parental role	<p>No, I never felt responsible for his condition. I always make sure he is safe. Maintaining proper hygiene. I don't know how he got this infection. I never gave top milk. I was so careful. He did not like when he was not bathed any day (P1)</p> <p>It's God's will only. We tried our best. We never let her face any problems. We did everything as the doctor advised us to do. Not even a single day we kept her without medication (P4)</p>
Fearing of losing the child	<p>No, they only said that we cannot tell you anything about your child's condition. I was very scared after seeing the child (P1)</p>
Gaining control over the situation	<p>I eat willingly so that my baby gets better and gets enough milk.</p> <p>No, I was not afraid. But I was a little scared as his condition was serious. Everybody does have a little fear</p>
Incurring financial loss	<p>My restaurant is closed and someone else is taking care of the poultry business. I have no idea what he is selling and how. I am suffering loss from there and from here as well (P5)</p> <p>I managed somehow. First COVID broke us, restaurants were closed. We have a small piece of land we use for farming. So whatever savings I had we used to manage the expenses. We put my sister-in-law's jewelry as mortgage.</p>
Compromising	<p>What more will I expect? My child is admitted here. Why would I get angry at them?</p> <p>There is no point fighting with them, as my child is already suffering. If they are treating her, that's enough for me.</p>

Illness and hospitalization of children in PICU have a huge impact on parents in terms of psychological and emotional stress. The present qualitative study explored the experiences of the parents of the admitted children in the PICU in terms of their needs and reactions. In this study, we describe five important areas, that is, need for information, counseling and education, developing trusting relationships, empathy from the HCT members and the support staff, and need for a dedicated PICU staff to address their queries as expressed by parents. Many parents feel overwhelmed with fear, anxiety, and stress upon seeing the child and the activities in the ICU, the medical equipment attached to the child making a lot of noises and the activated alarms.<sup>13</sup> They depend on the HCT for information on the patient's condition and progress due to the restricted entry to PICU.<sup>14</sup> Staff communication and behavior may have a strong determinant on the emotional and mental health of family members during their stay in PICU.<sup>15</sup> On asking the parents as to "what they knew about the child's condition," often the initial response is that "no one has told them anything"; however, on talking further, many mention that the doctors had described the disease condition. The initial denial response of the parents

can be attributed to the emotional turmoil occurring due to acute catastrophic illness of the child.

In the present study, parents exhibited mixed feelings of distress in terms of anxiety, depression, and frustration and reactions due to their child's hospitalization. They needed someone who could listen to them. The most influencing stress observed in the parents by us was the fear of losing the child. There are several pieces of research evidence which suggests that access to information is the most important step in helping parents to cope.<sup>5,15</sup> Most of the parents reported of receiving the information about the condition of the child from the HCT. Periodic information provided by the HCT about the child, his day-to-day progress, and response to treatment tailored according to the educational status of the parents, without any medical jargons and keeping all the channels of communication open with parents can reduce the stress of the parents. Our findings are congruent with an interpretive descriptive study performed in the PICU of one Canadian, quaternary care pediatric hospital in which the parents felt the same and emphasized on improving communication with the staff to strengthen the parent-staff partnerships.<sup>16</sup> In the present study, parents felt good with the encouraging involvement



of the HCT child's care. Some studies have similarly emphasized reinforcing parenthood during the stay of the child in the PICU.<sup>2,17</sup> Unlike developed countries, the concept of FCC in India is at infancy stage. Most of the PICUs in India have very restricted provisions for parents at the child's bedside and no involvement in the care of the child. Introducing the concepts of primary care nursing and family-centered care would be useful in strengthening the partnership between parents and the HCT. Nurses due to their round-the-clock availability and proximity to the parents can play a crucial role by liaising between parents and HCT and thereby relieving the parental distress. The results of the present study can be used in providing care to the admitted children in PICU and keep a path open to the concept of FCC, which is currently missing in most hospitals in India.

In the present study, three researchers independently reviewed the data before deciding on the agreed meaning of the data. Credibility and generalizability of the data were enhanced by the process of checking the verbatim independently and discussing later on for mutual understanding of the phenomenon explored. The experiences described by the parents directly impacted the transferability and dependability of the findings, hence adding rigor to the study. A similar study can be replicated in other settings for improving the generalizability of the study findings. Our study recommends for introducing the concepts of primary care nursing and family-centered care in PICU to oversee the care delivered to the admitted children and their parents in PICU.

## CONCLUSION

Healthcare team should address to the needs of the parents of critically ill children to relieve the parental distress and improving their coping abilities and strengthening the partnership between parents and the HCT.

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